UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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Lamond Family Foundation Distinguished
Professor In Human Genetics
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September 18, 2018

David Teitel, M.D.,
Chair, Executive Council
UCSF Academic Senate

Dear Dr. Teitel,

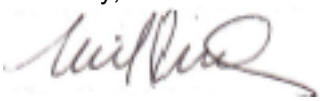
We are writing to inform you of three minor changes to our application to establish a new Masters Program in Genetic Counseling. These changes resulted from the Budget Resource Management review that occurred following approval by the Graduate Council. The changes are listed below and are incorporated into the attached application packet.

1. Class cohorts have been increased from 10 to 11 students per year
2. A revised budget (pg. 57) now reflects the increase in class cohort size and an increase in student fees from $42,000 to $44,000/year
3. Teaching FTE in the program has increased. The prior proposal mistakenly only included teaching effort to be charged to the program, not the total effort devoted to teaching. The correct figure is 1.32 FTE for teaching.

We are committed to establishing one of the premier genetic counseling programs in the United States and continuing with the standard of excellence that has defined many other UCSF educational programs. The group of clinical geneticists, genetic counselors and researchers at UCSF is enthusiastic about this program and eager to see it come to fruition. Additionally, support for this program extends beyond UCSF and into the Bay Area genetics community.

Thank you for your consideration of our proposal, we look forward to hearing back from the Academic Senate. Meanwhile, should you have any questions, please feel free to contact Cindy Morgan, our Proposed Program Director, at cindy.morgan@ucsf.edu.

Sincerely,



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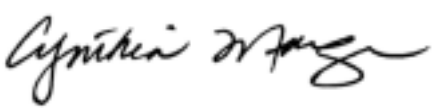

Cynthia Morgan, M.S., L.C.G.C
Interim Program Director

PROPOSAL TO ESTABLISH A SELF-SUPPORTING GRADUATE DEGREE PROGRM FOR THE MS DEGREE IN GENETIC COUNSELING AT THE UNIVERSITY OF CALIFORNIA SAN FRANCISCO

September 2018

This proposal was developed by a group of faculty and staff from the Department of Pediatrics, Department of Medicine and the Institute of Human Genetics. Input was obtained from UCSF faculty and staff members, UCSF Medical Center staff and the Graduate Division.

Program Coordinating Committee Members:

- Neil Risch, PhD
- Ophir Klein, MD, PhD
- Cynthia Morgan, MS, LCGC*
- Anne Slavotinek, MBBS, PhD*
- Marta Sabbadini, PhD, MS, LCGC
- Summer Segal, MS, PhD, LCGC
- Liane Abrams, MS, LCGC
- Kara Weisiger, MS, LCGC

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SECTION 1: INTRODUCTION

The UCSF Master's Program in Genetic Counseling conforms to the MS Plan II of the UCSF Graduate Council Regulations and Rules which requires a minimum 36 academic units and a comprehensive exam. A capstone research project will replace the comprehensive exam. The target date for admission of the first cohort of 11 students is Fall Quarter 2020. A cohort of 11 students will be matriculated each fall quarter and will graduate after 7 quarters of didactic coursework and clinical training.

1.1. Aims and Objectives

The UCSF Institute for Human Genetics and the Department of Pediatrics, Division of Medical Genetics are proposing a new Master of Science (MS) degree in Genetic Counseling. The UCSF Masters of Science Program in Genetic Counseling (The GC Program) is a course of study intended for students with Bachelor's or post-graduate degrees, who are committed to gaining proficiency in the practice of clinical medical genetics and genetic counseling. Students will immerse themselves in advanced human and molecular genetics, gain competency in adeptly interpreting increasingly complex data from sophisticated testing technologies, develop and execute an original research project, integrate the core principles of humanistic counseling into their clinical encounters and foster personal and professional engagement in the social and ethical issues surrounding the rapidly evolving field of genetics.

The MS program has a rigorous curriculum that will be completed within two academic years. It is a fulltime endeavor and part time study is not supported due to the need for coordinated progression through the curriculum and clinical internships. The primary objective is to train students in the core concepts of human genetics and psychosocial counseling theory. The curriculum is comprised of didactic instruction, clinical exposure to build foundational clinical skills, supervised internships in clinics and industry, and a capstone research project. The course work provides a strong foundation in molecular and human genetics, cytogenetics, population genetics, clinical genetics, advanced genomic testing technologies and counseling theory. The counseling curriculum will prepare students for the considerable amount of time they will spend immersed in clinical rotations beginning summer quarter at the end of the first year. During their clinical training students will progress from observing clinical interactions to independently counseling and providing case management to patients and/or families affected with, or at risk, of genetic disease. Additionally, students will engage in a capstone research project that will enable them to investigate an original topic of interest related to genetic counseling. Supplementary activities such as case conferences, grand rounds, journal clubs, seminars and scientific meetings will also enrich the educational experience. Overall, The GC Program will provide training in a field of interdisciplinary academic study that will form the cornerstone for a contemporary understanding of the etiology, manifestations, diagnosis and lived experience of genetic disease.

1.2. Historical Development of the Field and Institutional Strengths

1.2.1 Historical Development of the Field

Genetic counseling as an independently recognized health care profession is relatively new in the practice of medicine, but it is one of the most rapidly growing specialties. The discovery of DNA led to scientific breakthroughs into the etiology and inheritance of many health conditions. This subsequently gave rise to questions of how to best impart newly discovered genetic information to patients and their families. The need for individuals trained in the complex science of genetics in conjunction with an understanding of the sensitive nature of genetic information and shared familial conditions gave rise to the field of genetic counseling.

The first genetic counseling training program was established in 1969 at Sarah Lawrence College in Bronxville, NY. Since the launch of this first training program, the profession has grown to over 4,000 American Board of Genetic Counseling (ABGC) certified genetic counselors. These graduates hold a master's degree from one of 37 accredited programs in the United States or 4 Canadian training programs. Additionally, there are 19 training programs in various stages of development in the United States in an effort to offset the unmet demand for genetic counselors (see Section 3D). Internationally, there are another 30 genetic counseling training programs throughout the world and undoubtedly more will be established in the near future.

Genetic counselors are members of the healthcare team and have advanced training in genetics and in psychosocial counseling. Although the profession of genetic counseling has grown hand-in-hand with genetic testing, genetic counseling does not equal genetic testing. "Genetic counseling is 'the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease.' Traditionally, this process includes collecting and interpreting the family and medical history, risk assessment, a comprehensive educational process for potential genetic testing, informed consent, and psychosocial assessment and support (National Society of Genetic Counselors' Definition Task Force et al. 2006)." These skills enable genetic counselors to interpret genetic test results, provide test or disease-related information, guide and support patients seeking information about how inherited diseases might affect them or their families, how family and medical histories may impact the chance of disease occurrence or recurrence, which genetic tests may or may not be appropriate for them, the limitations of those tests, and supporting informed and autonomous choices about healthcare decisions. This same unique skill set is also frequently provided to other non-genetics care providers.

1.2.2 Institutional Strengths

UCSF is well positioned to support the proposed genetic counseling program due to its distinction as one of the leading health science education and biomedical research centers in the world. The strong and expanding clinical genetics service, clinical genomics laboratories and decades of experience training genetic counselors also provide all the necessary components of a successful genetic counseling training program.

1.2.2.1 Distinguished Medical Center

UCSF Medical Center and Benioff Children's Hospital are among the most distinguished healthcare institutions in the world, and are renowned for their integration of medical research and clinical care for the benefit of patients. US News & World Report annual surveys consistently rank UCSF as among the nation's premier medical centers, and as the best medical center in California. Patients travel from around the state, nation and the world to receive care from UCSF's expert health professionals. The expertise among the clinical faculty is unparalleled and will be drawn upon to educate The GC Program's students. UCSF has clinical genetics services on campuses in San Francisco, (Parnassus Heights, Mission Bay, Mt. Zion and the Zuckerberg San Francisco General Hospital), Oakland and Fresno that will provide students with opportunities for patient encounters from culturally diverse backgrounds and socioeconomic statuses. UCSF also has close relationships with other major health care systems located within the San Francisco Bay Area, such as Kaiser Permanente, providing students with opportunities that reach beyond the campus boundaries. This rich healthcare environment attracts outstanding students and faculty and provides many opportunities for training and employment for UCSF students and graduates.

1.2.2.1.2 Clinical Genetics Services

UCSF has built one of the largest clinical genetics services on the west coast. The San Francisco (Parnassus Heights, Mission Bay, Mt Zion and the Zuckerberg San Francisco General Hospital) and Oakland campuses currently employ 34 genetic counselors, 8 clinical medical geneticists (physicians) and 3 laboratory geneticists (PhDs). There is active recruitment program for several more clinical geneticist positions, a physician scientist position and genetic counselor positions. Additionally, UCSF-Fresno has another 4 genetic counselors and 2 clinical geneticists. These clinicians serve the following clinics, which will also function as clinical rotation sites for students:

- Cancer Risk Program
- Pediatric Cancer Risk Clinic
- Craniofacial Center
- Prenatal Diagnosis Center
- Fetal Treatment Center
- Medical Genetics and Genomics Clinic
- Disorders of Sexual Development Clinic
- Biochemical Genetic Medicine Clinic
- Lysosomal Disease Center
- Personalized Genomics Clinic
- The NF/Ras Pathway Clinic
- Memory and Aging Center
- Huntington's Disease Clinic
- Polycystic Kidney Disease Center of Excellence
- Ophthalmology Genetics Clinic
- Cardiovascular Genetics Program
- Dermatology Genetics Clinic

- Hearing loss Genetics Clinic
- Preventive Genomics Clinic
- Medical Genetics at Benioff Children's Hospital, Oakland

UCSF also runs a Clinical Exome laboratory, Clinical Cancer Genomics laboratory and a Cytogenetics laboratory; all of which provide advanced diagnostics and opportunities for students to learn about the most current technologies (see Section 1.2.2.2.2).

1.2.2.2 World-Renowned Research Institution

UCSF is a world-renowned biomedical research institution and it ranks in the top group of higher learning institutions in total federal funding for research and training. In 2016, UCSF was the nation's top public recipient of research funding from the National Institutes of Health, and second among all institutions nationwide. The culture of innovation and multidisciplinary collaboration has resulted in faculty winning nearly every leading prize in the health sciences and countless discoveries in the treatment and prevention of disease. Among faculty members are five Nobel laureates, 35 National Academy of Sciences members, 61 American Academy of Arts and Sciences members, 97 National Academy of Medicine members, and 26 Howard Hughes Medical Institute investigators.

1.2.2.2.1 Institute for Human Genetics (IHG)

The Institute for Human Genetics (IHG) is an organized research unit serving as the central hub for human genetics research, education, and practice at UCSF, and will provide the academic home for this project. Initiated in 2006 with Dr. Neil Risch as its founding director, the major aim of the IHG is to create an exciting, productive, and collaborative environment for research, training, and clinical application in human genetics. The IHG also provides institutional support and resources, such as the Genomics Core Facility (GCF), which has a large variety of state of the art technology platforms and support services for cost effective, flexible solutions for genomics projects of any size, ranging from full-service, large-scale projects to equipment-only support.

In addition to Dr. Risch, all of clinical geneticists and PhD genetics researchers participating in this proposed program are members of the IHG. The Institute has grown considerably over the past 10 years through active recruitment. Currently, the IHG membership includes over 75 active researchers, educators, and practitioners. Most of these individuals are in the forefront of methodological developments in areas such as prenatal and pediatric genetics, human evolution and population genetics, genetic epidemiology, computational genomics, molecular methods, functional genomics, reproductive decision making, and bioethics. The Institute and its members have gained international recognition when US News and World Report ranked UCSF in the top 5 internationally in molecular biology and genetics for the past 3 years.

1.2.2.2.2 Genomic Medicine Initiative (GMI) and Clinical Genomic Medicine Laboratory (CGML)

The Genomic Medicine Initiative is a UCSF-wide effort established by the Chancellor and Dean of the School of Medicine in 2013. The mission of the UCSF GMI is to seamlessly transition the latest techniques from the UCSF research community into patient care, giving patients access to international experts in genomic medicine. It is an interdepartmental, interdisciplinary effort harnessing knowledge and experience across a large number of departments and research groups. This blends the providers and services of these departments into an efficient, knowledgeable team, including clinical geneticists, genetic counselors, molecular pathologists, bioinformaticians, and bioethicists. The GMI focuses on improving patient experience by reducing the time for a diagnosis, and often enabling a better treatment plan. Its three areas of concentration are cancer, undiagnosed or inherited diseases, and newborn genetics. The GMI, and its affiliated Genomic Medicine Laboratory (GML), are co-directed by Drs. Pui Kwok and Neil Risch. It has several years of experience in providing whole exome sequencing to UCSF patients, now with CLIA certification in both the cancer tumor setting and undiagnosed germline genetics setting.

1.2.2.2.3 Recent NIH-Funded Research Initiatives in Clinical Genetics

UCSF has recently been awarded several large NIH grants in the field of clinical genetics and precision medicine. These include a Clinical Sequencing Evidence-generating Research (CSER2) grant entitled "Program in Prenatal and Pediatric Genomic Sequencing". This multi-dimensional grant investigates the use of exome sequencing to facilitate prenatal diagnoses of suspected genetic conditions and the effectiveness of exome sequencing in pediatric patients with previously undiagnosed developmental disease; while also examining the clinical utility of sequencing in diverse populations. UCSF will enroll approximately 1,100 patients over the next several years, the majority of whom will be from underserved and underrepresented minority populations. In addition to investigating the clinical utility of this testing, there is also a bioethics component of the study which will use both qualitative and quantitative measures to explore the personal utility of this testing for families, reasons for declining, and other ethical questions surrounding exome sequencing. This project will provide students with invaluable experience being part of a large-scale research project and will also expose them to cutting-edge uses of sequencing technology in clinic, combined with the opportunity to explore the ethical considerations that arise when new technologies are introduced in clinical settings.

A second project, funded by the National Institute for Human Genome Research (NHGRI), is a retrospective study focusing on the use of exome sequencing as an adjunct or substitute for traditional mass spectrometry methodology for newborn screening (called "NBSeq"). The project is based in the State of California Newborn Screening program, which examines over 50 genetic metabolic disorders in its screening protocols. Archived specimens on over 1,600 infants that received a positive or negative newborn screen via classic methodologies will undergo exome sequencing. The study will investigate the sensitivity and specificity of exome sequencing to detect the conditions found by traditional methods, as well as determine if the time to diagnosis can be reduced

in critically ill newborns. Results of this study will impact the interpretation of exome sequence data in the newborn screening setting and influence the current model of public health newborn screening programs. This project will be particularly relevant to the field of genetic counseling as case management for many newborn screening cases is currently provided by genetic counselors and genetic counselors will inevitably be called upon if exome sequencing replaces traditional biochemical methods.

1.2.2.3 UCSF Library

The UCSF Library and Center for Knowledge Management is one of the preeminent health sciences libraries in the world, containing an extensive and exceptionally rich collection of monographic and periodical literature in the health sciences, with substantial holdings in the biological and physical sciences, the social sciences, psychiatry, and psychology. This collection contains over 844,214 volumes, 57,440 electronic full-text serials and 13,068 electronic health sciences serials. The library incorporates state of the art library computer systems, such as MyAccess that replaces the card catalog with a streamlined computer search system. The library also houses The Center for Instructional Technology which offers a wide range of documentation and training on using the Collaborative Learning Environment (CLE). The CLE provides a versatile framework designed to meet the current and future needs for learner-centered environments, collaborative learning, and other collaborative activities at UCSF. Library materials not available on the San Francisco campus may be requested through other University of California campuses.

Special collections contain both secondary and primary source material from the earliest medical history to contemporary projects in AIDS, tobacco control, biotechnology, and managed care. All faculty and students have access to print and electronic resources regardless of UCSF departmental or programmatic affiliation.

Digital Library: GALEN is the Digital Library at UCSF. PubMed@UCSF is publicly available, but access to full text articles is limited to computers on the UCSF network or to approved offsite computers. It provides access to the MEDLINE database as well as other NLM databases, and is strong in clinical and basic sciences, nursing, dentistry, and health care planning and administration from 1966 to the present. References published between 1958 and 1965 can be viewed through OLDMEDLINE. The MELVYL Catalog is used to locate books at all UC libraries, and California Periodicals to find journals/titles at other University of California, California State University, and California libraries. Many other important databases are available, including Current Contents, BIOSIS, and PsycINFO.

Center for Knowledge Management: The Center for Knowledge Management is an innovative division of the library. Its multidisciplinary staff develops knowledge bases and on-line tools for the health sciences, pursues applied research projects related to UCSF informatics problems, serves as a laboratory for graduate students who are interested in using new technologies to solve important health sciences information problems, and supports the library's sophisticated computing and communications infrastructure.

Interactive Learning Centers: The Interactive Learning Centers maintain student-computing facilities in the library and in the Medical Sciences Building, with PC and

Macintosh computers, printers, software, documentation, consulting support, and connections to the Internet. Electronic classrooms are available at both locations for reservation by UCSF faculty members. The Multimedia Development Lab (MDL) provides hardware, software, and consulting support for development of curriculum-integrated, educational materials. Video digitizing, flat art scanning and slide scanning are among the capabilities available in the MDL. Education and Consulting Services offers curriculum-integrated instruction and scheduled seminars that assist students and faculty in the use of information management tools such as databases, the Internet, and personal file management software.

1.2.2.4 Experience Training Genetic Counselors

UCSF faculty and staff already have over 40 years of experience training genetic counselors. UCSF involvement initially began in 1973 when the University of California Berkeley (UCB) hosted a genetic counselor training program. UCSF served as UCB's primary clinical training site and UCSF staff genetic counselors and clinical geneticists mentored students in clinical internships, provided course lectures and served as research project mentors. Graduates of this program were frequently hired at UCSF and approximately one quarter of UCSF's current genetic counselor population are graduates of the UC Berkeley program.

The UCB program closed in 2002 due to factors unrelated to the program and a new genetic counseling training program was launched in 2008 through the California State University (CSU) system. This program is administratively based at CSU Stanislaus, but the students complete all their training in the San Francisco Bay Area. Again, UCSF plays a significant role in the training of these students and there is a Memorandum of Understanding to house much of their training program at UCSF. All UCSF medical genetics clinics regularly host CSU students for clinical rotations, 6 UCSF genetic counselors serve as course instructors and have agreed to teach in the proposed UCSF program, and numerous clinicians and researchers have provided lectures, laboratory tours, served as research mentors or otherwise supported the program. All of these individuals have agreed to participate in the new UCSF program and express enthusiastic support.

CSU Stanislaus has voluntarily elected to sunset their current training program due to the upcoming retirement of their leadership core. The last cohort of students will be graduating in the spring of 2020. The leadership team at CSU Stanislaus has been working with UCSF to create a genetic counseling training program at UCSF, and they have been serving as mentors in the development process of the GC Program.

1.3. Timetable for Program Development

We have developed a new overall curriculum for the Master's Program in Genetic Counseling. September 2020 is our target to matriculate the first class of up to 11 students. An additional cohort of 11 students will matriculate the second year for an eventual steady state of 20 students per academic year. This class size is consistent with other genetic counseling programs throughout the country as the availability of clinical sites for rotations in the field of medical genetics limits the ability to enroll large classes.

As the landscape of clinical medical genetics continues to evolve and more genetic counselors are integrated into clinical care and industry settings, we will continue explore ways to increase class cohort size. Enrollment of students in The GC Program will not affect enrollment in other UCSF programs.

The proposed timeline for developing the MS program is shown in Table 1.

Table 1.

Date	Proposal Status	Action	Action
6/ 2017	Decision to pursue GC program		
6-12/ 17	Draft full MS proposal	Regular meetings of MS committee	Collection of existing course materials, development of new courses, identification of teaching faculty, selection of Advisory Board
12/17	Completion of UCSF proposal		
2/18	Submission of proposal to Graduate Division		Begin drafting ACGC application
3/18	Graduate Division submits proposal to Graduate Council	Budget submission to BRM	
5/18	Submit to Academic Senate		
7/18	Submit to Chancellor for approval		
8/18	Submit to UC CCGA for approval		Begin website design
12/19	Submit to UCOP for approval		
1/2019		Submission of Application for Candidacy to ACGC	
4/ 19		Acceptance of Application for Candidacy and Submission of Program proposal to ACGC	Submission of course forms for proposed new courses
4/19			Begin marketing program in anticipation of entering Match program

7/2019		Permission of ACGC to enter Match program	
12/2019			UCSF Application deadline
1/ 2020			Applications reviewed
2-4/ 20			Candidate interviews
3/ 20		ACGC approval as "Accredited New Program" received prior to March 2020	
5/ 20		Rankings released, admissions offered	
9/ 20	First cohort of students matriculates, Class of 2022		

1.4. Relationship of the Proposed Program to Existing Programs at UCSF

The Masters Program in Genetic Counseling program will be the only program in genetic counseling at UCSF. There are no known negative effects on existing graduate programs. The presence of a genetic counseling training program will elevate the existing genetics educational programs and create a comprehensive genetics service at UCSF.

1.4.1 Relationship to Medical Genetics residency program

UCSF has a physician medical genetics residency training program for physicians that has been in operation for decades. This proposed genetic counseling program will function as a sibling program to the residency program, as clinical geneticists and genetic counselors professionally collaborate and work side-by-side. Under the current residency program, genetics residents receive clinical training by many of The GC Program's faculty and have attended CSU genetic counseling program classes taught by UCSF faculty and staff. Dr. Joseph Shieh, director of the residency program, is supportive of our proposed program, and we will work together to guide the future of medical genetics education at UCSF.

1.4.2 Relationship to School of Nursing, Department of Physiological Nursing

The UCSF School of Nursing, Department of Physiologic Nursing offers a Genomics Minor for MS nursing students. The content in the 3 courses required to fulfill the Genomics minor parallels curriculum in our proposed program but is addressed with greater depth in The GC Program. The GC Program faculty have a strong relationship with the Genomics minor program and have consistently lectured and coordinated courses in the Genomics minor curriculum. Dr. Elena Flowers, director of the Genomics minor, is supportive of our proposed program and there have been discussions about

partnering to provide genetics education to both groups of students.

1.4.3 Relationship to School of Medicine

The UCSF Medical School incorporates genetics and genomics education throughout the integrated Bridges curriculum. Instructional faculty from our proposed program have actively participated in the medical school teaching curriculum by serving as small group leaders, developing clinical teaching cases, contributing to curriculum development and creating an elective entitled, Genomic and Precision Medicine elective for medical, pharmacy, nursing and dental students. Dr. Katherine Hyland, director of the Medical Genetics component of the Bridges integrated medical school curriculum has been a frequent mentor and collaborator on this proposal. Discussions have occurred on ways to combine genetics educational resources and enhance the curriculum of both programs.

1.4.4 Relationship to UCSF Medical Center

UCSF has recently appointed Aleksandar Rajkovic, MD, PhD as Chief Genomics Officer (CGO). Dr. Rajkovic is very supportive of the GC Program as he was involved with the University of Pittsburgh Genetic Counseling Program while on faculty at that institution. We are exploring ways that the CGO can support the program and advance the genetic counseling profession at UCSF.

Genetic counseling students will participate in clinical rotations at UCSF sites listed in Section 1.2.2.1.2. All patient encounters that students participate in will be mentored and directly supervised by certified genetic counselors or certified medical geneticists employed at UCSF. As the supervisor will be present for each encounter, all billing for student encounters will occur under the certified provider and will not negatively affect reimbursement for the Medical Center. This is the same model that is used for other medical trainees, such as medical students, and as has been utilized in the clinical training of genetic counseling students from outside programs.

1.4.5 Inter-professional genetics education

Incorporating genetics education into all disciplines of study has become a priority of the Institute for Human Genetics (IHG). The IHG has recently convened a Human Genetics Education Committee to increase the visibility of human genetics education on campus, coordinate and share existing teaching resources, ensure sustainability of current resources, collaborate on best educational practices and provide a mechanism for sharing classes amongst existing professional school and programs. This committee, chaired by Dr. Katherine Hyland, currently has representatives of the School of Nursing, Medical School, basic science doctoral programs and the GC Program. The committee will continue to recruit members, as needed, to ensure representation from all disciplines studying genetics.

1.5. Relationship of the Proposed Program with Other UC Institutions

UC Irvine hosts the only existing genetic counseling training program among the University of California intuitions. This program has been offered since 1973 and enrolls

4-6 students per year. Given the geographic distance, a new UCSF program is not anticipated to significantly impact the UC Irvine training program. At UC Irvine, all didactic instruction occurs on campus and is conducted by regional faculty and staff. Clinical rotations take place in southern California, primarily in Orange County and the greater Los Angeles area, and to date, have not negatively impacted resources in the Bay Area. Therefore, we do not anticipate the new UCSF program to compete for resources with the UC Irvine program. Over many years, UC Irvine students have periodically participated in a summer clinical rotation at a UCSF, or UCSF-affiliated clinical sites. This has occurred on average once every 3-5 years and at UCSF, we remain open to hosting students from other UC institutions as long as the training needs of the students from all programs are met. Discussions with Pamela Flodman, program director at UC Irvine, have confirmed her willingness to reciprocally host UCSF students as long as the needs of students from all programs are met. The possibility of an inter-UC summer exchange program has also been explored and will continue to be investigated.

UC Los Angeles (UCLA) is currently developing a genetic counseling training program with projected launch date of fall 2020. Didactic instruction will take place on the UCLA campus and draw on that institution's resources. Clinical rotations are designed to occur within UCLA system or in the greater Los Angeles region. As with UC Irvine, given the geographic distance, the UCSF and UCLA programs are not expected to negatively impact each other or pull resources from either institution. We have been in close contact with the UCLA leadership team and have been collaborating on the development process. At UCSF, we are open to hosting students from other UC institutions as long as the training needs of the students from all programs are met. Discussions with Dr. Christina Palmer, proposed program director at UC Los Angeles, have confirmed her willingness to also reciprocally host UCSF students as long as the needs of students from all programs are met. The possibility of an inter-UC summer exchange program has also been explored and will continue to be investigated.

UC Davis (UCD) is also developing a genetic counseling program with a projected start date of Fall 2020. The UCD program will draw on the faculty and staff at UC Davis for didactic instruction so we do not anticipate our mutual programs negatively impacting instructional resources at either institution. UC Davis has served as a periodic clinical training site for students in both the CSU Stanislaus and UC Berkeley genetic counseling training programs. On average, one student per two years would participate in a single clinical rotation at UC Davis. UCD will be giving priority to their own students so we do not anticipate using this training site in the same capacity after the UCD program is launched. Given the infrequent use of UC Davis we don't expect the loss of this clinical training site to have a significant impact on a UCSF program. Discussions with the UCD leadership team including Drs. David Segal, Katherine Rauen and Frederic Chedin have confirmed a willingness to work cooperatively to build our programs and collaborate on training ventures that could be of benefit to students on either UC campus. At UCSF, we are open to hosting students from other UC institutions as long as the training needs of the students from all programs are met and UCD is also willing to also reciprocally host UCSF students. The possibility of an inter-UC summer exchange program has also been explored and will continue to be investigated.

1.6. Administration and Governance of the Program

1.6.1 Administration of the Program

The master's degree program in Genetic Counseling and Genomics will be administered by the Institute of Human Genetics (IHG) and Department of Pediatrics. As sponsoring organizations, they will help integrate the GC Program with other IHG activities, provide administrative space and staffing support, access to shared workspaces for students, and access to conference and meeting rooms for seminars at the UCSF Mission Bay and Parnassus campuses. Academic appointments will occur through the Department of Pediatrics.

1.6.2 The GC Program Governance

The Institute for Human Genetics will be the students' home and UCSF Genetic Counseling Graduate Group (GGGC) will be the overall governing group for the GC Program. The GGCC will be comprised of 5 committees and associated members, and instructional faculty. GGGC committees include Executive, Advisory Board, Admissions, Curriculum Steering, and Capstone Research. Bylaws and Regulations and Procedures for the GGGC are included in Appendix 1. The MS degree will be granted by the UCSF Graduate Division.

The governing body of the GGGC is the Executive Committee, which will be composed of GC Program leadership (see Section 6.1), a member of the Institute of Human Genetics and a budget advisor. The principle responsibilities of the Executive Committee include implementing the GC Program, furthering program development, establishing relationships and serving as liaison with other departments or organizations both within and outside UCSF, and ensuring timely and accurate communication with instructional faculty.

The Advisory Board will provide counsel and assist in implementation of the Accreditation Council for Genetic Counseling (ACGC) requirements for achieving accreditation. Once the program is established, the Advisory Board will help to ensure maintenance of accreditation; continuing relevance of The GC Program by proposing changes to meet the evolving needs of the genetic counseling profession; promoting the program in the greater community and by providing a forum for discussion of Faculty, or other, concerns. There will be 8-10 individuals on the Advisory Board. Members will have varied backgrounds but will represent a broad spectrum of constituencies relevant to the genetic counseling profession; research, clinical care, education and private industry. The Program Director and Assistant Director and Medical Director will be *ex-officio* members. The GC Program has already begun seeking recommendations for members, has received several nominations, and will convene the inaugural Advisory Board after institutional approvals are in place.

The Curriculum Steering Committee will assess the effectiveness of current curriculum, review changes in existing courses, proposals for new courses and, identification and evaluation of new instructors to fill vacancies. Curriculum effectiveness will be assessed through student course evaluations, clinical rotation supervisor evaluations, assessment of instructional faculty and performance on the board certification examination (see Section

2.3.6.1. Proposals for new courses will be submitted to the Curriculum Steering Committee and undergo review to ensure that the proposed course logically fits within the context of the GC Program. Curriculum Steering Committee oversight is also designed to ensure that courses meet Accreditation Council for Genetic Counseling (ACGC) standards and Practice Based Competencies, avoid unnecessary course duplication, and reflect any issues relating to student concerns. The Curriculum Steering Committee is currently composed of 5 members of the UCSF genetics community plus the proposed Program Director, and has already provided input on the development of the proposed courses. Once the program has been established, the Curriculum Steering Committee shall consist of five members comprised of at least two GC Program instructional faculty and at least one clinical rotation supervisor. The Program Director and Assistant Director and Medical Director will be *ex-officio* members.

The Capstone Research Committee (CRC) will oversee the research curriculum and Capstone projects for the GC Program. The CRC will review and approve student Capstone Research Proposals to ensure projects are of appropriate scope and rigor for the program. The CRC will maintain quarterly contact with research advisors to ensure students are making appropriate progress on Capstone projects and assist in creating programs of remediation for struggling students. Additionally, the CRC will assess the effectiveness of the current research curriculum, review changes to existing research courses and create proposals for new research-related courses, if needed. The Capstone Research Committee shall consist of three members including the Research Coordinator (see section 6.1.4), who serves as committee chair. The remaining members are comprised of one member of the IHG and one genetic counselor. The Program Director, Assistant Director and Medical Director will be *ex-officio members*.

The Admissions Committee will be responsible for reviewing and evaluating applications to the GC Program and overseeing recruitment. The committee will interview select applicants, or nominate interviewers, and then shall select and admit genetic counseling students to the GC Program. The Admissions Committee will also make recommendations regarding recruitment strategies that will result in successful recruitment of a high quality, diverse student population. The Admissions Committee shall consist of five members comprised of at least three genetic counselors. The Program Director and Assistant Director will be *ex-officio* members.

The GGGC Regulations and Procedures (see Appendix 1) and Masters Program in Genetic Counseling handbook (see Appendix 2) describe program regulations including, but not limited to: information on institutional governance policies on the UCSF Code of Conduct, academic standards, requirements for progression within the program, student grievances, remediation, withdrawal or dismissal from the program and allegations of harassment.

All genetic counseling programs within the United States and Canada must undergo professional accreditation by the Accreditation Council for Genetic Counseling (ACGC). The mission of ACGC is to advance quality in genetic counseling education by developing educational standards, regularly evaluating programs and accrediting programs so as to ensure minimum program requirements are in place to graduate

competent genetic counselors. The ACGC Standards of Accreditation for Graduate Programs in Genetic Counseling and Practice Based Competencies; which address clinical training fieldwork experience, program leadership positions and evaluation processes govern how this program was developed. Initial new program accreditation is granted for three years after ensuring a minimum level of competence has been developed in all programmatic domains. Full accreditation must be achieved after three years and may be granted for up to 8 years with continual renewal expected.

1.7. Plan for the Evaluation of the Program

The GC Program will undergo continuous evaluation to help refine and improve the program in the initial phase, and as it evolves throughout the years. This continuing evaluation will help ensure that curriculum remains valid in the rapidly changing field of genetics, students are receiving adequate support from the program to achieve professional success, that clinical rotation sites are meeting program and student expectations, that clinical rotations sites are receiving adequate programmatic support, and that the standards and competencies established by the ACGC are being met by the students. Evaluation assessment and plans for any necessary modifications will be documented and kept within the Program records.

The following outcome measures will be utilized by the program as part of the evaluation process:

- Course evaluations – Students will complete standardized course evaluations for each course taught within the program. These evaluations will be reviewed by Program leadership, teaching faculty for the respective course and the Curriculum Steering Committee.
- Instructional Faculty and/or Primary Course Directors – Students will evaluate the performance of the instructional faculty and/or primary course directors as part of the course evaluations. This evaluation will include an assessment of teaching methods and effectiveness in teaching course materials. If consistent concerns are noted, program Leadership will meet with the instructor / primary course director to craft a plan for modification and/or improvement. These changes will be documented and maintained in the Program records.
- Clinical or Industry rotation site evaluations – Evaluations of the clinical rotation sites will be conducted by both the program leadership and the students. Program leaders will evaluate each site to ensure that students are receiving adequate facility access including necessary equipment, access to appropriate patient populations or data, and that students are receiving adequate on-site supervision and mentoring of their performance to fulfill the Program's expectations of the rotation experience. Students will also evaluate the rotation site using the same criteria to ensure their needs are consistently being met.
- Exit interview – Students will be asked to participate in an exit interview upon completion of the program to provide direct feedback on their experience. This will allow students to reassess curriculum and their rotation experiences following the completion of the program. It will also allow students to provide feedback on topics not captured in the above evaluations.
- Program Leadership – Program Leadership will also undergo annual evaluation to

ensure Program goals are being met, adequate instructional resources are available for the instructional faculty and that students are provided necessary tools for success. Evaluations will include input from students, program instructors, clinical site supervisors and other UCSF colleagues as appropriate, at the end of each academic year. The IHG member of the Executive Committee (see Program Bylaws) shall be responsible for distributing, collecting and summarizing the evaluations, and then reporting the results to the Program Leadership.

- Student performance on the American Board of Genetic Counseling Certification Exam (see Section 2.3.6.1) - If consistent deficiencies in specific examination categories are identified, changes to the curriculum and/or program design will be implemented.
- Alumni and Employer surveys – Career outcomes of the graduates from both the graduate and employer perspective will be collected. These evaluations will begin after graduation of the second cohort of students.
    - At two and five years post-graduation, each graduate will be requested to submit a *curriculum vitae* (for extracting current position, job responsibilities, peer reviewed publications, teaching experience, and other major professional achievements) and to complete a survey assessing the impact of the program on their current skills and expertise, how the program affected their career choice and ability to obtain a desired job.
    - Employers will be surveyed about Program graduates' level of educational preparation for the workforce, identified knowledge or skill gaps, degree to which a graduate required additional training for their position and overall satisfaction with the Program's graduates' job performance.

The GC Program Leadership will review the program in conjunction with the Advisory Board. In the first year of the program, meetings with the Advisory Board will occur at least once prior to the completion of the first academic year and then upon graduation of the first cohort. After the first year, the findings from the evaluations outlined above will be shared with the Advisory Board on an annual basis. Any issues requiring modification or remediation will be addressed with the Advisory Board and a plan and timeline for appropriate adjustments to be incorporated into the curriculum will be created.

In addition, the GC Program will undergo financial review with UCSF's Budget and Resource Management department three years after the start of the program to ensure financial viability. The UCSF Graduate Council and the Graduate Division will conduct an Academic Program Review of the program every eight years.

The Program Director will be responsible for keeping records of the above outlined evaluations and data that will provide the basis for annual reports of program performance. This data will be presented to the program Leadership, Advisory Board and the ACGC on an annual basis. This information will also be used for the Academic Program Review conducted by the Graduate Division and the Graduate Council, every 8 years.

SECTION 2. PROGRAM

2.1. Candidates for the Master's Degree in Genetic Counseling and Genomics

Students will be recruited through the UCSF Master's Program in Genetic Counseling website, journal advertisements, and at scientific meetings at a regional and national level. Regionally, the program will be promoted at events such as the Northern California Genetics Exchange and the Northern California Coalition of Genetic Counselors meetings. Nationally, the GC Program will be promoted at annual organizational meetings such as those of the National Society of Genetic Counselors, American Society of Human Genetics and American College of Medical Genetics and Genomics. The program leadership is already receiving inquiries from prospective applicants from word of mouth communication in the community. Prospective applicants often request to observe in clinic and these requests cannot be accommodated for non-UCSF employees due to privacy issues. The program will host "Day in the Life of a Genetic Counselor" presentations for these individuals and use this platform to promote the developing program. Additionally, CSU Stanislaus desires to remain connected to the practice of clinical genetics after the closure of their genetic counseling program in 2020 (Section 1.2.2.4). The GC Program leaders have held preliminary discussions with CSU about involvement in the UCSF GC Program and will continue to pursue this relationship. CSU Stanislaus, along with other CSU campuses, has a large and diverse undergraduate population and the GC Program's continued relationship with CSU Stanislaus will be utilized to promote the program within that campus and other CSU campuses to potentially establish an undergraduate pipeline.

2.1.1 Applicant Qualifications

Students who have completed an undergraduate degree from an accredited institution will be considered for admission to the GC Program. Prospective students must have successful completion of courses (or their equivalents) in introductory genetics, statistics, organic chemistry (or biochemistry) and psychology to ensure an adequate foundation in the sciences before undertaking the GC Program curriculum. Additionally, applicants are highly encouraged to have paid or volunteer experience in advocacy or counseling. Such experience is of significant value in the field of genetic counseling as it demonstrates the candidate's appreciation and understanding of a counseling or supportive role. The GC Program intends to maintain a strong counseling core so a solid awareness for the counseling relationship is critical before applying to the program. This experience may derive from a variety of settings such as: Planned Parenthood, crisis hotlines, peer counseling or working with individuals with physical disabilities or intellectual impairment. Other experiences that demonstrate the development of interpersonal communication skills or the opportunity to work with a variety of individuals seeking information, resources, guidance, counseling or other support services is also acceptable. Applicants may obtain this experience through employment or part time volunteer work.

GRE scores will not be required. Any student desiring to provide GRE scores from the general exam may include these with the rest of their application materials. In such a case, the GRE scores will be reviewed, but not considered as a significant component of

the application. Any student including GRE scores must provide scores from the last 5 years.

Proficiency in English is required for admission into the Program. Applicants whose native language is not English will be eligible under the same conditions, but they must take the Test of English as a Foreign Language (TOEFL, http://www.toefl.org) and achieve a minimum acceptable score. Acceptable scores are as follows:

- 550 (paper version)
- 213 (computer version),
- or IELTS exam with a minimum score of 7

Alternatively, applicants may also demonstrate proficiency in English if they have completed one year of full-time study at an accredited university in the United States with a minimum GPA of 3.2.

2.1.2. Foreign Language

Foreign language proficiency will not be required for admission into the program. Applicants are strongly encouraged to demonstrate intermediate proficiency in at least one language other than English as foreign language skills are highly valued in the practice of genetic counseling, but this will not be required for admission. The majority of journals and scientific meetings of relevance are in English.

2.1.3 Diversity

UCSF celebrates diversity and is committed to building a broadly diverse and inclusive community. The GC Program also places a high value on diversity and has a deep appreciation for the perspectives and rich experiences that a varied student body and faculty can bring to the educational process. The UCSF Office of Diversity and Outreach leads the campus effort to foster a culture of equity and inclusion by serving as the central resource for internal and external community members. It fosters a collaborative culture by leading outreach efforts to increase the number of underrepresented students at all levels of the educational pipeline and to increase the diversity of the pool for faculty, staff and leadership positions. Additionally, it is the home of a wealth of resources such as the Multicultural Resource Center, Diversity Hub, LGBT Resource Center, free on-demand training and many other programs to support a welcoming climate.

The genetic counseling profession remains largely female and often does not fully reflect the racial/ethnic diversity of the patient populations it serves despite efforts by the professional society to increase ethnic and racial diversity. In an effort to reach underrepresented applicants, the UCSF Office of Diversity and Inclusion will be featured prominently on the homepage of the GC Program's website. As the website will be an integral marketing tool, featuring this resource will highlight UCSF's and the GC Program's commitment to foster an environment inclusive to everyone.

The program will also participate in outreach efforts to recruit the most diverse applicant pool. "Day in the Life of a Genetic Counselor" seminars (see Section 2.1) will be

conducted at all UCSF campuses, including Oakland and Fresno. Promotion of the GC Program will also occur at CSU campuses, which possess diverse student bodies. Efforts will begin with Stanislaus and SF State (see Section 2.1). Webinars about genetic counseling will also be featured on the GC Program website and will feature information about the diverse environments present throughout UCSF.

2.2. Program of study

This intensive, full-time, seven quarter program exceeds the educational objectives of the MS degree requirement established by the UCSF Graduate Division. Students will be required to complete 60 units of classroom and clinical study, while also completing a capstone project. This curriculum gives students a comprehensive understanding of the medical, scientific, and psychosocial aspects of clinical genetics and produces highly desirable and sought-after graduates for employers.

2.2.1 Specific Fields of Emphasis

The didactic and experiential components of The GC Program curriculum support the development of competencies the following domains: (I) Genetics Expertise and Analysis; (II) Interpersonal and Psychosocial Counseling (III) Provision of Genetics Education; and (IV) Professional Development & Practice. All students will engage in the same curriculum. Students desiring to specialize in a particular field of genetics may pursue this through their capstone research project and focused clinical rotations. For example, a student desiring to gain expertise in cancer genomics could participate in clinical rotations at the UCSF Cancer Risk Program and the Clinical Cancer Genomics Laboratory; while also pursuing a capstone project related to clinical cancer genetics. The targeted experiential learning provided through these intellectual pathways will allow students to explore areas of interest at a greater depth than provided through classroom teaching. Additionally, it will allow students to learn from the broadest and most diverse community at UCSF as the majority of faculty teach and mentor trainees outside of the classroom setting.

2.2.2 Plan for a Master's Program

The Program will conform to the Masters of Science Plan II as outlined by the UCSF Graduate Council Regulations and Procedures. This plan requires 36 units of coursework and comprehensive examination (or capstone project, see Section 2.3.5).

2.2.3 Unit Requirements

The minimum University of California requirement for a master's degree is three quarters in residence and completion of 36 units of study. This 7 quarter 60 unit program meets and exceeds the minimum requirement. The course of study is typical for contemporary genetic counseling programs.

2.2.4 Required Courses

All courses in the program are required, rather than recommended. The curriculum has been designed specifically to satisfy ACGC professional accreditation requirements and

is similar to established genetic counseling programs throughout the United States. Additionally, the content has been carefully curated to ensure adequate preparation for the certification examination while also providing a solid foundation in the practice of clinical genetics. The two-year program consists of 6 quarters of didactic coursework with the majority of classroom study occurring in the first academic year (the summer quarter is dedicated to a clinical rotation and capstone work). In the second academic year, the number of academic units is significantly decreased to allow students to focus on clinical training and have adequate time for their research. This is a rigorous master's degree program, but not so difficult as to be overly challenging to complete in seven quarters of full time study.

A sample curriculum showing the sequence of courses is illustrated in Table 2. All proposed courses are described in Section 5A. The masters degree will be awarded only after successful completion of the coursework (full unit requirements), clinical internships and acceptance of the final capstone project.

Clinical exposure to the practice of medical genetics begins in the second quarter of the program. Students will enter clinical rotation sites during the Externship I and function as clinical assistants in order to build practical skills that cannot be acquired in the classroom. Involvement will continue to build throughout the quarter and progress to Externship II in quarter 3. In Externship II, students will increase their interaction with patients and begin actively participating in professional care. Beginning in the 4th quarter students are immersed in clinical training and ultimately receive 4 quarters of solid clinical training. Clinical rotations at UCSF, UCSF affiliates and community genetics centers (such as Kaiser Permanente and Sutter Health) will provide opportunities for face-to-face encounters with individuals and families affected by, or at risk of, a broad range of genetic conditions. Additionally, rotations in UCSF laboratories and local industry sites will provide the chance for students to learn about genetic diagnostics.

Students are required to pass each clinical rotation (12 total units) with satisfactory evaluations from the clinical supervisor. Additionally, students must collect a minimum of 50 core-qualifying clinical cases for their American Board of Genetic Counseling (ABGC) logbook. These cases are a requirement for eligibility for the certification examination and reflect a student's robust and evolving clinical involvement. Core-qualifying cases focus on the development of fundamental clinical counseling roles and must have active participation in the domains of Management, Education and Counseling. Examples of skills in each of the domains include:

- Management: case preparation, collection/documentation of medical or family history, collection/documentation of a pedigree, risk assessment, evaluation/coordination of genetic testing, clinical documentation
- Education: providing patient/client education on inheritance pattern, risk counseling, diagnosis/prognosis/natural history, testing options and possible results/benefits/limitations, results disclosure, research options/consent

- Counseling: establishing rapport/contracting, psychosocial assessment, psychosocial support/counseling, resource identification/referral, self-assessment/self-reflection

The GC Program will be responsible for ensuring that each of these roles is adequately represented in the full clinical case experiences of the student. Any student participating in a rotation in a clinical or laboratory setting, whether academic or private industry, must be supervised by a board certified genetic counselor or clinical geneticist as required by the ABGC.

Prior to launch of the program, GC Program leadership will develop an electronic log book for students to document cases. This logbook will be maintained within the students' files, but will not include any patient identifiers or protected health information.

Table 2

	Monday	Tuesday	Wednesday	Thursday	Friday	Total Units
Quarter 1 Fall	Human & Molecular Genetics (2 units)	Principles of Counseling (2 units)	Clinical Cytogenetics (2 units)	Advanced Medical Genetics I (2 units)		13
	Clinical Embryology for Genetics Clinicians (on-line) (1 unit)	Research Methods for Genetic Counselors I (2 units)		Genes, Populations and Pedigrees (2 units)		
Quarter 2 Winter	Research Methods for Genetic Counselors II (1 units)	Counseling Theory to Practice (2 units)	Variant Interpretation & Advanced Technologies (2 units)	Advanced Medical Genetics II (2 units)		11
	Graduate Seminar in Genetics I (1 unit)	Reproductive Genetics (2 units)				
		Externship I (1 unit)				
Quarter 3 Spring	Cancer Genomics (3 units)	Genetic Counseling Foundational Skills (2 units)	Social, Ethical and Legal Issues in Genetics (2 units)	Advanced Medical Genetics III (2 units)		12
	Graduate Seminar in Genetics II (1 unit)					
		Externship II (1 unit)				
	Capstone Research Project (1 unit)					
Quarter 4 Summer	Clinical Internship I (3 units)					3
Quarter 5 Fall	Advanced Genetic Counseling Skills (2 units)					7
	Clinical Internship II (3 units)					
	Capstone Research Project (2 units)					

	Monday	Tuesday	Wednesday	Thursday	Friday	Total Units
Quarter 6 Winter	Advanced Topics in Genetic Counseling (2 units)					7
	Clinical Internship III (3 units)					
	Capstone Research Project (2 units)					
Quarter 7 Spring	Professional Formation (2 units)					7
	Clinical Internship IV (3 units)					
	Capstone Research Project (2 units)					

2.2.5 Description of capstone element

2.2.5.1 Capstone Overview

The purpose of the Capstone Project is to allow students to gain experience in research project development and implementation, institutional requirements for research, research methodology and data analysis, evidence-based approaches to problem solving, professional writing, and self-directed learning in order to increase their professional growth and contribute to the field of genetic counseling. Additionally, the Capstone Project will allow students to deeply explore fields of interest and collaborate with faculty from many disciplines.

The Capstone element will be governed by a Capstone Research Committee (CRC) to provide structure, support the students and optimize success. The CRC will be comprised of 3 members of UCSF faculty and staff with professional interests in genetics and/or genetic counseling. The committee will be chaired by the Capstone Research Coordinator (see Section 6.1.4).

Each student will implement an individual, original graduate level investigation that has been approved by the program's Capstone Research Committee. Projects can range in topic area and may include, but are not limited to, laboratory involvement, detailed clinical case studies and systematic literature review and critique, that answer a specific question or illustrates a novel concept, analysis and interpretation of data from an existing research project or database to answer a new question, survey development or development of clinical practice or educational tools. The Capstone Project culminates in an oral presentation of the project and submission of a substantive paper that reflects a deep understanding of the topic. The paper may take the form of a publishable manuscript submitted to a peer-reviewed journal, traditional research paper or other

scholarly project as approved by the Capstone Advisory Committee. Publication and/or professional presentation is strongly encouraged, but not mandatory.

2.2.5.2 Capstone Development

During the first quarter of the program students take the course "Research Methods for Genetic Counselors" (see Section 5A) to provide them with the foundation to formulate their Capstone Research Proposal. Students must select a Capstone Project topic by the end of the first quarter of the first year and are encouraged to pursue a topic that piques their personal interests while also contributing to the knowledge or practice of genetic counseling. Students who have not selected a topic by the deadline will receive enhanced mentoring from The Capstone Research Committee.

During the second quarter of the first-year student will take the course "Research Methods for Genetic Counselors II" (see Section 5A). This course applies the content learned in the first quarter course and assists students in the development and design of their Capstone Project. By the end of this course students must submit a 3-5 page (excluding references) Capstone Project Proposal for approval by the Capstone Research Committee. This proposal must include an introduction to the topic, description of the area of investigation including defined goals and/or hypotheses, literature review including critique of prior research (or products), description of the project including research methods, and references. Once the Capstone Project has been approved, students may embark on their research project. Additionally, students are provided with necessary assistance in selecting a research advisor that will oversee their research project. Research advisors will consist of UCSF faculty, staff genetic counselors and genetics professionals from external rotation sites.

In the first year of the program, students will begin work on their research project in the third quarter to seek any necessary institutional approvals, such as IRB approval. The majority of work for the project is executed during the second year of study.

2.2.5.3 Capstone Project

The Capstone project is the culminating experience for students of the GC Program. The purpose of the Capstone requirement is to prepare students with the knowledge and skills required to contribute to the field of genetic counseling by engaging in activities such as performing research; or developing community or professional education programs; or developing clinical practice tools or educational service programs that benefit those affected by genetic disorders. It concludes with the submission and presentation of a scholarly paper, or first-author, submission-ready manuscript, or scholarly product (such as education materials, education program or clinical practice tools previously approved by the Research Committee) that reflects a deep understanding of the chosen topic.

Students are required to demonstrate rigor and value with their chosen project. Rigor is defined as a systematic, logical and thorough approach to the design and implementation of a Capstone project that addresses a clearly defined question or significant problem; and includes an evaluation process based on appropriate metrics, collected and analyzed using methods that provide a valid and reliable determination of project outcomes. Value

is defined as the potential to make a contribution to improving the practice of genetic counseling. Scholarly papers are documents that communicate results of the Capstone project with the following criteria: clearly defined primary objectives, documentation of the importance of the project within the previously published literature, description of the design and implementation of the study or project, results or answers to the study question(s) and interpretations and/or conclusions of the findings. Publishable manuscripts must be of sufficient quality to submit to a peer-reviewed journal approved by the Research Committee and follow the requirements of the selected journal. Students selecting a non-research type of project must submit a copy of any "product" (clinical practice tool, education manual etc.) produced as part the Capstone project along with a Capstone Experience Project Report. The Capstone Experience Report describes and documents the background work, comprehensive literature review (including other sources of information such as consultation with other professionals), methods or activities to complete the project and results (description of the product and details of any assessments or evaluations of the product). The purpose of this report is not to duplicate the product, but provide description and documentation of the overall efforts involved in completing the project.

Submission of the aforementioned scholarly work and successful oral presentation (Section 2.2.5.5) is required for graduation. Additionally, students will be strongly encouraged to submit an abstract of their Capstone project to the National Society of Genetic Counselors (NSGC) annual education conference or other relevant scientifically recognized national or international conference.

2.2.5.4 Capstone Mentoring

Each project is completed under the guidance of the student's research advisor and CRC. The research advisor will be the students' primary supervisor and will be a member of the UCSF faculty or staff, or surrounding genetics community. Students are encouraged to maintain frequent contact (at least monthly) with their advisors in order to ensure timely progression of their research projects. Upon approval of the Capstone Project students will meet with their research advisor to devise a detailed work plan including; timeline for completing the project, specific requirements, deadlines for research milestones, writing and draft submission, and defense. The timeline will be submitted to the Capstone Research Coordinator for review and approval. The Capstone Research Coordinator will contact research advisors for updates on student progress at 3 month intervals throughout the project's duration. Students experiencing difficulties with their project, or not meeting milestones, will meet with the Research Coordinator to devise a course of remediation.

2.2.5.5 Capstone Defense

Each student will submit a substantive paper, publishable manuscript or other scholarly project that encompasses their research project and demonstrates their depth of understanding of the content. This document, or scholarly project, will be presented and defended by the student to at least a 5-member committee consisting of: a UCSF faculty member that has not been involved in the Capstone Project, the GC Program Research

Coordinator, a member of the Program leadership team, the student's capstone research advisor, a genetic counselor of their choosing and any other desired guests. Paper submission and project defense will occur prior to the end of the 7th academic quarter. In order to fulfill the requirements of this program, the defense will need to be deemed successful by a majority of the committee.

2.2.6 Student Guidance

A strong student guidance program rounds out the course of study. To help students achieve academic success, several layers of guidance will be provided throughout their educational experience. Guidance will begin immediately upon entering the program with two foundational relationships. The first is a peer connection with an experienced GC Program student and the second, a relationship with an academic mentor. As described in other sections, additional guidance is also provided during the Capstone Project and clinical training rotations. For the Capstone Project, each student selects a Capstone Project advisor who helps guide the endeavor (see section 2.3.5.4) and the entire research program is overseen by Capstone Research Coordinator (see section 6.1.4) who reports to the Program Director. Students will also be mentored during each of their clinical rotations by a site rotation supervisor who is board certified genetic counselor or clinical geneticist (see Section 2.3.4 and Appendix 4). The clinical training program is overseen by the Assistant Program Director and site supervisors report to the Assistant Program Director

Each first year student (with the exception of the inaugural cohort) will be paired with a second year student "buddy". This buddy relationship will provide initial peer support for incoming students while also allowing for unique first-hand insights into how to successfully navigate the GC Program. Additionally, this relationship will also likely provide information of a practical nature; such as living in the Bay Area, housing, transportation etc.

The GC Program leadership will pair buddies upon completion of the spring quarter. The second year student of the pair will be required to reach out to their buddy during the summer in order to help ease the transition into the Bay Area (if relevant) and entry into GC Program. During the academic year, buddies should meet in person at least once per quarter throughout the first year. Additional in-person meetings or other points of contact are highly encouraged throughout the first year. Student buddies are not expected to address academic issues or other areas of concern, but are to serve as peer resources.

In the fall quarter, each incoming student will be assigned an academic mentor who is a UCSF faculty member, practicing genetic counselor or other member of the UCSF genetics community. The academic mentor shall function as a partner who is committed, for the duration of the program, to providing guidance through courses and clinical training experiences, being an academic advocate, facilitating decision making, promoting the growth and professional development of the beginning genetic counselor and otherwise providing support to ensure student success. Academic mentors are not required to report the contents or outcomes of their meetings to GC Program leadership and will be encouraged to provide a confidential outlet for students. If an academic

mentor feels that information brought to their attention by the student should be shared with the Program Director or other GC Program leadership, the mentor will inform the student of such.

At a minimum, academic mentors will be expected to:

- Share expectations of the mentor-mentee relationship at the first meeting.
- Communicate directly, (via telephone, email or in-person) at least once per month with their mentee. The first interaction will be initiated by the academic mentor and should be in-person. The content and direction of these communications should be dictated by the mentee's needs, but should also include reviewing academic progress, identifying areas of difficulty, answering questions, assisting students in navigating the UCSF system, providing emotional support and facilitating decisions (for example, Capstone Project selection, clinical rotation site preferences etc.).
- Communicate directly, (via telephone, email or in-person) at least once per quarter with their mentee during the second year of the program, but more frequent interaction is encouraged. The decrease in frequency is due to the fact that the student will also be under close supervision from their Capstone Project advisor (see section 2.3.5.4) and clinical rotation supervisors. Those specific individuals should be the student's first resource while engaging those endeavors, however, a student may also desire to discuss issues related to these projects with their academic mentor to get a broader perspective.
- Maintain an "open door policy" in regards to communication from their mentees.
- Demonstrate consideration and respect for the student's time by being punctual for scheduled meetings and returning correspondence in a timely manner
- Get feedback from the student on the mentoring relationship and make appropriate adjustments
- Be a role model for the student and be sensitive to academic or personal problems that may interfere with the learning process

At a minimum, mentees will be expected to:

- Demonstrate consideration and respect for the academic mentor's time by being punctual for scheduled meetings and returning correspondence in a timely manner
- Initiate meetings with the mentor after the initial relationship has been established
- Ask for feedback, including specific details.
- Inform the mentor how the mentee prefers feedback (directly, softly, with humor etc)
- By the 2nd quarter of the second year, present a draft of goals and objectives for their career

2.2.7 Certification and Licensing Requirements

2.2.7.1 Certification

Students successfully graduating from the UCSF Masters of Genetic Counseling program will be eligible to apply for the American Board of Genetic Counseling (ABGC)

certification examination. Genetic counseling certification (Certified Genetic Counselor or CGC®) is a voluntary process that occurs upon receiving a passing score on the standardized comprehensive written examination conducted by the ABGC. Certification ensures a genetic counselor has met the minimum education requirement that includes attending an accredited program and attainment of the standards, knowledge and skills to enter professional practice. Although certification is currently voluntary, the majority of employers in the United States require their genetic counseling employees to achieve CGC® credentialing. Additionally, an increasing number of insurance companies are requiring their subscribers to visit a certified genetic counselor prior to paying for genetic testing.

ABGC certification lasts for 5 years and diplomates are required to recertify every 5 years. Certification is maintained by participating in 125 continuing education hours over the 5-year period. Those not meeting the continuing education hour requirement must retake the ABGC certification exam.

2.2.7.2 Licensure

Genetic counselors have achieved licensure in California and 17 other states; 30 states are in an active process of obtaining genetic counselor licensure and 2 are not currently pursuing licensure. In California, a Genetic Counseling license is required for any person employed as, practicing as, or using the title of Genetic Counselor. Licenses must be renewed every 3 years and require 45 hours of continuing education during that 3-year period [1]. In states requiring genetic counselors have a license to practice, the CGC® certification is a requirement to obtain a license. Licensed and certified genetic counselors use the title, LCGC.

2.3 Field examinations

Field examinations will not be required but students are required to pass each clinical rotation (12 total units) with satisfactory evaluations from the clinical supervisor. Student evaluation forms may be found in Appendix 4.

2.4 Qualifying examinations

No written or oral qualifying examination is required.

2.5 Thesis and/or dissertation

The Master of Science Plan II does not require a thesis or dissertation. Students in the Masters Program in Genetic Counseling will be required to execute a capstone project as described in Section 2.3.5

2.6 Comprehensive Examination

The MS Plan II requires a Comprehensive Examination. The comprehensive examination for this program consists of a capstone project (see Section 2.3.5). The capstone for this program is a substantive research project in the field of genetic counseling. The focus of each student's project is determined by the interest of each student; however, the research project is expected to meet a standard of quality. The final

project will be undertaken after consultation and approval by the program's Capstone Research Committee in the first year.

2.7 Special Requirements

The program has no requirements over and above the Graduate Division requirements.

2.8 Relationship to Doctoral Programs

The Masters of Science degree is terminal degree in the field of genetic counseling.

2.9 Special Preparation for Careers in Teaching

The program does not provide preparation for a teaching career.

2.10 Normative time from matriculation to degree

The time from Matriculation to degree for full-time students will be seven consecutive quarters. This program is designed for full-time enrollment. This is a rigorous master's degree program, but not so difficult as to be overly challenging to complete in seven quarters of full time study. Students who must take a leave of absence may only re-enter the program after receiving permission from the Program Director and Co-director (see Appendix I, Regulations and Procedures). This strict requirement is necessary due to the progressive curriculum, development of clinical skills during internships and finite number of clinical rotations.

Section 3. PROJECTED NEED

3.1. Student Demand for the Program

The Association for Genetic Counseling Program Directors (AGCPD) collects, tracks and analyzes applicant and admissions data. This data is not published as it is voluntarily self-reported from accredited genetic counseling programs in the United States and Canada, and has been noted to have some inconsistencies. Despite these inconsistencies, the data is shared amongst genetic counseling program directors and serves to illustrate the continuing trend of increasing student demand.

Student demand for genetic counseling programs continues to increase, paralleling the growing public awareness of genomic medicine and explosion of available genetic tests. From 2010 through 2017 the number of applicants to genetic counseling programs increased approximately 78%. More specifically, from 2010 to 2013 the number of applicants increased 13%, from 2014-2016 applicants increased another 24% and from 2016–2017 the number of applicants increased an additional 20%. The applicant trend is not anticipated to decrease.

Admission to genetic counseling programs remains highly competitive with an overall annual matriculation rate among applicants at approximately 25%. The 2017 AGCPD admissions data revealed that there were 1,299 unique applicants and 49% of those applicants were offered interviews by at least one program. Yet, only about 27% of applicants matriculated into accredited programs in 2017. This trend has been consistent

over many years and demonstrates that despite the launch of more genetic counseling programs the number of available training positions does not meet demand.

Applicant demographics have remained relatively consistent over the past decade and in 2017 the majority of US applicants reported to reside in California. California residents reportedly made up 8% of the total number of applicants with the next largest cohort (at 5%) coming from Pennsylvania. Approximately 20% of applicants are international and of those international applicants, 72% are from Canada. The UCSF Masters in Genetic Counseling intends to recruit students from throughout the United States and the international community. Given the applicant demographic trends we expect our cohorts to be filled with students from throughout the country and possibly some international students.

3.2. Opportunities for placement of graduates

Employment opportunities for genetic counselors are becoming increasingly diverse and can include roles in direct patient care, diagnostic laboratories, pharmaceutical companies, education, research, patient advocacy groups, healthcare advisors, public health and private industry. Recent graduates have had the good fortune of multiple job offers as well as the ability to negotiate the terms of their employment. National Society of Genetic Counselors President Jehannine Austin, PhD, MS was quoted in 2016 as stating, "So we're in a position at the moment where people who graduate with genetic counseling [master's] degrees essentially have their pick of what they would like to do,".[2]

The Genetic Counselor Workforce Working Group (WFWG) reported, "a near-zero unemployment rate for certified genetic counselors, and near 20% annual growth in job postings for certified genetic counselors between 2013 and 2016" (see Appendix 5).

The U.S. Bureau of Labor Statistics projects a growth rate of 29% for genetic counseling positions over the years 2014-2024. This far exceeds the average growth rate of 7% for all occupations and 10% rate of other healthcare practitioners or technical professionals.[3]

Locally, the California State University-Stanislaus Master of Science in Genetic Counseling Program shared employment data for their program from graduation years 2013-2016. Virtually 100% were employed as a genetic counselor within 6 months of graduation. 2016 was the only year without 100% employment within six months as 2 students elected, for personal reasons, to postpone their employment search.

3.3. Importance to the discipline

Genetic testing continues to have an ever-increasing role in healthcare. Genetic results can help refine a diagnosis, guide prognosis, determine a therapeutic regimen (such as the most appropriate chemotherapy) and tailor disease surveillance and prevention methods for individuals found to be at heighted disease risk. Plummeting prices for genomic testing has enabled accessibility and created more awareness of heritable disease among healthcare providers; as well as sparking the general public's

interest in DNA-based tests. Per Concert Genetics, a company that tracks the genetic testing industry, "as of May 2017 there are over 70,000 genetic testing products on the market today with approximately 10 new testing products entering the market daily".[4]

The majority of healthcare providers do not receive adequate (or any) training in medical genetics and the rapidly evolving field makes it improbable that professionals not receiving specific training in clinical genetics will possess current knowledge.[5,6,7] There are less than 1,600 certified MD clinical geneticists in the United States, and as a result, genetic counselors are becoming increasingly important members of the healthcare team.

Many non-genetics providers, as well as the public, have the perception that genetic testing is simple; one undergoes testing and the result is either positive or negative; therefore, it is easy to interpret and apply to patient care. The reality is that genetic testing is not appropriate for every patient and the results are complicated. There are positive and negative results, inconclusive results, uninformative results and countless testing options; all of which need to be catered to each patient. Correct interpretation of the results guides medical management not just for the patient, but often for the entire family since genetic information is shared among blood relatives. Negative patient outcomes have been published due to incorrect tests being ordered, misinterpretation of results, incorrect risk assessment and inadequate pre and post-test counseling.[8,9,10,11,12] These errors have resulted in patients receiving unnecessary prophylactic surgeries, unneeded tests and medical interventions, psychosocial distress, delayed diagnoses, and false reassurances with inadequate medical management due to a misunderstanding, or over-interpretation of results. As the use of genetic testing expands into disciplines where genetics has not traditionally been practiced, these risks will continue to increase. Testing options will also continue to grow more and more complex and the associated risks will also continue to increase. It is unrealistic to expect practicing clinicians to re-train in genetics, or for medical schools to add comprehensive genetics training to their curriculums. Therefore, genetic counselors must be utilized to bridge the knowledge gap in contemporary healthcare and ensure maximum benefit and minimal risk from the use of genomic information.

Genetic counselors also help reduce health care costs by ensuring appropriate utilization of genetic testing. Several studies have demonstrated that between 30-50% of healthcare dollars spent for genetic testing are wasted or spent on inappropriate tests.[8, 13,14,15,16] This is a direct consequence of most ordering clinicians having little knowledge of clinical genetics, current policy guidelines or sufficient time to investigate the most appropriate test. One reference laboratory found that over a 21-month period, 26% of complex genetic tests were ordered incorrectly. Genetic counselor review and modification of the ordered tests (following consultation with the ordering clinician) averaged $48,000 per month in cost-savings to the referring institutions, $792 per misordered test and saved almost 1.2 million health care dollars over the course of the study.[13] Another study found a savings of $2,015.32 per ordering modification recommended by the genetic counselor.[14] The skills of genetic counselors are critical in preventing inefficient use of limited healthcare dollars as the majority of ordering clinicians order incorrect genetic tests, or too much testing. Although employing genetic counselors in the laboratory may

seem counterintuitive to business, such utilization management models result in increased health insurance reimbursement rates by maintaining the value of genetic tests. Due to concerns about the incorrect use of genetic testing, in 2013 Cigna became the first national insurance company requiring genetic counseling by a certified provider prior to payment for breast or colon cancer genetic testing. Cigna expanded this requirement in 2016 to also include reimbursement for exome sequencing, several inherited cardiovascular conditions and microarray analysis for pediatric cases.

3.4. Ways in which the program will meet the needs of society

As increasing amounts of genomic data become available for both the ill and healthy individual, and pressure from the public for genetic testing rises, the need for professionals trained in the meaning and implications of the data and the impact on the individual and their family members is increasing. There are not enough genetic counselors to meet the existing needs of the population. With approximately 4,000 certified genetic counselors in the United States this translates to roughly one genetic counselor per 80,000 Americans.

In anticipation of the rapidly increasing demand for genetic counselors, several genetics professional societies commissioned The Genetic Counselor Workforce Working Group (WFWG). The WFWG projected workforce supply and demand for US-based certified genetic counselors from 2017-2026 (Appendix 5). The commissioners included: American Society of Human Genetics (ASHG), National Society of Genetic Counselors (NSGC), American Board of Genetic Counselors (ABGC), Accreditation Council for Genetic Counseling (ACGC) and Association of Genetic Counseling Program Directors (AGCPD). The study focused on calculating the supply and demand for genetic counselors delivering care directly to patients in a variety of settings and indicated a shortage of genetic counselors engaged in direct patient care. Assuming demand of one genetic counselor per 100,000 people in the United States, supply is expected to reach equilibrium in 2023 or 2024. If the demand assumption is based on one genetic counselor per 75,000 people, then equilibrium is not reached until 2029- 2030. This program will address the shortage by sending more trained genetic counselors into the workforce.

Finally, the deluge of genomic data will continue raise troubling ethical and important social questions for clinicians and care providers. Training in medical ethics is a required component of the genetic counseling curriculum and students will be challenged to apply ethical principles to the contemporary practice of clinical genetics. In their professional careers, genetic counselors will be increasingly called upon to provide consultation for individual patients, clinicians and the general public surrounding ethical dilemmas about incomplete knowledge, unanticipated findings, privacy and confidentiality, reproductive choices, personal autonomy and the potential for eugenics.

3.5. Relationship of the program to research and/or professional interests of the faculty

The proposed program is compatible and consistent with the professional and research interests of faculty throughout the UCSF community. As noted earlier, in 2013 UCSF unified the efforts of UCSF researchers and clinicians to translate genetics research into clinical care by establishing the campus-wide UCSF Genomic Medicine Initiative (see Section 1.2.2.2.2)

3.6. Program Differentiation

The UCSF GC Program will distinguish itself from other genetic counseling programs by capitalizing on the rich resources of UCSF and the Bay Area. As described earlier, the combination of world-renowned clinical and research institutions in one site is unparalleled to the majority of programs (see section 1.2.2). UCSF students will be clinically trained by experts in their field and have the chance to be mentored by award winning researchers for their Capstone Project. Additionally, many contemporary genetic counseling programs have curtailed components of the counseling curriculum to make room for increased instruction in fields of molecular biology and technology. At UCSF, we feel that a genetic counseling training program should maintain a strong counseling core. Doing so will root students in the human side of medicine and promote the counseling skills needed to apply the science to the lives it affects. This aligns with the growing trend in medical education to promote whole person care.

Very few genetic counseling training programs have campuses located in such culturally and socioeconomically diverse locations such as the Bay Area and Fresno. Both areas host a wide range of ethnic and racial diversity, but the Bay Area has some of the most affluent areas in the nation, while Fresno has a poverty level almost twice the national average. San Francisco and the surrounding communities are home to technology and elite educational institutions, while the Fresno area has a high school dropout rate exceeding that of the rest of the state; almost 50% of the population speaks languages other than English at home; and a low health literacy rate. There are 32 Health Resource and Services Administration (HRSA) defined Medically Underserved Areas in the region of the San Joaquin Valley surrounding Fresno and the UCSF-Fresno campus provides the opportunity to provide genetics services to underserved communities. These diverse locations offer opportunities for students to practice in both urban and rural settings, privileged and underserved communities, and everything in-between, while serving to highlight the psychosocial and socioeconomic differences between the two areas.

Finally, the GC Program will take advantage of residing in the epicenter of technology, Silicon Valley. The San Francisco Bay Area is the home of numerous private genetic testing companies, all of which employ genetic counselors in a variety of roles. These roles include, but are not limited to, counseling services, marketing, sales, Medical Science Liaison, policy makers, community education and genomic data interpretation. The diverse careers of genetic counselors in local industry settings illustrate the broadening application of genetic counseling skills and will allow students to envision varied employment options after graduation. The opportunity for students to train in a

variety of private industry settings is unique to the San Francisco Bay Area and will be a draw for applicants desiring careers outside of the traditional patient care role.

Section 4. LIST OF CORE FACULTY MEMBERS, RANK AND HIGHEST DEGREE

A list of faculty and staff members, ranks, and highest degree and accompanying curriculum vitae that include professional qualification and recent publications are included in Appendix 3.

Section 5. COURSES

5A. Proposed Core Courses

Description of Proposed New Courses
Each entry below contains a course description suitable for entry into the university course catalog under the proposed Genetic Counseling(GENC) heading. The GENC designation is subject to approval by the Committee on Courses.

Quarter 1

GENC201: Human and Molecular Genetics (2 units)
Course Director: Marta Sabbadini, PhD, MS, LCGC

This course is an advanced exploration of the fundamental principles in human molecular genetics and the molecular basis of disease. These topics are illustrated through discussion of gene and genome structure, regulation of gene expression, DNA damage and repair, human genetic variation, the basis of heredity such as Mendelian and non-Mendelian inheritance patterns, mechanisms of genetic disease and an introduction to testing methodologies.

Course Objectives: Upon completion of the course students will be able to:

1. Describe normal gene structure and regulation
2. Describe how sequence variation occurs and leads to disease
3. Identify epigenetic mechanisms that control gene expression and can lead to disease
4. Provide examples of human disease that illustrate molecular pathologic mechanisms
5. Explain testing methodologies and ascertain which clinical scenarios are most appropriate for each method

GENC202: Clinical Cytogenetics (2 units)
Course Director: Jingwei Yu, MD, PhD

This course will provide an introduction to the fundamentals of clinical cytogenetics and the indications for cytogenetic analysis while highlighting the enduring significance of the field in the era of genomic sequencing. Students will learn about chromosome morphology and organization, cytogenetic naming conventions, the relationship of cytogenetic disorders to human disease, transmission of cytogenetic anomalies and the analytical tools used for diagnosis and investigation of human genetic variations. An opportunity to visit the cytogenetic laboratory will also be available.

Course Objectives: Upon completion of the course students will be able to:

1. Articulate the significance of cytogenetic analysis
2. Describe human chromosome structure and cytogenetic nomenclature
3. Identify varying mechanisms leading to chromosomal abnormalities and their relationship to disease
4. Explain the reproductive implications for various chromosomal anomalies and compute risk calculations
5. Critique the applications and limitations of current cytogenetic testing methodologies

GENC203: Research Methods for Genetic Counselors (2 units)
Course Director: Julie Harris-Wai, PhD, MPH

This course serves as an introduction to the Capstone Research project and provides a foundation in the necessary tools to conduct a research project. Students will learn about the quantitative and qualitative research models utilized in investigations relevant for genetic counselors, the scientific method, how to formulate a research question, study design, writing human research protocols, the IRB process and obtaining informed consent. The quantitative component will include survey development and various statistical analyses using SPSS software. The qualitative component will include interviewing skills, focus groups and questionnaire sessions, interview guide development, and various approaches to qualitative data analysis.

Course Objectives: Upon completion of the course students will be able to:

1. Compare and contrast the various methods to quantitative data analysis
2. Compare and contrast the various methods to qualitative data analysis
3. Appreciate the purpose of the IRB and the protections it offers to human subjects
4. Demonstrate how to formulate an appropriate research question
5. Recognize components of study design including study population, data collection and data analysis

GENC204: Principles of Counseling (2 units)
Course Director: Summer Segal, MS, PhD, LCGC

This course provides an introduction to the fundamental principles of counseling and the psychosocial aspects the clinical encounter. Emphasis is given to the exploration of the impact of medical care on the individual and family, family dynamics and communication styles, the lived experience of illness, the search for the meaning in loss and cultivation of multicultural competencies. Course readings provide foundational knowledge of relevant concepts, and class discussions encourage the comparison of different perspectives and applications.

Course Objectives: Upon completion of the course students will be able to:

1. Identify common emotions and defenses experienced by patients and/or families during a medical crisis
2. Recognize differing family systems and communication methods within such systems
3. Develop an understanding of the concepts of narrative medicine and the lived experience of illness
4. Develop multicultural awareness and competency

GENC205: Advanced Medical Genetics I (2 units)
Course Director: Kara Weisiger, MS, LCGC

This course seeks to provide students with the fundamentals of applied medical genetics. Students will be introduced to medical genetics terminology, the genetics medical evaluation and a broad range of genetic conditions and syndromes from a systems approach. Discussion of genetic conditions will focus on the clinical symptoms, natural history, diagnostic methods, prognosis, management and available treatments in a case-based learning format. Students will learn from, and interact with, experts in their respective fields gaining an in-depth understanding of the conditions covered in the course and related issues they will encounter in their careers.

Course Objectives: Upon completion of the course students will be able to:

1. Recognize the components of a medical genetics work-up.
2. Define a syndrome and explain variable expressivity using specific examples
3. Describe key features of the disease models presented in class, recognize how these models represent categories of disease and apply this knowledge to patient and/or pedigree evaluation.
4. Apply the principles and concepts from GENC201 and 202 to real case examples when determining disease etiology and recurrence risks
5. Develop an appropriate testing strategy for individuals suspected of a genetic condition and apply the testing results.

GENC206 : Genes, Populations and Pedigrees (2 units)
Course Director: Cindy Morgan, MS, LCGC

This course will utilize the fundamental concepts of population genetics to illustrate allele distribution and factors influencing allele and disease frequency. These theoretical concepts will then be applied to clinical scenarios as students learn to obtain medical histories, construct a pedigree using the conventions of proper pedigree construction, identify inheritance patterns and perform risk calculations. Factors confounding accurate pedigree analysis will also be introduced and students will learn advanced mathematical techniques for risk assessment.

Course Objectives: Upon completion of the course students will be able to:

1. Describe fundamental principles of population genetics that influence allele frequency
2. Elicit a targeted or comprehensive family history to construct a pedigree using standard international nomenclature and identify common inheritance patterns
3. Develop an appreciation for utilizing the pedigree as a psychosocial tool
4. Calculate disease and/or carrier risk for Mendelian inheritance patterns utilizing pedigree data, test results and/or known genotype frequencies
5. Differentiate empiric from known risk and use advanced techniques such as Bayesian analysis to calculate probabilities
6. Interpret complicating factors in risk calculation such as consanguinity, non-paternity, variable expression and penetrance

GENC207: Clinical Embryology for Genetics Clinicians (on-line) (1 unit)
Course Director: Ronald Bachman, MD

This course will familiarize students with key aspects of human prenatal development from conception through birth. Focus is given to formation of the germ layers, developmental mechanisms and organ system formation in order to provide an understanding of the pathophysiology of congenital anomalies, malformation syndromes and the impact of teratogens. Students will view pre-recorded lectures and meet weekly with the instructor via video conferencing for questions and applied exercises.

Course Objectives: Upon completion of the course students will be able to:

1. Describe the stages of normal human embryologic development
2. Recognize the embryological basis of common birth defects and apply this knowledge to clinical situations
3. Correlate potential teratogenic risks with embryonic developmental stages

Quarter 2

GENC208: Research Methods II (1 unit)
Course Director: Julie Harris-Wai, PhD, MPH

This course builds upon GENC203 by applying the knowledge gained in that course towards the development of a 3-5-page Capstone Project Proposal. Students will be guided through the process of formulating an original research question, assessing necessary resources for the project, determining appropriate methodologies, identifying barriers to completion and crafting strategies to overcome any barriers. Additionally, the IRB protocol submission process and manuscript development will be discussed. Students will be encouraged to develop a project according to their interests and research goals. Students will present ideas and outlines of their Capstone project for evaluation by their peers prior to submitting their written proposal to the Capstone Advisory Committee by the end of the quarter.

Course Objectives: Upon completion of the course students will be able to:

1. Understand the IRB review and approval process
2. Formulate an original research question applicable to the field of genetic counseling
3. Assess methodologies for research analysis
4. Design a research project of appropriate scope
5. Develop a 3-5 page Capstone Research Proposal for submission the Capstone Advisory Committee

GENC209: Counseling Theory to Practice (2 units)
Course Director: Kelsey McClelland, MS, LCGC

This course builds on the skillset acquired in GENC204 and aims to translate counseling theory to the practice of genetic counseling. Teaching is structured around key components of a genetic counseling encounter as students will learn techniques for interacting with and engaging patients, conducting effective interviews, performing a psychosocial assessment and assessing risk perception. Additionally, students will explore the differences between face-to-face interactions as compared to alternative service delivery models; such as telemedicine. Experiential learning through genetic counseling role plays will allow students to develop their skills prior to entering the clinics.

Course Objectives: Upon completion of the course students will be able to:

1. Describe activities for initiating and ending the genetic counseling session
2. Define contracting and describe steps in the goal-setting process
3. Develop effective interview questioning skills through practice and feedback
4. Demonstrate proper utilization of a medical interpreter
5. Develop an understanding of the components of psychosocial assessment including interpretation of non-verbal communication

6. Develop a strategy for counseling couples and/or families, including minors
7. Recognize the nuances of risk perception and acquire tools for reframing risk

GENC210: Reproductive Genetics (2 units)
Course Director: Allyson Scott, MS, LCGC

This course will address the physiology of pregnancy and common pregnancy complications, teratogens, prenatal screening tests, diagnostic testing, infertility and assisted reproductive technologies, commonly observed prenatal anomalies, pregnancy termination and fetal therapies. Additionally, the psychosocial aspects of pregnancy and loss will be addressed. Following this course, students will be prepared for clinical practice in reproductive genetic counseling.

Course Objectives: Upon completion of the course students will be able to:

1. Outline the stages of normal a pregnancy
2. Describe prenatal screening and diagnostic procedures and then compare and contrast the results provided in each evaluation
3. Calculate accurate risk assessments based on screening results, family history or prenatal findings
4. Develop an appropriate testing strategy for individuals identified with a fetal anomaly or risk of inherited disease
5. Cultivate an understanding of the experience of a prenatal patient and describe how this impacts the genetic counseling session
6. Integrate and apply the principles and concepts from GENC201 and 202 to real case examples
7. Recognize and articulate both sides in ethical dilemmas that arise in reproductive genetics

GENC211: Advanced Medical Genetics II (2 units)
Course Director: Kara Weisiger, MS, LCGC

This course is a continuation of GENC205 and follows the same format of addressing genetic conditions from a systems-based approach (pulmonary, disorders of sexual differentiation, craniofacial, neurodegenerative etc). Discussion of genetic conditions will focus on the clinical symptoms, natural history, diagnostic methods, prognosis, management and available treatments in a case-based learning format. Students will learn from, and interact with, experts in their respective fields gaining an in-depth understanding of the conditions covered in the course and related issues they will encounter in their careers.

Course Objectives: Upon completion of the course students will be able to:

1. Describe the key features of the disease models presented in class, recognize how these models represent categories of disease and apply this knowledge to patient and/or pedigree evaluation.

2. Apply the principles and concepts from GENC201 and 202 to real case examples when determining disease etiology and recurrence risks
3. Develop an appropriate testing strategy for individuals suspected of a genetic condition and apply the testing results.

GENC212: Graduate Seminar in Genetics (1 unit)
Course Director: Cindy Morgan, MS, LCGC

This course will explore various aspects of genetics and genetic counseling through guest lectures and discussion of recent journal articles. Students and guest lecturers will present on topics covering a wide spectrum of issues relevant to the genetic counseling profession and research in the field. Class review of journal articles will enable students to become better consumers of the scientific literature, consider important components when developing research methodologies, critique research-based writing and cultivate presentation skills. The format will also allow students to talk through ideas for their Capstone Research Project.

Course Objectives: Upon completion of the course students will be able to:
1. Develop critical reading skills
2. Interpret a variety of research studies and critique analytic methodologies used in peer reviewed journals
3. Develop presentation skills

GENC213: Variant Interpretation & Advanced Technologies (2 units)
Course Director: Shannon Rego, MS, LCGC

This course provides an introduction to the latest techniques for discovering genomic alterations; especially as applied to clinical care. The multidisciplinary application of genomic sequencing will be addressed but there will be a primary focus on exome sequencing and variant interpretation. Developing technologies will introduced and contrasted with existing technologies. Students will develop critical thinking skills related to testing strategies and genomic data interpretation. The course structure includes lecture, interactive learning activities, and case discussion.

Course Objectives: Upon completion of the course students will be able to:
1. Develop an understanding the lines of evidence used in variant interpretation
2. Gain familiarity and comfort with current, core genetics databases used in variant analysis
3. Demonstrate ability to classify a variety of genetic variants
4. Discuss the implications of test results and interpret the clinical significance
5. Compare and contrast former, current and future testing technologies
6. Formulate methods of communicating complex genetic testing information to patients of varying educational backgrounds and non-genetics professionals

GENC214: Externship I (1 unit)
Externship I is an opportunity to give first year students clinical exposure, to develop practical skills and familiarize themselves with individuals and families affected by a variety of genetic disorders prior to embarking on clinical rotations. Under the supervision of established genetic counselors or medical geneticists, students will develop genetic counseling skills through authentic patient encounters or pre-curated exercises. Students will spend approximately 4 hours per week in Externship I and placements include both clinical and industry settings.

Course Objectives: Upon completion of the course students will be able to:

1. Navigate the electronic medical record
2. Gain comfort in conferring and eliciting personal information via telephone
3. Select an appropriate genetic testing laboratory and determine all necessary steps to complete testing
4. Use common genetics databases to identify patient literature and/or support group resources
5. Conduct a thorough medical chart review and identify areas to update as needed

Quarter 3

GENC215: Cancer Genomics (3 units)
Course Co-Directors: Nicola Cadeñas, MS, LCGC and Niki Lovick, MS, LCGC

This course provides an understanding of the role of genes in acquired, familial and inherited forms of cancer**.** Discussion of common types of cancer as well as rare hereditary cancer syndromes by body system are explored**.** The course also addresses surgical options, cancer treatment(s), the psychosocial aspects of cancer, risk assessment, germline testing, genomic tumor profiling and cell-free tumor analysis. Following this course, students will be prepared for clinical practice in cancer genetic counseling.

Course Objectives: Upon completion of the course students will be able to:

1. Distinguish between cancers commonly observed in the general population versus hereditary cancer syndromes
2. Describe key features observed in rare cancer syndromes and the application to pedigree analysis
3. Calculate accurate risk assessments for hereditary cancer syndromes
4. Develop an appropriate testing strategy for individuals suspected of a hereditary cancer syndrome and apply the results
5. Integrate and apply the principles and concepts from GENC201 and 202 to real case examples
6. Cultivate an understanding of the experience of a cancer patient and describe how this impacts the genetic counseling session.

GENC216 : Social, Ethical and Legal Issues in Genetics (2 units)
Course Director: Julie Harris-Wai, PhD, MPH

This course will provide an introduction to social, ethical and legal issues that arise in the practice of genetic counseling and clinical genomics. Broad currents in moral philosophy and ethical thought will be explored and applied to specific contemporary topics that genetic counselors may encounter. Legal cases that have impacted the field of genetic counseling will be discussed and the dilemmas surrounding emerging technologies such as direct-to-consumer testing, gene therapy and gene editing will also be addressed.

Course Objectives: Upon completion of the course students will be able to:

1. Gain understanding of different ethical perspectives
2. Recognize the significance of prior legal decisions in the practice of clinical genetics
3. Become familiar with important contemporary ethical dilemmas in the practice clinical genetics and genetic counseling
4. Apply the National Society of Genetic Counselors's Code of Ethics to prior and emerging ethical dilemmas

GENC217: Graduate Seminar in Genetics (1 unit)
Course Director: Cindy Morgan, MS, LCGC

This course will explore various aspects of genetics and genetic counseling through guest lectures and discussion of recent journal articles. Students and guest lecturers will present on topics covering a wide spectrum of issues relevant to the genetic counseling profession and research in the field. Class review of journal articles will enable students to become better consumers of the scientific literature, consider important components to develop appropriate research methodologies, critique research-based writing and cultivate presentation skills. The format will also allow students to talk through ideas for their Capstone Research Project.

Course Objectives: Upon completion of the course students will be able to:

4. Develop critical reading skills
5. Interpret a variety of research studies and critique analytic methodologies used in peer reviewed journals
6. Develop presentation skills

GENC218: Advanced Medical Genetics III (2 units)
Course Director: Kara Weisiger, MS, LCGC

This course is a continuation of GENC211 and follows the same format of addressing genetic conditions from a systems-based approach while also exploring more complex genetics sub-disciplines such as biochemical genetics, cardiovascular genetics, mitochondrial disorders and pharmacogenetics. Discussion of genetic conditions will

focus on the clinical symptoms, natural history, diagnostic methods, prognosis, management and available treatments in a case-based learning format. Additionally, expanding applications of genetic testing such as public health and preventive screening, and precision medicine will be discussed. Students will learn from, and interact with, experts in their respective fields gaining an in-depth understanding of the conditions covered in the course and related issues they will encounter in their careers.

Course Objectives: Upon completion of the course students will be able to:

1. Describe the key features of the disease models presented in class, recognize how these models represent categories of disease and apply this knowledge to patient and/or pedigree evaluation.
2. Apply the principles and concepts from GENC201 and 202 to real case examples when determining disease etiology and recurrence risks
3. Develop an appropriate testing strategy for individuals suspected of a genetic condition and apply the testing results.

GENC219 : Genetic Counseling Foundational Skills (2 units)
Course Director: Marta Sabbadini, PhD, MS, LCGC

This course continues to build on the skills developed in GENC204 and GENC209 as students refine the skills necessary for a genetic counseling session. Focus is placed on maintaining a patient-centered session that promotes autonomy while building genetic counselor self-awareness. Students will explore personal reactions to patient encounters, develop an understanding of the origin of patient reactions, continue to assess patient psychosocial needs, develop tools to communicate complex information, identify psychosocial barriers to understanding and/or decision making, and begin to explore the arena of self-care. Course readings provide foundational knowledge of relevant concepts, and class discussions encourage the comparison of different perspectives and applications.

Course Objectives: Upon completion of the course students will be able to:

1. Define empathy and recognize its functions in the genetic counseling process
2. Develop an awareness of personal reactions to patient encounters and construct strategies for self-reflection and managing personal emotions
3. Translate complex information to patient-appropriate levels while identifying any psychosocial barriers to a patient's understanding and/or decision making
4. Evaluate a psychosocial assessment to determine appropriate interventions and/or referrals
5. Recognize the need for professional boundaries and self-care

GENC220: Externship II (1 unit)
This course is a continuation of Externship I and will build upon the skills acquired during that course. Under the supervision of established genetic counselors or medical geneticists, students will prepare for the professional role by increasing their interaction

with patients and actively participating in professional care. Students will spend approximately 4 hours per week in Externship II and placements include both clinical and industry settings.

Course Objectives: Upon completion of the course students will be able to:

1. Gain comfort in conferring or eliciting personal information via telephone while using a medical interpreter
2. Obtain family histories from a patient or via medical history forms and construct the pedigree in hand drawn and electronic formats
3. Draft an insurance authorization request or Letter of Medical Necessity
4. Create a case outline of prior to a patient encounter

Quarter 4

GENC221 :Clinical Rotation I (3 units)

Students embark on the first of a sequence of clinical rotations in the summer between first and second year. Students will gain practical experience and apply content learned in their coursework to provide genetic counseling services in a variety of diverse clinical settings such as oncology, pediatrics or reproductive genetics. Clinical Rotation I takes place under the supervision of board certified genetic counselors and/or clinical/medical geneticists and requires that students be present in clinics full time for 8 weeks. Rotations are available in the Bay Area, Fresno or potentially, in other locations of interest.

Quarter 5

GENC222 : Advanced Genetic Counseling Skills (2 units)

Course Director: Summer Segal, MS, PhD, LCGC

This course addresses more complex and challenging psychosocial topics for health care providers such as death and dying, cultivating hope, crisis intervention and facilitating difficult conversations. Theoretical constructs introduced in GENC204 will be applied to authentic clinical scenarios enabling students to lessen anxiety about encountering the potentially strong emotions experienced by patients. Strategies and tools for facilitating emotional healing will provided so that students gain competency in managing challenging encounters. The use of role plays and the sharing of challenging topics and/or moments experienced during genetic counseling internship will allow for real world application of classroom topics.

Course Objectives: Upon completion of the course students will be able to:

1. Become familiar with the coping process and the importance of hope
2. Gain comfort in addressing emotionally difficult topics such as death and dying

3. Recognize the components of crisis intervention and identification of support resources for the patient and genetic counselor
4. Define the difference between guilt and shame
5. Further cultivate an awareness of empathy and its function in the genetic counseling process
6. Continue to improve communication skills with individuals, families, and service providers

GENC223: Capstone Project (2 units)
The Capstone Project allows students to gain experience in research methods, evidence-based approaches to problem solving, professional writing, and self-directed learning in order to increase their professional growth. Students will implement an original graduate level investigation that has been approved by the program's Capstone Advisory Committee, pass an oral presentation of their project and submit substantive paper. The paper may take the form of a publishable manuscript, traditional research paper or other scholarly project as approved by the Capstone Advisory Committee. Additionally, the Capstone Project allows students to collaborate with faculty from many disciplines.

Course Objectives: Upon completion of the course students will be able to:

1. Complete an original, independent project of their own design that contributes to the field of genetic counseling
2. Submit a publishable manuscript or substantive paper

GENC221 : Clinical Rotation II (3 units)
Students will complete one, 10 week rotation in the first quarter of the second year at sites in the Bay Area, Fresno or other locations of interest. Students will gain practical experience and apply content learned in their coursework to provide genetic counseling services in a variety of diverse clinical, laboratory or industry settings. The clinical training program is designed to provide each student with increasingly complex case management and critical thinking experiences over the course of the second year. Clinical Rotation II takes place under the supervision of board certified genetic counselors and/or clinical/medical geneticists and requires that students be present in clinics three days per week.

Quarter 6

GENC 224:– Advanced Topics in Genetic Counseling (2 units)
Course Director: Cindy Morgan, MS, LCGC

This course focuses on advanced practical aspects of the genetic counseling profession, the delivery of genetic medicine and also provides opportunity for sharing and processing of challenging topics and/or moments experienced during the genetic counseling

internship. Topics span genetic discrimination, contemporary issues in disability, and leadership development while also providing an introduction to the business of healthcare. As payors continue to recognize the value of genetic counseling students need to understand billing and reimbursement, coding, public versus private payors, credentialing and healthcare system delivery models. The business of healthcare will be addressed in the context of clinical and laboratory settings while evaluating these systems against public health initiatives.

Course Objectives: Upon completion of the course students will be able to:

1. Demonstrate disability awareness including the impact and contributions of the genetic counseling profession on the disability community.
2. Recognize the significance of GINA (Genetic Information Nondiscrimination Act) as well as its limitations
3. Appreciate the components of leadership development and advocacy
4. Outline the differences between public and private payors
5. Evaluate CPT and ICD10 coding to report genetic counseling services and identify the documentation necessary to secure reimbursement for genetic services
6. Compare and contrast public versus private healthcare delivery systems
7. Recognize the personal role in the larger healthcare system

GENC223: Capstone Project (2 units)

The Capstone Project allows students to gain experience in research methods, evidence-based approaches to problem solving, professional writing, and self-directed learning in order to increase their professional growth. Students will implement an original graduate level investigation that has been approved by the program's Capstone Advisory Committee, pass an oral presentation of their project and submit substantive paper. The paper may take the form of a publishable manuscript, traditional research paper or other scholarly project as approved by the Capstone Advisory Committee. Additionally, the Capstone Project allows students to collaborate with faculty from many disciplines.

Course Objectives: Upon completion of the course students will be able to:

1. Complete an original, independent project of their own design that contributes to the field of genetic counseling
2. Submit a publishable manuscript or substantive paper

GENC221 : Clinical Internship III (3 units)

Students will complete one, 10 week rotation in the second quarter of the second year at sites in the Bay Area, Fresno or other locations of interest. Students will gain practical experience and apply content learned in their coursework to provide genetic counseling services in a variety of diverse clinical, laboratory or industry settings. The clinical training program is designed to provide each student with increasingly complex case management and critical thinking experiences over the course of the second year.

Clinical Rotation III takes place under the supervision of board certified genetic counselors and/or clinical/medical geneticists and requires that students be present in clinics three days per week.

Quarter 7

GENC225: Professional Formation (2 units)
Course Director: Kelsey McClelland, MS, LCGC

This course prepares students to enter the professional world. Practical skill building includes areas such as resume preparation, job interview techniques, self-marketing and board examination preparation. These topics are interwoven with discussions about discovering one's own professional self-identity, professional fulfillment and techniques for managing stress to prevent burn out. Time will also be allowed for the sharing and processing of challenging topics and/or moments experienced during the genetic counseling internship.

Course Objectives: Upon completion of the course students will be able to:

1. Build a concise and effective resume
2. Understand the components of the job search including constructing professional cover letters, interviews and negotiation
3. Ensure readiness for the ABGC certification examination
4. Evaluate personal goals for achieving professional self-fulfillment
5. Identify triggers or signs of personal stress and develop an effective strategy for self-care

GENC223: Capstone Project (2 units)
The Capstone Project allows students to gain experience in research methods, evidence-based approaches to problem solving, professional writing, and self-directed learning in order to increase their professional growth. Students will implement an original graduate level investigation that has been approved by the program's Capstone Advisory Committee, pass an oral presentation of their project and submit substantive paper. The paper may take the form of a publishable manuscript, traditional research paper or other scholarly project as approved by the Capstone Advisory Committee. Additionally, the Capstone Project allows students to collaborate with faculty from many disciplines.

Course Objectives: Upon completion of the course students will be able to:

1. Complete an original, independent project of their own design that contributes to the field of genetic counseling
2. Submit a publishable manuscript or substantive paper

GENC221 : Clinical Internship VI (3 units)
Students will complete one, 10 week rotation in the third quarter of the second year at sites in the Bay Area, Fresno or other locations of interest. Students will gain practical

experience and apply content learned in their coursework to provide genetic counseling services in a variety of diverse clinical, laboratory or industry settings. The clinical training program is designed to provide each student with increasingly complex case management and critical thinking experiences over the course of the second year. Clinical Rotation VI takes place under the supervision of board certified genetic counselors and/or clinical/medical geneticists and requires that students be present in clinics three days per week.

Section 6. RESOURCE REQUIREMENTS

6.1 Faculty and Staff Support

To implement the program, the team includes a Program Director (0.5 FTE), an Assistant Program Director (0.5% FTE), Medical Director (0.05% FTE), Research Coordinator (0.1% FTE) and a Program Administrator (1.0% FTE).

Revenue from student fees funds all personnel and operational expenses for the program (Section 6.7.1). Fiscal year 2022-23 funds program reserves. There is no anticipated net negative fiscal impact on teaching capacity or operations of other programs on the campus.

6.1.1 Program Director

The Program Director is a fulltime UCSF employee with at least 0.5 FTE dedicated to the GC Program. The Program Director possesses the qualifications dictated by the Accreditation Council for Genetic Counseling (ACGC) and outlined in the STANDARDS OF ACCREDITATION FOR GRADUATE PROGRAMS IN GENETIC COUNSELING[17]. These qualifications include being an ABGC certified genetic counselor with a minimum of 5 years experience as a genetic counselor while being knowledgeable and experienced in the genetic counseling profession, teaching, clinical supervision and other related subjects.

The Director leads, coordinates and manages The GC Program while also providing oversight of the program budget to ensure fiscal stability, managing marketing and recruitment activities, supervising hiring of Program Faculty and helping to facilitate Faculty development. The Director reviews curriculum to ensure students fulfill the Clinical Competencies as outlined by the ACGC and assists in curriculum revision and updates. The Director is continually involved in strategic planning, development and vision of the Program and serves as the primary liaison within UCSF and the genetic counseling professional societies. The Program Director also has direct contact with the students by serving as an instructor for 2 classes to first year students. The Program Director also supervises the Assistant Program Director, Research Coordinator, Program Administrator and Web Developer.

6.1.2 Assistant Program Director

The Assistant Program Director (0.5 FTE) possesses the qualifications dictated by the Accreditation Council for Genetic Counseling (ACGC) and outlined in the

STANDARDS OF ACCREDITATION FOR GRADUATE PROGRAMS IN GENETIC COUNSELING[17]. These qualifications include being an ABGC certified genetic counselor, or complementary professional, that holds at least a master's degree with professional certification (if available) and a minimum of 3 years professional experience in this field. Additionally, the Assistant Program Director will have knowledge and experience in the genetic counseling profession and related subjects.

The Assistant Program Director is responsible for supporting the Program Director and is primarily in charge of clinical education. This responsibility includes scheduling and coordinating student extern and internships with the clinical sites, ensuring students receive adequate on-site supervision, assisting internship supervisors in assessing students' satisfactory progression in the clinical experience, appropriate placement of students in clinical internships based on achievement of the ABGC clinical competencies, evaluation of clinical internship sites incorporating student feedback and assisting in the procurement of additional training sites. The Assistant Program Director will also have direct contact with the students by teaching 2 classes to first and/or second year students and supervising student research projects. The Assistant Program director will also support the program by helping with program admissions, marketing and recruitment and be involved in strategic planning, development and outcomes assessment. The Assistant Program Director also supervises the Research Coordinator, Program Administrator and Web Developer.

6.1.3 Medical Director

The Medical Director possesses the qualifications dictated by the Accreditation Council for Genetic Counseling (ACGC) and outlined in the STANDARDS OF ACCREDITATION FOR GRADUATE PROGRAMS IN GENETIC COUNSELING[17]. These qualifications include certification as a clinical geneticist by the American Board of Medical Genetics and Genomics (ABMGG) or equivalent Canadian credentialing organization.

The Medical Director is an active participant in the program and ensures the curriculum supports the development of the required ACGC competencies and that graduates are prepared to enter the current workforce. The Medical Director will advise the Director and Assistant Director on medical aspects of the curriculum including new and contemporary practices in the field of medical genetics and diagnostics. The Medical Director will ensure implementation of new recommendations to the curriculum and provide any needed support for the GC faculty. The Medical Director also collaborates with the Program Director and Assistant Director to continually evaluate the program including the clinical internship sites, assist students with capstone projects, assists in the evaluation of student performance and assists in the establishment of relationships with internal and external partners of the program. Additionally, the Medical Director will also be asked to provide periodic lectures to first year students. Day-to-day management of the GC Program will reside with the Director and Assistant Director.

6.1.4 Research Coordinator

The Research Coordinator will provide general oversight of the Capstone Project. This position includes serving as Chair of the Capstone Research Committee that will approve student capstone proposals to ensure that the proposals are of appropriate scope and rigor. The Research Coordinator will help students struggling identify an appropriate project. Additionally, the Research Coordinator will monitor student progress on their capstone project, serve as a liaison to student research mentors, conduct regular assessments to ensure students complete the project prior to graduation and provide remediation assistance to students struggling with the Capstone Project. The Research Coordinator will report student progress on Capstone Projects to the Program Director and Assistant Director.

6.1.5 Web Developer

The web developer will be responsible for designing, coding, maintaining and updating the GC Program's website while ensuring compliance with UCSF standards. The Web Developer will assist in designing a visually appealing website with a user-friendly design and clear navigation. Programmatic content will be provided by the Program leadership and the web developer will sure accurate links to UCSF departments and services for students and prospective applicants. The GC Program's website will be utilized as a marketing and recruitment tool so website optimization is essential in order to obtain the largest pool of qualified applicants.

6.1.6 Program Faculty

The team of course leaders will consist of existing UCSF faculty and staff members and one external instructor, who commit to develop, teach and coordinate the new GC Program courses listed above. A total of 1.32 FTE will be distributed among them. Faculty course instructors will each receive up to 0.07 FTE (equivalent of 146 hours per quarter or 14.6 hours/week/quarter) for each course they teach. This figure has been derived from a decade of prior instructional experience in the CSU genetic counseling program by several of the GC Program teaching faculty. All courses will be developed prior to launch of the program as an in-depth review of program curriculum (including syllabi) is a major component of the professional accreditation process. The GC Program is able to achieve this through several avenues. Courses utilized in the CSU genetic counseling program will simply require modification to fit the UCSF GC Program. The GENC207: Clinical Embryology for Genetics Clinicians, has existing pre-recorded lectures and therefore requires a lower level of compensation compared to other courses. Additionally, the GC Program also currently has FTE funding to develop the research, ethics and counseling curriculum. Thus, the 1.32 FTE for course instructors will be to maintain and provide instruction in existing courses.

As the GC Program's budget develops a surplus, increases in faculty support will be explored. Both the Program Director and Co-Director will teach 2 courses as part of their leadership responsibilities. The Program Director and Co-Director will coordinate with the Advisory Board and the Curriculum Steering Committee to replace faculty as needed.

Numerous genetic counselors are serving as course directors in the GC Program. This model is in the best service of the students as they will receive instruction from individuals possessing an intimate understanding of the genetic counseling profession, including the necessary depth of knowledge, scope of practice and mentoring experience to foster successful professionals. This model is consistent with the vast majority of accredited genetic counseling programs in the country. Additionally, this model is similar to other professional degree programs, including those at UCSF.

The chosen genetic counselor course directors are veteran genetics educators and were deliberately recruited to the GC Program. Six of the genetic counseling course directors are successful course instructors from the CSU Stanislaus genetic counseling program. Seven of the genetic counselors are genetics educators in the genetics curriculum in the UCSF Medical School and regularly serve as small group facilitators, and three are members of the UCSF Medical School Medical Genetics Curriculum Committee. The genetic counseling teaching faculty will be enhanced by breadth and expertise found in the UCSF faculty. Numerous faculty members have already offered to provide lectures on topics within their area of expertise, and several courses are designed as a series of lectures from faculty experts. Deep faculty relationships have already been cultivated during the execution of the CSU genetic counseling courses taught on the UCSF campus and these will continue with the launch of the UCSF GC Program.

Throughout the country, many genetic counselors serving as educators, whether to genetic counseling students or other medical trainees, have achieved faculty status at their institution. The 2018 National Society of Genetic Counselors Professional Status survey found that over 25% of respondents have achieved faculty positions at their institution (see Appendix 7). This percentage reaches virtually 100% when narrowing the focus to those genetic counselors involved in genetic counseling training programs (personal communication with US program directors). All genetic counselors serving as course directors in the UC Irvine genetic counseling program have been granted faculty status. UCSF has been slower to adopt to this practice and only three of the genetic counselors serving as course directors have already achieved faculty status within the Department of Pediatrics. The MS degree is the terminal degree in the field of genetic counseling and the GC Program will work with its course instructors to help them attain faculty status in their home Department, or the Department of Pediatrics, so as to meet the standard set by other genetic counseling programs.

6.1.7 Program Administrator

The Program Administrator (1.0 FTE) reports to the Program Director and assists with developing procedures and systems to ensure effective operation of the program. The Program Administrator serves as a point person for student and staff inquires, manages the admission procedures in the Office of Student Affairs, assists with course and class scheduling, provides technical support to program faculty and assists in coordination of daily program needs.

6.1.8 Succession Plan for Program Director, Assistant Director and Medical Director

If necessary, replacement of the Program Director, Assistant Program Director or Medical Director will be decided jointly by the Chief of Medical Genetics in the Department of Pediatrics and Director of the Institute for Human Genetics upon advisement from the GC Program's Advisory Board. Decisions regarding replacement of the Assistant Director will also include the Program Director.

6.2 Library Acquisition

There are no anticipated additional costs for library acquisitions as the books and journals necessary for the practice of genetic counseling are already available at the UCSF library.

6.3. Computing Costs

No additional computing costs, outside of personal computers for staff, are needed. Clinical rotation sites already have encrypted computers available for student use and on-campus internet is already available to matriculated students. Students desiring their own laptop or tablet for class activities or homework will need to provide their own device. Matriculated students may receive the standard desktop support available from the UCSF Library's Learning Tech Support Center.

6.4. Equipment

Special equipment is not required for this program. Students will rotate and observe in existing UCSF clinical laboratories, such as the cytogenetics, molecular and exome laboratories but this will not require additional equipment. Classrooms and lecture halls at the Parnassus and Mission Bay campuses are already equipped with audio-visual presentation equipment. Program faculty use department issued computers and students may use their personal computers to access any on-line content.

6.5. Space and Other Capital Facilities

Faculty: Office space to accommodate the faculty and staff of the program is provided by the Department of Pediatrics and Institute of Human Genetics.
On-campus classes: Classrooms and conference rooms at both campuses easily accommodate groups of 11-13 individuals (students and instructors). UCSF Educational Technology Services has confirmed that there will be available classroom space for the GC Program on the Mission Bay campus in 2020.

6.6 Other Expenses

6.6.1 Guest Lecturers

Guest lecturers from community genetics clinics and local industry will enrich the teaching program and program faculty will be encouraged to invite guest lecturers to their courses. Additionally, the program anticipates hosting professional development workshops, such as Clinical Supervision training; Leadership Development, for program faculty and clinical affiliates. Expenses such as honorarium, economy travel, meal and other expenses will be covered by the program.

6.6.2 Incidental Expenses

Brochures and advertising, teaching materials, software and other educational support costs will be covered by program fees as the program becomes self-sufficient.

6.6.3 Clinical Internship Support

Program funds to cover incidental expenses such as identification badges, administration fees etc. will be available to non-UCSF clinical internship sites when UCSF students are participating in an internship.

The Program also intends to utilize the UCSF Fresno campus as a clinical rotation site for students interested in this opportunity. Program funds for housing support are available, if needed, for 1-2 second year students desiring to train at UCSF Fresno for 1-2 clinical rotations in the second year. The GC Program has communicated with the UCSF-Fresno Office of Undergraduate Medical Education (UME), the organization that coordinates housing for UCSF School of Medicine and School of Dentistry students, and confirmed that The GC Program's students will be eligible for UCSF-coordinated housing. A list of alternative housing options has also been provided by the UME office in the event that the UCSF housing is at capacity. The GC Program will continue to explore external funding sources to potentially expand the number of training opportunities in Fresno.

No new resources will be required to fund operating costs as the Masters Program in Genetic Counseling will be entirely self-funded (see Section 6.7.1).

6.7 Program Budget and Fees

The GC Program has been designed with a lean budget to ensure that it remains competitive with other genetic counseling programs. The program fees begin at $44,000/year for the two-year program. This initial fee is determined to be competitive to other self-supporting and private school genetic counseling programs, although is costlier than other state-supported genetic counseling programs within California and the country. As this program is funded entirely on student fees, increasing expenses results in increases in student fees and a less desirable program. While the demand for genetic counseling training programs and the reputation of UCSF will be sure to attract applicants, the strongest pool of applicants will be obtained by keeping student fees competitive with other institutions.

The program fee remains constant over two years (no annual increase) for each cohort in the program. Fees will have ordinary annual increases for each new cohort enrollment into the program.

The GC Program is also investigating sharing teaching resources with existing campus programs as a means of containing costs. For example, discussions have occurred with Elena Flowers, RN, PhD director of the genomics minor program in the UCSF School of Nursing about utilizing courses such as GENC206 for the nursing students. In such a scenario, nursing students would attend GENC206 with the genetic counseling students and have full access to course content and resources. FTE support for the course instructor would be transferred to the GC Program from the School of Nursing. The

amount of support would be commensurate with the number of students attending the course. Each genetic counseling cohort currently consists of 11 students with up to 0.07 FTE instructor/quarter. Adding an additional 10-11 students could warrant an additional 0.05 FTE for the quarter. The GC Program is also receptive to genetic counseling students attending courses in other existing programs and providing FTE support from the GC Program student fees. These arrangements will be explored with more vigor once institutional approvals for the GC Program have occurred. The IHG Genetics Education Committee will be helpful in facilitating these relationships.

6.7.1 Self-sustaining Fiscal Model

A detailed five-year funding plan has been developed and is presented in Table 3. This plan enables the program to become self-sufficient in the second academic year and reliant only on student fees. However, the expectation is that continued fund raising success will allow for direct costs offsets, in addition to the creation of a scholarship pool. This will enable the program to remain attractive and competitive with other genetic counseling programs.

Table 3. Five Year Fiscal Projection

UCSF Cost of Education Model
Self-Supporting Graudate Professional Degree Program

Program: Masters in Genetic Counseling
Chartstring: DeptID-3080-ProjectID

	2020-21 Year 1		2021-22 Year 2		2022-23 Year 3		2023-24 Year 4		2024-25 Year 5	
Projected Enrollment First Year Students	11		11		11		11		11	
Projected Enrollment Second Year Students	-		11		11		11		11	
Total Students Per Year	11		22		22		22		22	
Annual Fee Level First Year (Requested Annual Fee Level)	$ 44,000		$ 45,320		$ 46,680		$ 48,080		$ 49,522	
Annual Fee Level Second Year (Requested Annual Fee Level)	$ -		$ 44,000		$ 45,320		$ 46,680		$ 48,080	
Projected Revenue										
Fee Revenue	$ 484,000		$ 982,520		$ 1,011,996		$ 1,042,355		$ 1,073,626	
Gift (e.g. Fee Scholarship) - Student Svcs Fees										
Other- Transfers Other Support										
Total Annual Revenue:	$ 484,000		$ 982,520		$ 1,011,996		$ 1,042,355		$ 1,073,626	
Projected Expenses (Level C Accounts)	FTE	Support Model Components $ Per Student	FTE	Support Model Components $ Per Student	FTE	Support Model Components $ Per Student	FTE	Support Model Components $ Per Student	FTE	Support Model Components $ Per Student
Faculty Salaries (As reported on Regents Table 4)	0.12 $ 35,290		0.12 $ 36,348		### $ 37,439		0.12 $ 38,562		0.12 $ 39,719	
Non-Faculty Academic Salaries	239,480		265,467		273,431		281,634		290,083	
Staff Salaries	100,458		103,472		106,576		109,773		113,066	
Benefits (faculty, staff and IAP)	145,368		156,605		161,303		166,142		171,126	
Occupancy Expense										
Supplies and Materials (general supplies & marketing materials)	15,000		16,500		16,995		17,505		18,030	
Services (GAEL, Campus Recharges, Honoraria, rotation site support	9,800		22,300		22,969		23,658		24,368	
Travel, Meetings & Entertainment student travel, receptions)	16,000		19,500		20,085		20,688		21,308	
Scholarship/Fellowship (Financial Aid)										
Professional memberships & expenses (eporting fees, memberships)	6,500		6,500		6,695		6,896		7,103	
Subtotal Department Support:	$ 567,895	$ 51,627	$ 626,691	$ 28,486	$ 645,492	$ 29,341	$ 664,857	$ 30,221	$ 684,803	$ 31,127
Student Services Costs (Estimates - subject to change)										
Student Academic Affairs services (excl SHCS)	$ 35,838	$ 3,258	$ 73,826	$ 3,356	$ 76,041	$ 3,456	$ 78,322	$ 3,560	$ 80,672	$ 3,667
Library	18,326	1,666	37,752	1,716	38,884	1,767	40,051	1,820	41,252	1,875
Graduate Division	7,337	667	15,114	687	15,568	708	16,035	729	16,516	751
Campus Community Center Facilities Fee	1,804	164	3,608	164	3,784	172	3,784	172	3,982	181
Graduate & Professional Student Association	297	27	594	27	594	27	594	27	594	27
Associated Students of the Graduate Division	396	36	792	36	792	36	792	36	792	36
Student Health & Counseling Services Fee	12,382	1,126	25,506	1,159	26,272	1,194	27,060	1,230	27,871	1,267
Student Health & Counseling Services Supplemental Fee	1,749	159	3,696	168	3,894	177	4,158	189	4,158	189
Student Health Insurance Premium	59,048	5,368	121,639	5,529	125,288	5,695	129,047	5,866	132,918	6,042
Subtotal Student Services Costs:	$ 137,177	$ 12,471	$ 282,527	$ 12,842	$ 291,116	$ 13,233	$ 299,842	$ 13,629	$ 308,755	$ 14,034
Total Direct Costs:	$ 705,071		$ 909,219		$ 936,609		$ 964,699		$ 993,558	
Net Revenue less Expense (Loss):	$ (221,071)		$ 73,301		$ 75,387		$ 77,657		$ 80,068	
Net Total (Loss)	$ (221,071)		$ 73,301		$ 75,387		$ 77,657		$ 80,068	
Prior Year Carry forward	$ -		$ (221,071)		$ (147,770)		$ (72,383)		$ 5,273	
Net position at 6/30/xx (Reserve)	$ (221,071)		$ (147,770)		$ (72,383)		$ 5,273		$ 85,341	

Section 7. GRADUATE STUDENT SUPPORT

All matriculated students in the UCSF Masters Program in Genetic Counseling are eligible for federal student loans and for loans and scholarships administered through UCSF.

As the program develops surplus revenues, projected by 2 years of operation (FY 2021-2022), we expect to use at least 50% of these funds to support student scholarships. The Program is especially invested in supporting students from underrepresented groups. We also hope to cultivate support from foundations, local industry and other sources to assist in developing a consistent source of funding for students.

This program is intended to be a rigorous 2-year course of instruction leading to the MS degree. As such, there will not be significant opportunity for students to participate in teaching responsibilities or research employment on campus.

Section 8. GOVERNANCE

As described in section 1.6 the GC Program has created the UCSF Graduate Group in Genetic Counseling (GGGC) which will govern the program under the purview of the Institute of Human Genetics and Department of Pediatrics. Bylaws and Regulations and Procedures for the GGGC are included in Appendix I.

Section 9. CHANGES IN SENATE REGULATIONS

This program does not require any changes in Senate Regulations.

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Appendices

Appendix 1. Genetic Counseling Graduate Group (GCGG) Bylaws, Rules and Procedures

Appendix 2. Master's Program in Genetic Counseling Student Handbook

Appendix 3. CVs Instructional Faculty

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Bylaws and Regulations of the University of California, San Francisco Graduate Group in Genetic Counseling (GGGC)

Bylaws of the Graduate Group in Genetic Counseling (GGGC)

I. NAME, MISSION and AFFILIATION:

a. **NAME:** The name of the organization is the UCSF Graduate Group in Genetic Counseling (GGGC)
b. **MISSION:** The mission of the GGGC is:
   i. To establish and administer the UCSF Masters Program in Genetic Counseling (GC Program).
   ii. To maintain responsibility for the educational policies and the curricula of the GC Program, and for periodically reviewing the manner in which these policies and curricula are implemented.
   iii. To serve as the primary advocate for the GC Program by creating opportunities for education, clinical experiences and research for the program's students, and fostering the scholarly basis for new and continuing efforts.
   iv. To hold jurisdiction over all academic matters and make policy recommendations in such areas as: admissions, curriculum, clinical rotations, capstone project, and overall objectives.
   v. To ensure conformity with the regulations of the Graduate Council of the University of California, San Francisco https://senate.ucsf.edu/graduate-council-regulations.
c. **AFFILIATION:** The GC Program is affiliated with the Institute for Human Genetics and the Department of Pediatrics

II. MEMBERSHIP

The GGCC will be comprised of 5 committees and instructional faculty. The Executive Committee will provide the primary oversight of the GGGC. New Committees may be proposed by any member of the GGGC with majority approval by the GGGC membership and Executive Committee.

a. **EXECUTIVE COMMITTEE**
   i. Purpose: The principle responsibilities of the Executive Committee are:
      1. To carry on the activities and services of the GC Program, and encourage its further development.
      2. To establish and maintain liaison with programs interested in genetic counseling or clinical genetics in other UCSF departments or organizations.

3. Take responsibility for informing entire instructional faculty about the affairs of the GC Program and hire instructional faculty when vacancies arise.
4. To oversee the GC Program and when changes seem desirable, to recommend these to the appropriate committee.
5. The Executive Committee shall also be responsible for helping to identify candidates to fill vacancies in the Advisory Board, Admissions Committee, Curriculum Steering Committee and Capstone Research Committee.

ii. Membership: The Executive Committee shall consist of the GC Program leadership, a member of the IHG and a budget advisor; for a total of 6 individuals. GC Program leadership consists of the Program Director, Assistant Program Director, Medical Director, and Research Coordinator.

iii. Term: The GC Program leadership will remain on the Executive Committee for the duration of their leadership roles. The IHG member and budget advisor will serve for two years and may elect to serve another term. Vacancies will be filled through nominations from existing Executive Committee members and membership will be voted on by the remaining Executive Committee members

iv. Meetings: Meetings of the Executive Committee will occur quarterly during the first two years of the GC Program. Beginning the third year of the GC Program, Executive Committee meetings will occur at least twice per year. A special meeting of the Executive Committee may be requested by written notice of three or more members. At meetings, presence of at least 50% of membership shall constitute a quorum.

b. ADVISORY BOARD

i. Purpose: The GGCC will utilize an Advisory Board to provide counsel and assist in implementation of the ACGC requirements for initial accreditation. Once the program is established, the Advisory Board will help to ensure maintenance of accreditation; continuing relevance of The GC Program by proposing program changes to meet the evolving needs of the genetic counseling profession; promoting the program in the greater community, providing program evaluation and by providing a forum for discussion of faculty, curriculum, or other concerns. Any issues requiring modification or remediation will be addressed with the Advisory Board and a plan, including timeline, will be created for appropriate adjustments to be incorporated into the GC Program.

ii. Membership: The Advisory Board will consist of 8-10 members who are genetics professionals from within UCSF and outside UCSF. Members will have varied backgrounds but will represent a broad spectrum of constituencies relevant to the genetic counseling profession; research, clinical care, education and private industry. The GC Program Director, Assistant Director, Medical Director and IHG Executive Committee representative will be *ex-officio members*. As the program becomes established, a recent alumnus will be invited to become a committee member.

iii. Term: For the initial installment of the Advisory Board, the GC Program leadership will solicit nominations and recommendations from the genetics community. Inaugural membership will be approved by the Executive Committee. The initial appointment of Advisory Board members shall be for two years. Following the first term, existing members may be reappointed by the

Executive Committee. Vacancies will be filled through nominations from existing Advisory Board members and/or Executive Committee and membership will be voted on by the remaining Advisory Board members.

iv. Meetings: Meetings will occur at least on an annual basis, preferably twice yearly; or as deemed necessary. In the first year of the GC Program, a meeting will occur prior to the completion of the first academic year and then upon graduation of the first cohort. A special meeting of the Advisory Board may be requested by written notice of five or more members. At meetings, presence of at least 50% of membership shall constitute a quorum.

c. ADMISSIONS COMMITTEE

i. Purpose: The GGGC Admissions Committee is responsible for reviewing and evaluating applications to the GC Program and overseeing recruitment. The committee will then interview select applicants, or nominate interviewers, and then shall select and admit genetic counseling students to the GC Program. The Admissions Committee will also make recommendations regarding recruitment strategies that will result in successful recruitment of a high quality, diverse student population.

ii. Membership: The Admissions Committee shall consist of five members comprised of at least three genetic counselors. The Program Director and Assistant Director will be *ex-officio members*.

iii. Term: Appointments will be for two years. Following the first term, existing members may be reappointed by the Executive Committee. Vacancies will be filled through nominations from existing Admissions Committee members and/or Executive Committee members. Membership will be voted on by the remaining Admissions Committee members and the Executive Committee.

iv. Meetings: The Admissions Committee will meet as necessary during the application and admissions season. An additional meeting will also occur in the spring of each year to review recruitment strategies.

d. CURRICULUM STEERING COMMITTEE

i. Purpose: The Curriculum Steering Committee will assess the effectiveness of current curriculum, review changes in existing courses and proposals for new courses. Curriculum effectiveness will be assessed through student course evaluations, clinical rotation supervisor evaluations, assessment of instructional faculty and performance on the board certification examination. Proposals for new courses will undergo review to ensure that the proposed course logically fits within the context of the GC Program. The Curriculum Steering Committee oversight is also designed to ensure that courses meet Accreditation Council for Genetic Counseling (ACGC) standards and Practice Based Competencies, avoid unnecessary course duplication, and reflect any issues relating to student concerns.

ii. Membership: The Curriculum Steering Committee shall consist of five members comprised of at least two GC Program instructional faculty and at least one clinical rotation supervisor. The Program Director and Assistant Director and Medical Director will be *ex-officio members*.

iii. Term: Following the first term, existing members may be reappointed by the Executive Committee. Vacancies will be filled through nominations from existing Curriculum Steering members and/or Executive Committee members. Membership will be voted on by the remaining Curriculum Steering members and the Executive Committee.

iv. Meetings: In the first year of the program, the Curriculum Steering Committee will meet quarterly. These meetings will include review of student course evaluations and feedback from instructional faculty. In the second year of the program, these meetings will also incorporate feedback from clinical rotation supervisors. Beginning in the second year of the program, the Curriculum Steering Committee will convene twice per year, with one meeting occurring prior to the start of the fall quarter. A special meeting of the Curriculum Steering Committee may be requested by written notice of two or more members. At meetings, presence of at least 50% of membership shall constitute a quorum.

e. CAPSTONE RESEARCH COMMITTEE

i. Purpose: The Capstone Research Committee (CRC) will oversee the research curriculum and Capstone projects for the GC Program. The CRC will review and approve student Capstone Research Proposals to ensure projects are of appropriate scope and rigor for the program. The CRC will maintain quarterly contact with research advisors to ensure students are making appropriate progress on Capstone projects and assist in creating programs of remediation for struggling students. Additionally, the CRC will assess the effectiveness of the current research curriculum, review changes to existing courses and create proposals for new research-related courses, if needed.

ii. Membership: The Capstone Research Committee shall consist of three members including the Research Coordinator, who serves as committee chair. The remaining members are comprised of one member of the IHG and one genetic counselor. The Program Director, Assistant Director and Medical Director will be *ex-officio members*.

iii. Term: Appointments shall be for two years. Following the first term, existing members may be reappointed by the Executive Committee. Vacancies will be filled through nominations from existing Capstone Research Committee members and/or Executive Committee members. Membership will be voted on by the remaining Capstone Research Committee and the Executive Committee.
Meetings: The Capstone Research Committee will meet at least three times during the academic year. The first meeting will occur in the first quarter to review the bank of research topics and potential research advisors for first year students. By the second year of the program, this meeting will also include a review of second year students' progress on their Capstone project. The second meeting will occur at the end of the second quarter to discuss student Capstone Project Proposals. At this meeting, the committee will also provide a plan for remediation for any project not receiving approval. During the second meeting (or the committee may elect to hold a separate meeting), second year students will be evaluated on the progress of their Capstone Projects. The committee may also need to reconvene to review revised Capstone Project Proposals. A third meeting will occur after students have presented their Capstone projects and

before the start of the first quarter of the next academic year. This meeting will review the curriculum and Capstone projects and make any recommendations for modification in subsequent years.

III. Amendments

a. Changes in these bylaws shall be made by approval of both the Executive Committee and at least two-thirds of the GGGC membership.
b. An amendment shall be voted on either at a duly scheduled GGGC meeting following the one in which it is proposed. Voting discussion and modification may take place on both occasions.
c. Voting may also occur by mail ballot, proposed changes shall be sent to the members at least one week in advance of the vote.

UCSF Masters Program in Genetic Counseling
Regulations and Procedures
Conforms to the Regulations and Procedures of the Graduate Council

I. Admission Requirements
    a. To be admitted to the Masters Program in Genetic Counseling (GC Program), applicants must:
        i. Hold a bachelor's degree, or its equivalent, from an accredited institution
        ii. Meet the minimum grade point average as determined by the GGGC and published annually by the Genetic Counseling Program
        iii. Be evaluated and accepted for admission by the GC Program Admissions Committee and the Dean of the Graduate Division.
    b. Applicants from non-English speaking countries must, in addition, demonstrate proficiency in English. For example, by obtaining the minimum score set by the Graduate Council on the Test of English as a Foreign Language (TOEFL) or an equivalent exam, or by completing one year of study with a GPA of 3.00 in a college or university in the United States.
II. Registration
    a. Students must register and meet the requirements for registration as defined in the Academic Senate Regulations 540-544.
        i. Graduate students whose research or study requires them to be out of the state of California throughout the quarter may apply to register in absentia. Students who register in absentia pay reduced student services fee and tuition and full student government and health fees (unless exempted by waiver).
    b. Students who fail to register must petition for leave of absence or withdrawal and may be subject to discontinuation. (see Section VIII.B.2).
    c. Students desiring to withdraw or request a voluntary Leave of Absence from the GC Program must consult with the Program Director and Assistant Director prior to initiating the process through the Office of the Registrar.
        i. Students desiring a voluntary Leave of Absence must submit a written request indicating the effective start and end dates and reason(s) for the leave.
        ii. The student will receive a written and electronic confirmation, or denial, of the request for a leave. If the leave is confirmed, the confirmation letter will include a date by which the student must notify their research mentor, program director and the Office of the Registrar of his/her intention to return.
        iii. A student returning to registered status after a leave of absence must gain approval of the GC Program Director and Assistant Director and petition for readmission
            1. Readmission would occur at a time point that meets the needs of the student as well as currently enrolled students.
    d. The GC program is designed as a full-time program of study due to the progressive curriculum and need for coordinated clinical rotations.

III. Course work

a. Follows the course of Master of Science, Plan II
    i. Thirty-six units and a comprehensive examination in the major subject are required. A Capstone Project will replace the comprehensive exam
    ii. A minimum of eighteen units must be taken in graduate (200 series) courses in the major subject. Of these, no more than twelve units numbered 250 may be applied toward the degree.
    iii. The Capstone Project should demonstrate the student's mastery of the major field and ability to think critically.
        1. A student who fails the Capstone Project presentation is allowed a second time to present after a suitable period of additional preparation. Students will register for an additional quarter of GENC223 to prepare for re-presentation
        2. A student who fails a second Capstone presentation is no longer eligible to receive the Master's degree (per Graduate Council Regulations, Appendix II).
    iv. Three quarters of academic residence are required for the Master's degree.

b. Student Conduct During Performance Assessments
    i. Instructional faculty or designees who are responsible for student performance assessment must inform the student prior to the assessment what materials are necessary, what may be in the student's possession or vicinity during the assessment, and what student conduct is required while undergoing the assessment.
    ii. Access to all other materials or information that may act as an unauthorized aid during the assessment is expressly prohibited.
    iii. Violation of this rule or other substantive evidence of academic misconduct related to performance assessment shall subject the student to academic disqualification, in accordance with the University of California 100.00 Policy on Student Conduct and Discipline.

c. Grades (per Graduate Council Regulations, Appendix II)
    i. Instructors are required to assign specific grades for all graduate students and must file course reports with the Registrar at the end of each quarter.

Letter	Description	Grade point equivalent
A	Excellent	4
B	Good	3
C	Fair	2
D	Barely passing	1
F	Failure	0
I	Incomplete	undetermined

ii. A course in which a student receives a grade of D or F cannot count as part of the unit requirement for a graduate degree, but is calculated in the total grade point average.
iii. Incomplete (I): A student, who has not met all requirements of a course, may be given the grade of "I" (Incomplete). A grade of "I" indicates that the instructor is not prepared to give a grade for the course because the student has not completed all requirements for the course, but the work is of passing quality.
    1. Students receiving an Incomplete must craft a plan for remediation, including a timeline for completion of the course requirements
    2. The Incomplete grade automatically becomes an "F" if the work is not completed and a grade is not submitted by the instructor within one year after the end of the course or the final examination.
iv. Pass/Fail: The grade S shall be awarded only for work that would otherwise receive a grade of B or better; the grade U is assigned whenever a grade of C, D, or F would otherwise be given.
    1. S/U grades are not counted towards grade point average but are counted toward unit requirement
v. A maximum of six units of course work for which S/U grading is elected may be used toward the unit requirements for a graduate degree

IV. Standards of Scholarship
- a. The GC Program's Standards of Scholarship are in Compliance with Graduate Council Standards https://senate.ucsf.edu/graduate-council-regulations#4
    - i. Graduate students must maintain a cumulative grade point average of 3.00 (B) and must make satisfactory progress toward the degree (see Section V for Satisfactory Progress).
    - ii. Students who fail to maintain a 3.00 grade point average or fail to make satisfactory progress toward the degree are subject to dismissal by the Dean of the Graduate Division after consultation with the GC Program leadership.
- b. A student seeking accommodations for protected disabilities must register with the responsible UCSF Office to seek institutionally approved accommodations.
    - i. Accommodations for protected disabilities must be sought in advance of the educational activities for which the accommodations are relevant.
    - ii. Failure to seek or to use institutionally approved accommodations will not be accepted as sufficient grounds to circumvent adverse action.

V. Requirements for Satisfactory Progress are in compliance with the UCSF Graduate Division Policy on Student Progress https://graduate.ucsf.edu/policy-student-progress
- a. Follow Student Expectations including: attend all classes, participate actively in all courses, come to class prepared, maintain academic integrity (as stated in the GC Program Code of Conduct, Appendix I)
- b. Good Academic standing
    - i. Students must pass all of their courses (grades of C or higher in any given class, but overall GPA equal to or greater than 3.0; which is equivalent to a B average).

1. No failing grades
2. Students with an Incomplete must demonstrate active progress on the individualized remediation plan

c. Capstone Project: Student is actively working towards an approved Capstone Project and meeting appropriate milestones. The student has met with their capstone mentors at least monthly once their project has been approved.
d. Complete all requested course/faculty evaluations.
e. Pass clinical rotations with a C grade or higher and demonstrate progress in achieving the ACGC Practice Based Competencies.
f. Maintain the highest standards of academic integrity, professionalism, and cultural humility during the course of the capstone project and clinical rotations.

VI. Normative Time from Matriculation to Degree

a. 2 academic years (7 quarters)
b. A master's candidate who has already completed six units of Capstone Project credit (GENC223) may, with the approval of the Capstone Research Coordinator, research advisor, and Program Director, enroll in GENC223 for two credit hours for a maximum of two quarters to complete the Capstone Project.
c. All the requirements for the master's degree must be completed within five consecutive calendar years in order to graduate from the program.
    i. Students not completing the requirements within 5 years are subject to dismissal.

VII. Academic Misconduct

a. Students are expected to follow University of California rules and regulations on academic misconduct. Each student is responsible for understanding and subscribing to the principles of academic integrity and will bear individual responsibility for his/her work. Any academic work (written or otherwise) submitted to fulfill an academic requirement must represent a student's original work.
b. Academic misconduct includes, but is not limited to the sections described below. Other acts not explicitly outlined within each section, but fitting the spirit of the code, will also be considered if allegations of academic misconduct are made.
    i. **Cheating:** Fraud, deceit, or dishonesty in an academic assignment or using or attempting to use materials that are not authorized, or colluding with others to do so (witnessing or knowledge of cheating/academic misconduct without reporting to the GC Program leadership)
        - Copying or attempting to copy from others during an exam or assignment
        - Communicating answers with another person during an exam
        - Pre-programming an electronic medium to contain answers or other unauthorized information for exams
        - Using unauthorized materials, prepared answers, written notes, or concealed information during an exam
        - Allowing others to do an assignment or portion of an assignment
        - Submission of the same assignment for more than one course without prior approval of all the instructors involved

- Collaborating on an exam or assignment with any other person without prior approval from an instructor
- Taking an exam for another person or having someone take an exam in place of the student

ii. **Plagiarism**: An author's work is her/her property and must be respected by documentation. Plagiarism is an intellectual theft and refers to the use of another's ideas or words without proper attribution or credit.
- Wholesale copying of passages from works of others (for example, books, articles, films, graphics, including websites or other electronic sources) into your homework, essay, papers, exams, qualifying papers, or class project without proper citing or acknowledgment.
- Use of the views, opinions, or insights of another without acknowledgment.
- Paraphrasing of another person's characteristic or original phraseology, metaphor, or other literary device without acknowledgment or proper citation.

iii. **False information and representation, fabrication, or alteration of information:**
- Furnishing false information in the context of an academic assignment.
- Failing to identify yourself honestly in the context of an academic obligation.
- Fabricating or altering information or data and presenting it as legitimate.
- Providing false or misleading information to an instructor or any other University official.

iv. **Theft or damage of intellectual property:**
- Furnishing false information in the context of an academic assignment.
- Failing to identify yourself honestly in the context of an academic obligation.
- Fabricating or altering information or data and presenting it as legitimate.
- Providing false or misleading information to an instructor or any other University official.

v. Alteration of University Documents
- Forgery of an instructor's signature on a letter of recommendation or any other documents.
- Submitting an altered transcript of grades to or from another institution or employer.
- Putting your name on another person's exam or assignment.
- Altering a previously graded exam or assignment for purposes of a grade appeal or of gaining points in a re-grading process.

vi. **Distribution or sharing of lecture notes or exam items/information**

to provide undue advantage to others or for commercial purposes:

- Selling, distributing, website posting, texting, emailing, or publishing course lecture notes, handouts, readers, recordings, exam items, confidential or other information provided by faculty to give advantage to others or for any commercial purpose, without the express written permission of the faculty

VIII. Procedures to notify a student of failure to meet criteria for satisfactory academic progress, unprofessional behavior or academic misconduct may include:

a. Informal verbal warning**.** Depending on the seriousness of the alleged misconduct or academic deficiency, an informal process of counseling and advising will occur among the Program Director, course director (or clinical supervisor) and student. The goal will be to educate the student about the policy and to provide a verbal warning.

b. Informal letter of performance expectations. More serious infractions will involve a confidential letter of performance standards that informs the student of future expectations and how to take steps to avoid academic difficulty, unprofessional behavior or allegations of misconduct. This letter will go in the student's file in the GC Program, but will not be filed with the Associate Dean of the Graduate Division unless further issues occur.

c. Formal process. A formal procedure will take place if the informal verbal warning or letter of performance expectations is not successful, and/or there are multiple occurrences of misconduct, and/or an egregious incident has occurred. Determination of egregious conduct will be made by the Program Director and the Executive Committee. A student cannot be dismissed from the program for a single egregious academic incident.

i. The Program Director will provide a written notice of the deficiency or allegation to the student and share the letter with the student's academic mentor. The student will be offered the opportunity to provide a written response within seven days. The Program Director will then meet with the student and mentor within 7 days of receipt of the written response, or 14 days of the original letter if the student does not send a written response, and take one of the following actions:

1. Develop an individual remediation plan

a) Individual remediation plans are a memorandum of understanding that clearly outline specific steps and associated deadlines that the student must fulfill in order to receive a satisfactory report. The consequence(s) of continued infraction(s) must also be included.

a. Individual remediation plans must be signed by the Program Director, student and academic mentor
b. A copy of the individualized remediation plan is filed in the students record in the GC Program and with the Associate Dean of the Graduate Division
c. Students unable to fulfill the expectations of the individualized remediation plan are subject to Probation or dismissal from the program.

2. After consultation with the Executive Committee place the student on probation (see Section VIIId).
3. Proceed with a formal in-depth Review Committee (see Section VIIIe).

d. Probation

i. Academic Probation

1. If a student's GPA is less than 3.0 (a B average) computed on the total of all final letter grades.
    a) If final grades are delayed in transmission to the faculty, disqualification may be postponed for 1 quarter.
2. Students with more than one incomplete grade may also be placed on academic probation.
3. If there is a documented incident of academic misconduct as defined in Section VII.
4. Students on academic probation are eligible to continue in the curriculum after an appropriate individualized remediation plan (as described in section VIII.iii) has been put in place.

ii. Probation secondary to unprofessional conduct

1. Documentation of unprofessional behavior by the GC Program leadership or a clinical rotation supervisor that is not amenable to any of the procedures outlined in sections VIII a-c.
2. Students on probation secondary to unprofessional conduct are eligible to continue in the curriculum after an appropriate individualized remediation plan (as described in section VIII.iii) has been put in place

iii. Probation Remediation

1. The student will be required to meet with the Program Director or Assistant Program director, and their academic mentor, in order to develop an individualized probation remediation plan that includes:
    a) Reason for student's probationary status
    b) Actions the student must take to return to good academic standing
    c) Timeline for actions to be completed
    d) Consequences for inability to fulfill the expectations of the individualized remediation plan
    e) Individualized remediation plans must be signed by the student, academic mentor and Program Director or Assistant Program Director.
    f) Probation individualized remediation plans will be filed in the students GC Program record and with the Associate Dean of the Graduate Division
2. Student will remain on academic probation until the requirements of the remediation plan have been met and probationary status has been removed by a definitive action of the GGGC Executive Committee.

3. Failure to meet requirements of the remediation plan will warrant an in-depth review of eligibility for dismissal

e. In-depth review of eligibility for dismissal
    i. The process for in-depth review of a student's eligibility for dismissal will follow Appendix VII of the UCSF Divisional Procedure for Student Grievance in Academic Affairs

IX. Student Academic Petitions and Grievances
    a. Students may petition the Dean of the Graduate Division for individual exceptions to academic regulations.
        i. If a petition is denied by the Dean, the student has the right to request further consideration by the Administrative Committee of the Graduate Council.
        ii. The Dean of the Graduate Division may refer a student petition to the Administrative Committee at his/her discretion.
        iii. Resolution of student grievances in academic matters shall be in accordance with the Bylaws of the San Francisco Division of the Academic Senate, Appendix VII – Divisional Procedure for Student Grievance in Academic Affairs.

UCSF Genetic Counseling Program Code of Conduct

- Maintain the highest standards of academic honesty
- Neither give nor receive aid in examinations or assignments unless such cooperation is expressly permitted by the instructor
- Be truthful with patients and report accurately all historical and physical findings, test results, and other information pertinent to the care of the patient
- Conduct research in an unbiased manner, report results truthfully, and credit ideas developed and work done by others
- Regard confidentiality as a central obligation of patient care
- Interact with patients in a way that ensures their privacy and respects their modesty
- Limit discussions of patients to members of the health care team in settings removed from the public ear (e.g., elevators, hallways, cafeterias)
- Treat patients and their families with dignity and respect, both in presence and in discussions with other members of the health care team
- Uphold a classroom atmosphere conducive to learning
- Interact with all members of the health care team in a considerate and cooperative manner
- Not use alcohol or drugs in any way that could interfere with clinical responsibilities

UCSF MASTERS IN GENETIC COUNSELING STUDENT HANDBOOK

(Insert Current Academic Year)

ABSTRACT

(Provide updated picture)

Cindy Morgan

Table of Contents

Welcome

Welcome to the Master of Science in Genetic Counseling degree program at UCSF! We look forward to working with you over the next two years.

This Student Handbook has been assembled to provide you with general information about the genetic counseling program. It also contains helpful information about UCSF policies and procedures, as well the sponsors of the program the Institute for Human Genetics (IHG) and the Division of Medical Genetics in the Department of Pediatrics.

You are welcome to expand and add information, and to share your suggestions on ways to improve this reference as you proceed through your program. **Keep it handy, as you will use it repeatedly over the next two years!**

Welcome Letter

Welcome letter from the Director (? And co-director, medical director)

Program Contacts:
Cindy.Morgan@ucsf.edu

XXX Assistant Director

Medical Director

Lynn.Duncan@ucsf.edu - 415-476-2470
Medical Director TBA

Section 1 - University Information:

Academic Calendar

All dates related to registration, payments of fees, drop/add dates, other administrative requirements and official school holidays are recorded on the UCSF Academic Calendar available at: https://registrar.ucsf.edu/academic-calendar

Academic Standards

See Standards of Scholarship

Campus Code of Conduct

For more information and updates, please visit: UCSF Campus Code of Conduct (http://chancellor.ucsf.edu/file/191)

UCSF Mission & Vision Mission: advancing health worldwide™

Vision: In advancing health worldwide, the University of California, San Francisco (UCSF) will

- Develop innovative, collaborative approaches for education, health care and research that span disciplines within and across the health sciences
- Be a world leader in scientific discovery and its translation into improved health
- Develop the world's future leaders in health care delivery, research and education
- Deliver the highest-quality, patient-centered care
- Build upon its commitment to diversity
- Provide a supportive work environment to recruit and retain the best people and position UCSF for the future
- Serve the local, regional and global communities and eliminate health disparities

UCSF Code of Ethics

The citizens of California entrust UCSF with the responsibility for providing high quality teaching, health care and research, and for assuring that the highest standards of ethical conduct and integrity are practiced in meeting these responsibilities. The professional conduct of each member of the campus community is expected to be consistent with and fully comply with these principles. All members of the campus community are expected to engage in the following:

- Integrity – conducting ourselves with integrity in our dealings with and on behalf of the University.
- Respectful behavior – treating everyone with civility, courtesy, tolerance and acceptance, and recognizing the worth, dignity and unique characteristics of each individual.
- Trustworthy conduct – including dependability, loyalty and honesty in communications and actions.
- Accountability – taking personal responsibility for one's actions and decisions

Principles of Community

The San Francisco campus of the University of California is dedicated to learning and teaching in the health sciences. As a graduate and professional school campus, UCSF serves society through four primary missions: teaching, research, patient care and public service. Faculty, staff and students on the UCSF campus are a composite of many races, creeds and social affiliations. To achieve campus goals, individuals must work collaboratively with mutual respect and with forbearance.

Several principles of community life are established to guide individual and group actions on the campus. Adherence to these principles is essential to ensure the integrity of the University and to achieve campus goals. UCSF faculty, staff and students are asked to acknowledge and practice these basic principles of community life:

- We affirm that members of the campus community are valued for their individual qualities, and members are encouraged to apply their unique talents in creative and collaborative work.
- We recognize, value and affirm that social diversity contributes richness to the University community and enhances the quality of campus life for individuals and groups. We take pride in our various achievements, and celebrate our differences.
- We affirm the right of freedom of expression within the UCSF community and also affirm commitment to the highest standards of civility and decency toward all persons.
- We are committed to creating and maintaining a community where all persons who participate in University activities can work together in an atmosphere free from all forms of abusive or demeaning communication.
- We affirm the individual right of public expression within the bounds of courtesy, sensitivity and respect.
- We recognize the right of every individual to think and speak as dictated by personal belief, to express individual ideas and to state differences with other points of view, limited only by University requirements regarding time, place and manner.
- We reject acts of discrimination, including those based on race, ethnicity, gender, age, disability, sexual orientation and religious or political beliefs.
- We recognize that UCSF is devoted to public service, and encourage members of the campus community to participate in public service activities in their own communities and recognize their public service efforts in off-campus community settings.
- We affirm that each member of the campus community is expected to work in accord with these principles and to make individual efforts to enhance the quality of campus life for all.

Addressing Issues and Concerns
Employees are encouraged to discuss questions or concerns with their immediate supervisor. If this is not practical or issues or conflicts arise that cannot be resolved between the individual and the immediate supervisor, the individual should raise the concerns through the department administrative or academic hierarchy. This may include the next level of manager, the department head, and the office of the dean or vice chancellor where the unit reports. Faculty with concerns or questions should discuss them with the department chair. MSOs and department chairs encountering ethical conflicts involving any campus member are expected to work through the associate dean of the school or the office of the vice chancellor to which they report. Students with questions or concerns should speak with their faculty of record or advisor, contact the student affairs office in their school, contact the Office of Student Life, or the Graduate Division for assistance. Postdoctoral scholars should address questions to their faculty principal investigator/mentor or the Graduate Division.

Whistleblower Policy
Under University policy, individuals are encouraged to use the University Whistleblower Policy if they have a good faith belief that an activity occurred or is continuing to occur that is not in compliance with federal or state law or University policy. Such individuals are protected from retaliation for making such a “protected disclosure.” A “protected disclosure” may be made to the campus whistleblower coordinator, clinical compliance officer, or any campus administrator, director, manager or supervisor. The campus policy may be found online: http://tiny.ucsf.edu/wb Whistleblower Coordinator (415) 502-2810

Faculty Misconduct
Academic Personnel Manual (APM) Section 015—The Faculty Code of Conduct establishes standards of professional conduct and includes listings of faculty responsibilities, ethical principles and types of unacceptable behavior. Faculty Misconduct occurs when there is a violation of the Faculty Code of Conduct as defined in APM 015 Part II—Professional Responsibilities, Ethical Principles, and Unacceptable Faculty Conduct. Concerns about possible faculty misconduct should be reported to the responsible academic dean or the vice/associate provost—Academic Affairs.

Research Misconduct
The campus adheres to the Department of Health and Human Services definition of Research Misconduct as follows: “fabrication, falsification, or plagiarism in proposing, performing, or reviewing research, or in reporting research results.” Research misconduct does not include honest error or differences of opinion. Concerns about possible research misconduct should be reported to UCSF Research Integrity Officer Theresa O’Lonergan. Individuals should not undertake investigations of suspected research misconduct on their own. The UCSF Integrity of Research Policy (Campus Administrative Policy 100-29) can be viewed at http://policies.ucsf.edu/policy/100-29 The Clinical Enterprise The mission of the UCSF Medical Center is "Caring, Healing, Teaching and Discovering" and its vision is "to be the best provider of health care services, the best place to work and the best environment for teaching and research." The UCSF Clinical Enterprise Compliance Program provides a Code of Conduct and Principles of Compliance for all members of the UCSF Medical Center and UCSF Benioff Children’s Hospital workforce, toward fulfilling its mission in accordance with ethical and legal obligations: http://tiny.ucsf.edu/medctrcodeofconduct

Campus Maps

San Francsico campuses

UCSF has major programs and departments located at twenty four sites in San Francisco
https://www.ucsf.edu/about/locations/campus-maps#active-default

Oakland: Benioff Children’s Hospital Oakland
https://www.childrenshospitaloakland.org/main/maps-locations/10.aspx

Fresno
https://www.communitymedical.org/CMC/media/Maps-Directions/campus-map-community-regional-medical-center.pdf

Counseling Services

See Student Services

Disability Accommodations

A student seeking accommodations for protected disabilities must register with the UCSF Student Disability Services Office to seek institutionally approved accommodations. Accommodations for protected disabilities must be sought in advance of the educational activities for which the accommodations are relevant. Failure to seek or to use institutionally approved accommodations will not be accepted as sufficient grounds to circumvent adverse action. Also see “Standards of Scholarship”.

Diversity

Office of Diversity and Outreach

UCSF celebrates diversity and is committed to building a broadly diverse and inclusive community. The GC Program also places a high value on diversity and has a deep appreciation for the perspectives and rich experiences that a varied student body and faulty can bring to the educational process. The UCSF Office of Diversity and Outreach leads the campus effort to foster a culture of equity and inclusion by serving as the central resource for internal and external community members

Electronics

Encryption: All laptops and devices connecting to any UCSF network system must be encrypted. Encryption is the process of encoding information so that only authorized persons can read it. It is used to protect confidential and legally protected data. You will

need to complete the encryption process before the beginning of classes in order to comply with UCSF security policies and access resources. Please encrypt your computer prior to orientation by following the instructions here. Before you begin, make sure your laptop has enough memory and the minimum requirements. If you need help with encryption process from IT, please sign up for the Encryption Clinic on XXX.

Comment [CM1]: Update with current info for 2020

Faculty Misconduct

The individuals in the link here may assist in providing information on the Faculty Code of Conduct or to assist in filing a complaint.

Financial Information

Fees

Current fees for the Masters Program in Genetic Counseling may be obtained through the Office of the Registrar: https://registrar.ucsf.edu/registration/fees/graddiv

Fees for the Genetic Counseling Program are assessed on a quarterly basis. Instructions for paying feels may also be found through the Office of the Registrar: https://registrar.ucsf.edu/registration/paying-fees

Financial Aid

Students may apply for financial aid through the UCSF Student Financial Aid Office. Aid is awarded based upon financial need and is usually in the form of loans or federal work-study. Students interested in a work-study position should indicate this in the financial aid application.

The GC Program encourages students to research and seek scholarships independently.
UCSF does not offer paid teaching assistantships during the academic year.

UCSF offers a cost-of living supplement (COLS) to incoming students based on need. You can find more information including eligibility for this program here. You must apply before June 18.

Comment [CM2]: Program may be obsolete by launch. Check for updates

Fitness & Recreation

Membership in UCSF Fitness & Recreation Facilities at both Parnassus (Millberry Union) and Mission Bay (Bakar) is included in student registration, using your UCSF ID.

Grading

Instructors are required to assign specific grades for all graduate students and must file course reports with the Registrar at the end of each quarter.

Grades are reported as follows:
https://registrar.ucsf.edu/faculty/grades/key

Letter	Description	Grade point equivalent
A	Excellent	4
B	Good	3
C	Fair	2
D	Barely passing	1
F	Failure	0
I	Incomplete	undetermined

A student, who has not met all requirements of a course, may be given the grade of "I" (Incomplete). A grade of "I" indicates that the instructor is not prepared to give a grade for the course because the student has not completed all requirements for the course, but the work to date, is of passing quality. A student receiving a grade of "I" must create a plan with the instructor to complete the course requirements as soon as possible in order to progress within the program. This grade automatically becomes an "F" if the work is not completed and a grade is not submitted by the instructor within one year after the end of the course or the final examination.

Pass-fail grades are reported as follows:

- S = satisfactory
- U = unsatisfactory

The grade S shall be awarded only for work that would otherwise receive a grade of B or better; the grade U is assigned whenever a grade of C, D, or F would otherwise be given.

Grades are available on the UCSF Student Portal.

Housing

UCSF offers quality on-campus housing and related services to UC San Francisco students, post-docs, residents, clinical fellows, and faculty. Information on campus housing and eligibility may be found through Housing Services. Information on off-campus housing may be found here or via community listing boards such as Craig's List or the San Francisco Chronicle.

Institutional Review Board (IRB)

https://irb.ucsf.edu/

Student researchers must comply with all requirements for protection of human subjects. The Human Research Protection Program (HRPP) reviews and monitors research involving human subjects at UCSF and several affiliate institutions to ensure the ethical and equitable treatment of the research subjects. Read more about the HRPP program.

The HRPP is comprised of these groups:

- The Institutional Review Board (IRB), which reviews human subject research studies — learn how to apply to the IRB,
- The Quality Improvement Unit (QIU), which conducts monitoring, education and other QI activities, and
- The Human Gamete, Embryo and Stem Cell Research (GESCR) Committe

Leave of Absence

See Withdrawal from Course / Program or Leave of Absence

Libraries

https://www.library.ucsf.edu/

The UCSF Library is one of the preeminent health sciences libraries in the world, containing an expansive digital and physical collection of the world's health sciences knowledge base. The Library contains an extensive and exceptionally rich collection of monographic and periodical literature in the health sciences, with substantial holdings in the biological and physical sciences, the social sciences, psychiatry, and psychology. Offering a diverse range of services and resources to the UCSF community and public visitors, the Library is a vital resource for learning, engagement and creativity within UCSF and beyond.

The Parnassus Library is UCSF's main library. To borrow materials, students must obtain a Library Borrower Account. To gain full access to online library resources and web-based courses while on campus, students must connect to the *UCSFwpa* wireless network via their MyAccess account. To access the online library remotely (off campus), students need to obtain a VPN account through UCSF IT Services

Locations:
Parnassus Library (Kalmanovitz Library & Center for Knowledge Management)
530 Parnassus Ave.
General Info: 415-476-2336
Tech Support & Interactive Learning Cntr: 415-476-4309
Reference & Info: 415-476-2337 or email info@library.ucsf.edu

Mission Bay Library
General Info: 415-514-4060

Resources at the libraries:
Tech Commons (https://learningtech.library.ucsf.edu/-/#): The Tech Commons is a dedicated space for students, faculty, and staff to **engage with technology** and explore **new teaching and learning opportunities**. IT staff maintain student-computing facilities in the library and in the Medical Sciences Building, with PC and Macintosh computers, printers, software, documentation, consulting support, and connections to the Internet. The multimedia and multi-use workstations provide support for development of curriculum-integrated, educational materials. The Learning Technologies Group offers curriculum-integrated instruction and scheduled seminars that assist faculty and education staff in the use of education technology. The IT specialists provide it support services to students at the Parnassus Library help desk and via phone and email.

Education & Research Services: The Library provides experts, resources, and services that help users find and manage information to support research. The team of staff librarians provide regular support with reference managers, copyright, publishing, open access, database searching, and systematic review.

Makers Lab (https://www.library.ucsf.edu/use/makerslab/): The Makers Lab is a creative space for learning, inspiration, and exploration at UCSF open to the UCSF community. Users can use a wide range of resources from 3d printer and 3d scanners to a sewing machine and play-doh. The Makers Lab provides free access to new tools and environments that foster creativity and discovery.

My Access

MyAccess is an authentication service used for many online systems and services available to UCSF students, including the student portal, the financial portal, the Collaborative Learning Environment (CLE), wireless internet access, and the Virtual Private Network (VPN). Students use MyAccess for all aspects of the GC program.

Once you receive your UCSF email address and activation instructions from the Office of the Registrar, register by going to the MyAccess website and entering your UCSF email address.

More information on registering your MyAccess account is available on the IT website.

Nondiscrimination Policy

https://registrar.ucsf.edu/student-records/nondisc

The University of California, in accordance with applicable Federal and State law and University policy, does not discriminate on the basis of race, color, national origin, religion, sex, gender identity, pregnancy,[1] physical or mental disability, medical condition (cancer related or genetic characteristics),

ancestry, marital status, age, sexual orientation, citizenship, or service in the uniformed services.[2] The University also prohibits sexual harassment.
This nondiscrimination policy covers admission, access, and treatment in University programs and activities.

[1]Pregnancy includes pregnancy, childbirth, and medical conditions related to pregnancy or childbirth.

[2]Service in the uniformed services includes membership, application for membership, performance of service, application for service, or obligation for service in the uniformed services.

For those seeking information on Divisional Procedures for Student Grievance in Alleged Unlawful Discrimination, please contact the **Office for Diversity and Outreach** for further information.

Undocumented Student Welcome Statement
https://registrar.ucsf.edu/student-records/nondisc

UCSF welcomes applications for admission from undocumented individuals, such as those who qualify under Deferred Action for Childhood Arrivals (DACA) and/or AB540. Please visit the UCOP Web site for more information.

Registration

Current registration dates may be found through the Office of the Registrar .

"Registration" refers only to paying the necessary fees. "Class sign-ups" are done by filing a study list on-line. The study list is the official record of courses for which students receive credit at the end of each quarter. The Registrar's Office sends students a notice when registration is open (approximately six weeks before each quarter begins). Each quarter, students will see a list of the required courses that the GC Program has filed for them. To enroll in courses, students should verify that the courses are correct and accept the study list. The list will include all required GC Program courses and students should not add any courses. Filing your study list is required to complete your registration each quarter. Late fees will be automatically assessed if study lists are not filed by the last day of the enrollment period.

A student who does not register must petition for leave of absence or withdrawal, or be subject to administrative withdrawal or dismissal.

A student returning to registered status after a leave of absence must gain approval of the GC Program Director and Assistant Director and petition for readmission. (See Withdrawal from Course / Program or Leave of Absence)

Student Services

Identification Badges
Student ID badges are required for daily access to campus buildings and for most campus activities. A valid government photo ID is required.

Students who are unable to pick up their IDs on the first day of orientation can make an appointment at either the Parnassus or Mission Bay police office:

Parnassus Campus: **415-476-2088**
ID cards, Fingerprinting and Notary
Mon-Fri @ 7:15am to 4:00pm
Drop in service available. Priority given to those with appointments.

500 Parnassus Ave. Millberry Union, floor P7 #MU18

Mission Bay Campus: **415-476-2088**
ID cards, Fingerprinting and Notary
Call ahead – no drop-in service
Mon 10:45am to 4:00pm • Tues-Fri @ 7:15am to 4:00pm
Office closed 12pm to 1pm Mon-Fri
600 16th St., Genentech Hall #124

In case of lost or stolen ID card, please report immediately by calling 415-476-1414 (24/7) or send an email to weid@police.ucsf.edu. Students are responsible for costs associated with replacing their ID card.

Student Disability Services
UCSF is committed to ensuring access to graduate education for all students. More information is available at Student Disability Services (SDS) / 415-476-6595 / email StudentDisability@ucsf.edu . See also Standards of Scholarship for more information.

Student Health & Counseling Services
All registered UCSF students have access to in-clinic healthcare services provided by Student Health & Counseling Services.

Student Health Insurance
UCSF students are automatically enrolled in the UC Student Health Insurance Plan (UC SHIP) when registering for classes. The health insurance plan includes medical, mental health, dental, vision, prescription and travel insurance benefits. All graduate students are REQUIRED to maintain continuous health coverage while enrolled at UCSF. If covered by another policy, students may apply for a waiver and receive a refund of these fees. STUDENTS MUST SUBMIT A COMPLETED AND APPROVED WAIVER APPLICATION TO OPT OUT. **Please pay close attention to the opt out deadline**, as insurance will cover the following quarter, and expense is included in the total student fee.

Student Success
https://success.ucsf.edu/home
The Student Success website contains a wide range of resources and services available at UCSF to help students achieve success while enrolled in their program and after graduation. Topics range from "Maximizing Your Learning Potential" to "Finding Your Inner Leader" to "Wellness: Finding Your Balance: and many more.

Travel Insurance
UC offers free travel insurance for students participating in UC sponsored and supervised off-campus activities, both domestic and international. Students who travel more than 100 miles outside of San Francisco are required to register for travel insurance before departure. Please visit the UC travel assistance website for detailed information on coverage, frequently asked questions, and registration.

Sexual Violence & Harassment Policy

Sexual harassment and sexual violence are prohibited both by law and University policy. It is the responsibility of UCSF to prevent, to correct, and when necessary, to discipline behavior that violates this policy on Sexual Harassment and Sexual Violence. [http://policy.ucop.edu/doc/4000385/SVSH]

Both University policy and the law prohibit retaliation against any individual who opposes sexual harassment, files a complaint, or assists or participates in any manner in an investigation or proceeding conducted by the University or an external agency.

For assistance with incidents of sexual violence, sexual harassment, dating violence, domestic violence, and stalking, please contact your Title IX Officer. If you are a student and desire confidential assistance contact your local CARE Advocate.

Local resource information can be found at Sexual Violence Prevention and Response: http://sexualviolence.universityofcalifornia.edu/gethelp/index.html

For questions about the University's policy, please contact Kathleen Salvaty at 510-987-9161, email Kathleen.salvaty@ucop.edu

Comment [CM3]: Check for current contact in 2020

The University's student disciplinary procedures emphasize education, personal growth, accountability, and ethical behavior — upholding standards of responsible conduct to protect the welfare of the University community. When formal fact-finding procedures are used, the procedures are designed to provide a prompt, fair, and impartial resolution of the matter. The University disciplinary process is an internal administrative procedure that is separate and distinct from external legal processes that may be available, civil or criminal.

Under these policies and procedures, the University will consider the effects of off-campus conduct when evaluating whether there is a hostile environment on campus, or in an off-campus education program or activity.

Standards of Scholarship

https://senate.ucsf.edu/graduate-council-regulations#4

Graduate students must maintain a cumulative grade point average of 3.00 (B) in their program of graduate study and must make satisfactory progress toward the degree as defined by the faculty of the Genetic Counseling program.

Students who fail to maintain a 3.00 grade point average or fail to make satisfactory progress toward the degree are subject to dismissal by the Dean of the Graduate Division after consultation with the faculty of the Genetic Counseling program.

Disability Accommodations

A student seeking accommodations for protected disabilities must register with the UCSF Student Disability Services Office to seek institutionally approved accommodations. Accommodations for protected disabilities must be sought in advance of the educational activities for which the accommodations are relevant. Failure to seek or to use institutionally approved accommodations will not be accepted as sufficient grounds to circumvent adverse action

Academic Misconduct

Students are expected to follow University of California rules and regulations on academic misconduct. Each student is responsible for understanding and subscribing to the principles of academic integrity and will bear individual responsibility for his/her work. Any academic work (written or otherwise) submitted to fulfill an academic requirement must represent a student's original work.

Academic misconduct includes, but is not limited to the sections described below. Other acts not explicitly outlined within each section, but fitting the spirit of the code, will also be considered if allegations of academic misconduct are made.

1) Cheating: Fraud, deceit, or dishonesty in an academic assignment or using or attempting to use materials that are not authorized, or colluding with others to do so (witnessing or knowledge of cheating/academic misconduct without reporting to the GC Program leadership)

- Copying or attempting to copy from others during an exam or assignment
- Communicating answers with another person during an exam

- Pre-programming an electronic medium to contain answers or other unauthorized information for exams
- Using unauthorized materials, prepared answers, written notes, or concealed information during an exam
- Allowing others to do an assignment or portion of an assignment
- Submission of the same assignment for more than one course without prior approval of all the instructors involved
- Collaborating on an exam or assignment with any other person without prior approval from an instructor
- Taking an exam for another person or having someone take an exam in place of the student

2) **Plagiarism**: An author's work is her/her property and must be respected by documentation. Plagiarism is an intellectual theft and refers to the use of another's ideas or words without proper attribution or credit.

- Wholesale copying of passages from works of others (for example, books, articles, films, graphics, including websites or other electronic sources) into your homework, essay, term paper, comp exam, qualifying papers, dissertation or class project without proper citing or acknowledgment.
- Use of the views, opinions, or insights of another without acknowledgment.
- Paraphrasing of another person's characteristic or original phraseology, metaphor, or other literary device without acknowledgment or proper citation.

3) False information and representation, fabrication, or alteration of information:

- Furnishing false information in the context of an academic assignment.
- Failing to identify yourself honestly in the context of an academic obligation.
- Fabricating or altering information or data and presenting it as legitimate.
- Providing false or misleading information to an instructor or any other University official.

4) Theft or damage of intellectual property:

- Furnishing false information in the context of an academic assignment.
- Failing to identify yourself honestly in the context of an academic obligation.
- Fabricating or altering information or data and presenting it as legitimate.
- Providing false or misleading information to an instructor or any other University official.

5) Alteration of University Documents

- Forgery of an instructor's signature on a letter of recommendation or any other documents.
- Submitting an altered transcript of grades to or from another institution or employer.
- Putting your name on another person's exam or assignment.
- Altering a previously graded exam or assignment for purposes of a grade appeal or of gaining points in a re-grading process.

6) Distribution or sharing of lecture notes or exam items/information to provide undue advantage to others or for commercial purposes:

- Selling, distributing, website posting, texting, emailing, or publishing course lecture notes, handouts, readers, recordings, exam items, confidential or other information provided by faculty to give advantage to others or for any commercial purpose, without the express written permission of the faculty

Transportation

The UCSF Campus Life Services Transportation page (http://campuslifeservices.ucsf.edu/transportation/) lists information about free campus shuttles, parking (cars, motorcycles, bicycles), maps and directions, and biking information.

- **Parking** - UCSF is located in a densely populated urban environment. A variety of parking locations are available on each campus and rates vary by location and time of day. http://campuslifeservices.ucsf.edu/transportation/services/parking/public_parking

- **Public Transportation** in the San Francisco Bay Area is extensive. Visit 511.org for transit and trip planning information, or download mobile application Nextbus for real-time transit information.

- **Shuttle Schedules** - Free UC San Francisco shuttles connect our five major campus locations in San Francisco: Parnassus Heights, Mission Bay, Mission Center, Mt. Zion and Zuckerberg San Francisco General. The shuttle network is designed to provide inter-campus accessibility, Monday to Friday, 5AM to 9PM, and ridership is restricted to UCSF faculty, staff, students, patients/family members, visitors and university guests. All UCSF shuttles are ADA accessible and equipped with wheel chair lifts. Shuttle timetables are available here.

Withdrawal from Course / Program or Leave of Absence

All courses in the Genetic Counseling curriculum are REQUIRED. Withdrawal from individual courses will prevent progression within the program and jeopardize a student's ability to graduate. Students wishing to withdraw from a class should consult the course director and the Genetic Counseling Program Director.

Students desiring to withdraw or request a Leave of Absence from the Genetic Counseling program must consult with the Genetic Counseling Director and Assistant Director prior to initiating the process through the Office of the Registrar. Students desiring a Leave of Absence must submit a written request indicating the effective start and end dates and reason(s) for the leave. Due to the progressive nature of the curriculum and scheduling of clinical rotations, readmission to the Genetic Counseling program requires permission from both the Director and Assistant Director. The student will receive a written confirmation or denial of the request for a leave. If the leave is confirmed, a student returning to registered status after a leave of absence must petition for readmission. Additionally, the confirmation letter will include a date by which the student must notify their research mentor, program director and the Office of the Registrar of his/her intention to return to graduate study. Readmission would occur at a time point that meets the needs of the student as well as currently enrolled students.

Section 2 – Program Information

During the two years spent as a graduate student in the Genetic Counseling program, students will learn the principles of human genetics and psychosocial counseling theory, and their application to health care. The curriculum of the program has been designed to provide in-depth knowledge on principles of human and medical genetics, the psychosocial impact of genetic disorders, interpretation and application of cutting edge technology, and the research process in genetic counseling. A variety of clinical rotations provide exposure to a wide range of individuals and/or families affected with, or at risk of genetic disease. Ultimately, students will acquire the knowledge and clinical skills to function as a competent genetic counselor in a wide variety of settings and roles.

In addition, students will gain experience through attendance and presentations at conferences, seminars, workshops and community outreach.

The primary objective is to train students in the core concepts of human genetics and psychosocial counseling theory. The curriculum is comprised of didactic instruction, clinical exposure to build foundational clinical skills, supervised clinical and industry internships and a capstone research project. The course work provides a strong foundation in molecular and human genetics, cytogenetics, population genetics, clinical genetics, advanced testing technologies and counseling theory. The counseling

curriculum will prepare students for the considerable amount of time they will spend immersed in clinical rotations beginning summer quarter at the end of the first year. During their clinical training students will progress from observing clinical interactions to independently counseling and providing case management to patients and/or families affected with, or at risk of genetic disease. Additionally, students will engage in a capstone research project that will enable them to investigate an original topic of interest. Supplementary activities such as case conferences, grand rounds, journal clubs, seminars and scientific meetings will also enrich the educational experience. Overall, The GC Program will provide a field of interdisciplinary academic study that will form the cornerstone for understanding the etiology, manifestations, diagnosis and lived experience of genetic disease.

Contact Information

Contact information for UCSF faculty and staff may be found at: https://directory.ucsf.edu/

Program Director:	Cindy Morgan Cindy.morgan@ucsf.edu 415-XXX-XXX
Assistant Program Dir:	XXX
Program Administrator:	XXX
Research Coordinator:	XXX

Academic Requirements

Student Expectations

Attendance: The learning goals of each course are aimed at graduate level competency. Students are expected to attend all classes, complete assignments prior to class, and arrive on time. If you need to miss class, please email the course instructors as soon as possible to notify them of the reason for your absence. Students are still responsible for material covered in class.

Participation: The courses move swiftly through a large compendium of material. Much of the learning occurs through interactive sessions that require preparation, reading, and oral or PowerPoint presentations. The faculty value the diverse background and skills within the class cohort and encourage cross-disciplinary debate and active, democratic participation. Students are asked to lead some seminars, develop teaching materials, and contribute actively to the learning process. One of the objectives of the Genetic Counseling program is for students to develop clear, articulate, and concise communication skills (both written and oral), which faculty evaluate in periodic reports and assignments. Additionally, participation is weighed heavily in the final grade for most classes. Please refer to course syllabi for details.

Preparation: Preparation for class requires time management. Reading assignments can be very long. Students should allocate time so that reading, written assignments, and preparation for examinations can be accomplished before class. The UCSF Academic Senate expects that students allocate three hours of preparation for each contact hour of lecture, and two hours of preparation for each contact hour of seminar

Required Academic Standards

The GC Program maintains academic standards that are in compliance with the UCSF Graduate Division. Graduate students enrolled in the program must maintain a cumulative grade point average of 3.00 (B), must make satisfactory progress in their clinical rotations and complete a capstone project. Additionally,

students are expected to meet all course requirements ethically and responsibly.

Students who fail to maintain a 3.00 grade point average or fail to make satisfactory progress toward the degree are subject to probation and/or dismissal by the GC Program. Any student demonstrating academic dishonesty, misconduct or unprofessional behavior may also be subject to probation and/or dismissal as described in the Disciplinary Actions section.

Criteria for satisfactory academic progression

Students in the GC Program are considered to be in good academic standing if they:

1. Follow Student Expectations (as described above) including: attend all classes, participate actively in all courses, maintain academic integrity (as stated in the GC Program Code of Conduct), and complete all requested course/faculty evaluations.
2. Are working towards an approved Capstone Project while meeting milestones, and have met with their capstone mentors at least monthly once their project has been approved.
3. Pass clinical rotations with a C grade or higher and demonstrate progress in achieving the ACGC Practice Based Competencies.
4. Students must maintain the highest standards of academic integrity, professionalism, and cultural humility during the course of the capstone project and clinical rotations.
5. Students must pass all of their courses (grades of C or higher in any given class, but overall GPA equal to or greater than 3.0, which is equivalent to a B average).
6. Any student that has received an Incomplete for a course is demonstrating active progress on a remediation plan.

Code of Conduct

The GC Program emphasizes the highest standards of ethical and compassionate behavior. In addition to the UCSF Code of Conduct outlined in Section 1, we ask students and faculty to uphold the following principles:

- Maintain the highest standards of academic honesty
- Neither give nor receive aid in examinations or assignments unless such cooperation is expressly permitted by the instructor
- Be truthful with patients and report accurately all historical and physical findings, test results, and other information pertinent to the care of the patient
- Conduct research in an unbiased manner, report results truthfully, and credit ideas developed and work done by others
- Regard confidentiality as a central obligation of patient care
- Interact with patients in a way that ensures their privacy and respects their modesty
- Limit discussions of patients to members of the health care team in settings removed from the public ear (e.g., elevators, hallways, cafeterias)
- Treat patients and their families with dignity and respect, both in presence and in discussions with other members of the health care team
- Uphold a classroom atmosphere conducive to learning
- Interact with all members of the health care team in a considerate and cooperative manner
- Not use alcohol or drugs in any way that could interfere with clinical responsibilities

Normative Time from Matriculation to Degree

Students are expected to complete the GC Program course of study according to schedule in two academic years. However, in some cases additional time may be necessary to finish the Capstone Project thus extending the time that a student remains in the program. A master's candidate who has already completed six units of Capstone Project credit (GENC223) may, with the approval of the Capstone Research Coordinator, research advisor, and Program Director enroll in GENC223 for two

credit hours for a maximum of two quarters to complete the Capstone Project. All the requirements for the master's degree must be completed within five consecutive calendar years in order to graduate from the program. Graduation will not occur until completion of the Capstone Project.

Course of Study

Course Schedule (sample)

	Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Total Units**
Quarter 1 Fall	Human & Molecular Genetics (2 units)	Principles of Counseling (2 units)	Clinical Cytogenetics (2 units)	Advanced Medical Genetics I (2 units)		13
	Clinical Embryology for Genetics Clinicians (on-line) (1 unit)	Research Methods for Genetic Counselors I (2 units)		Genes, Populations and Pedigrees (2 units)		
Quarter 2 Winter	Research Methods for Genetic Counselors II (1 unit)	Counseling Theory to Practice (2 units)	Variant Interpretation & Advanced Technologies (2 units)	Advanced Medical Genetics II (2 units)		11
	Graduate Seminar in Genetics I (1 unit)	Reproductive Genetics (2 units)				
		Externship I (1 unit)				
Quarter 3 Spring	Cancer Genomics (3 units)	Genetic Counseling Foundational Skills (2units)	Social, Ethical and Legal Issues in Genetics (2 units)	Advanced Medical Genetics III (2 units)		12
	Graduate Seminar in Genetics II (1 unit)					
		Externship II (1 unit)				
	Capstone Research Project (1 unit)					
Quarter 4 Summer	Clinical Internship I (3 units)					3

	Monday	Tuesday	Wednesday	Thursday	Friday	Total Units
Quarter 5 Fall	Advanced Genetic Counseling Skills (2 units)					7
	Clinical Internship II (3 units)					
	Capstone Research Project (2 units)					
Quarter 6 Winter	Advanced Topics in Genetic Counseling (2 units)					7
	Clinical Internship III (3 units)					
	Capstone Research Project (2 units)					
Quarter 7 Spring	Professional Formation (2 units)					7
	Clinical Internship VI (3 units)					
	Capstone Research Project (2 units)					

Course Descriptions

See Course Catalog

Course Evaluations

Students are asked each quarter to provide constructive feedback to improve the curriculum and the overall genetic counseling program. **Completion of evaluations is required**. Evaluations are anonymous, brief and require only a few minutes to complete. The program leadership takes these evaluations seriously and appreciate students' constructive feedback given in a professional and timely manner.

Students should always feel free to give feedback directly to the course leaders or the program directors, either informally or by appointment. At the end of the academic year, the program directors conduct exit interviews with each student to gather feedback about the program as a whole.

Course Material

Course syllabi, materials and assignments are posted on the online Collaborative Learning Environment (CLE) (https://courses.ucsf.edu/) also known as Moodle. Information for individual courses, announcements and events related to the program are updated on this site throughout the year.

Because changes may be introduced during the quarter, students should rely on the daily schedule posted on Moodle and NOT on the original syllabus.

Course announcements that appear on Moodle are automatically sent by email to the student's UCSF account. Students should check their UCSF mailbox at least daily for important announcements, changes and updates – particularly if using other email accounts.

Usage Policy: Moodle courses and materials are intended solely for individuals who are permitted access to the curriculum. These may not be reproduced or disseminated. Sharing of accounts, course, files, web links, or other materials with anyone other than an enrolled or authorized individual is a violation of the usage policy. Moodle materials may be protected by copyright, and any further use of this material may be in violation of federal copyright law and UC policies.

The Copyright at UCSF guide includes a great deal of helpful information on copyright and fair use, including a section titled Best Practices for Posting Materials to your CLE Course.

Accessing CLE/Moodle:

1. Use Firefox or Internet Explorer as your internet browser
2. Go to https://courses.ucsf.edu/
3. Enter your MyAccess ID and password to log in
4. Select a course from the list of courses you are registered for on the left side of the screen.

Moodle usually includes a separate folder for lecture and seminar materials for each class.

Capstone Project

The capstone project provides a rich opportunity to explore an interest area in considerable depth, gain experience in research project development and implementation, institutional requirements for research, research methodology and data analysis, evidence-based approaches to problem solving, professional writing, and self-directed learning in order to increase professional growth and contribute to the field of genetic counseling. Students are required to develop a longitudinal project starting in the winter quarter of the first year, which culminates in a final written and oral presentation at the end of the second year. Students work with UCSF staff and faculty to develop an appropriate project.

Additional information and requirements for the Capstone project will be provided in the Research Methods for Genetic Counselors I class.

Clinical Rotations

Clinical rotations begin in the summer quarter of the first year and continue through the second year. The first rotation in the summer is scheduled as an 8-week block and the remainder are scheduled as 10 week blocks. Rotations available at a variety of sites within the UCSF campuses, UCSF Fresno, at community genetics centers and local industry. Opportunities for additional off-site rotations in the second year may be discussed with the Program Assistant Director and Program Director. Students may indicate a preference for a rotation site, but placements are determined by a student's training needs and site availability. Rotations are available at the following UCSF clinics:

- Cancer Risk Program
- Pediatric Cancer Risk Clinic

- Craniofacial Center
- Prenatal Diagnosis Center
- Fetal Treatment Center
- Medical Genetics and Genomics Clinic
- Disorders of Sexual Development Clinic
- Biochemical Genetic Medicine Clinic
- Lysosomal Disease Center
- Personalized Genomics Clinic
- The NF/Ras Pathway Clinic
- Memory and Aging Center
- Huntington's Disease Clinic
- Polycystic Kidney Disease Center of Excellence
- Ophthalmology Genetics Clinic
- Cardiovascular Genetics Program
- Dermatology Genetics Clinic
- Hearing Loss Genetics Clinic
- Preventive Genomics Clinic
- Medical Genetics at Benioff Children's Hospital, Oakland

Conduct

During clinical rotations, students are expected to act in a professional manner, limiting conversations to appropriate content and not discussing confidential information in public areas. Refrain from texting or doing personal emails, to remain engaged in the training experience. Leave work areas clean after use. Students must maintain UCSF standards regarding online media and must refrain from posting anything related to patients or clinical training experiences.

Confidentiality Agreements and HIPAA Training

Students must sign a Confidentiality Agreements with the various institutions prior to participating in any clinical activities including observations and clinic conferences. This is to preserve patient confidentiality. Due to HIPAA regulations students may NOT copy and maintain any patient records, including the pedigree. All pre-case and post-case write-ups must have patient names, etc. redacted.

Dress Code

Students should wear their UCSF ID badge at all times when involved in any patient situation.

Appropriate attire and demeanor is expected when seeing patients, on consults, in patient areas or when otherwise engaging in professional activities at all clinical rotation sites. Check with the clinic you are assigned to regarding dress codes as some settings are stricter than others. Students are expected to promote a professional image and in general:

- Clothing should be clean, neat, in good repair and appropriate for the profession
    - Pants, skirts, blouses, sweaters, dress shirts, ties, jackets, blazers are all acceptable
    - Jeans are not encouraged but may be worn at the discretion of the clinical site. If jeans are allowed, they should be in good repair without holes or tears
- Casual, or athletic wear, such as sweat suits or yoga pants, are not acceptable in clinical sites
- Shorts are not acceptable
- Shoes shall be appropriate for the work environment and compliant with professional attire. Flip flops are not appropriate and open-toed sandals are at the discretion of the clinical setting
- Caps or head coverings are not acceptable unless they are for religious purposes or part of a uniform
- Chewing gum, eating or drinking when seeing patients is unprofessional and should never be done.

Log Book

Each student will keep a "Logbook of Supervised Cases" and other materials documenting their clinical training of ALL patients he/she sees, including all observations. This log should include all information needed to satisfy documentation of the student's role in each case as well as detailed notes on the cases and counseling strategies. **Patient identifiers (such as patient name or hospital number) must never be used on the logbook.** Students will assign a unique identifier for each case seen.

The logbook should reflect the depth and breadth of the student's clinical experience. A link for an electronic log form will be provided to you before embarking clinical rotations. Logbooks will be reviewed by the supervising genetic counselor and Assistant Program Director at the end of each clinical rotation. Additionally, all student cases in the logbook must be completed to the satisfaction of the Program Director and Assistant Program Director prior to the student leaving the program. These materials become a permanent part of each student's portfolio and will be collected prior to the student exiting the program

Dress Code

Dress on campus tends to be very casual and you may wear jeans and other casual clothing when attending class or engaged in campus activities. However, some items should never be worn such as very short shorts, revealing clothes (see through blouses, tube tops, etc) or dress that is provocative in nature.

There are different rules when participating in clinical internships (see Clinical Rotations).

Electronics

Computer access**:** Students wishing to use a computer during class will need to provide their own device. Clinical rotation sites generally have computers available for students to use during their rotation. Computer availability should be verified with internship sites at the beginning of each rotation.

Class policy: The GC Program limits the use of electronics during all classes. Students may use laptops or tablets to take notes, but no electronic devices are permitted while taking an examination or quiz, unless expressly allowed by the instructor. Cell phones should be turned to vibrate when in classes, conferences, or clinical/fieldwork rotations. Please refrain from texting or doing personal emails when in class and clinic.

Faculty Biographies

Biographies or links may be found on the program's website

Food and Drink

Food or drinks in patient areas or laboratories is prohibited. Food and drink in classrooms is allowed at the discretion of the instructor.

Grading

See Grading in Section 1 above

The Capstone Research project will be graded on a pass/fail basis.

Guidance

Each student will be provided with several layers of guidance to ensure success in the GC Program. Students will be mentored by a GC Program "buddy", an academic mentor, Capstone Project advisor and clinical rotation supervisors.

Academic Mentor

Each first year student will be assigned an academic mentor who is a UCSF faculty member, practicing genetic counselor or other member of the UCSF genetics community. The academic mentor shall function as a partner who is committed, for the duration of the program, to ensuring success of the student and being an academic advocate. Mentors and students should meet at least monthly in the first year and quarterly in the second year. First year students should expect to be contacted by their mentor within the first month of the school year.

Student Buddies

Incoming students will be assigned a second year "buddy" to serve as a peer resource for any question related to the GC Program, UCSF or the San Francisco area. Buddies will be paired in the spring quarter and incoming students should expect to be contacted by their buddies during the summer before school starts. Buddies should meet at least quarterly during the first year, but more frequent contact is encouraged.

Review of Student Academic Performance

The GC faculty and administration will respond to academic difficulty and any alleged acts of academic dishonesty or unprofessional behavior in a respectful and supportive manner that emphasizes fairness, timeliness, due process, and transparency. Such a response may include any of the following:

Disciplinary Actions

Informal verbal warning. Depending on the seriousness of the alleged misconduct or academic difficulty, an informal process of counseling and advising will occur among the Program Director, course director (or clinical supervisor) and student. The goal will be to educate the student about the policy or academic issue and to provide a verbal warning.

Informal letter of performance expectations. A confidential letter of performance standards will be given to the student informing him/her of future expectations and how to take steps to avoid academic difficulty, unprofessional behavior or allegations of misconduct. Issues relating to academic difficulty will also incorporate an individual remediation plan developed in conjunction with the appropriate course instructor. This letter will go in the student's file in the GC Program, but will not be filed with the Graduate Division unless further issues occur.

Formal process. A formal procedure will take place if the informal verbal warning or letter of performance expectations is not successful, and/or there are multiple occurrences of misconduct, and/or an egregious incident has occurred. Determination of egregious conduct will be made by the Program Director. A student cannot be dismissed from the program for a single egregious academic incident.

1. The Program Director will provide a written notice of the allegation or academic issue(s) to the student, and share the letter with the student's academic mentor and the Associate Dean of te Graduate Division. The student will be offered the opportunity to provide a written response within seven days. The Program Director will then meet with the student and mentor within 7 days of receipt of the written response, or 14 days of the original letter if the student does not send a written response, and take one of the following actions:
    a. Develop an individual remediation plan. Individual remediation plans are a memorandum of understanding that clearly outline specific steps and associated deadlines that the student must fulfill in order to receive a satisfactory report. The consequence(s) of continued infraction(s) must also be included. A copy of the individualized remediation plan is filed with the GC Program and the Associate Dean of the Graduate Division. Students unable to fulfill the expectations of the individualized remediation plan are

subject to Probation or dismissal from the GC Program.

b. After consultation with the Executive Committee, place the student on probation with an appropriate remediation plan.
c. Determine the student is eligible for dismissal and proceed with a formal in-depth Review Committee through the Graduate Division.
    i. If a Review Committee is warranted, the committee composition and a potential appeal will follow Appendix VII of the UCSF Divisional Procedure for Student Grievance in Academic Affairs

Probation

A student may be placed on probation if, at the close of any quarter, his/her grade-point average is less than 3.0 (a B average) computed on the total of all final letter grades. If final grades are delayed in transmission to the faculty, disqualification may be postponed for 1 quarter. Students with more than one incomplete grade may also be placed on academic probation.

A student may also be placed on probation for unprofessional behavior as documented by the Genetic Counseling Program leadership or a clinical rotation supervisor.

Students with probationary status may continue with the GC Program curriculum, but are subject to supervision by the faculty of the GC Program. Any student placed on probation will be required to meet with the Program Director or Assistant Program director, and their academic mentor, in order to develop an individualized probation remediation plan that includes: the reason for student's probationary status, actions the student must take to return to good academic standing, timeline for actions to be completed and consequences for inability to fulfill the expectations of the individualized remediation plan. Individualized remediation plans must be signed by the student, academic mentor and Program Director or Assistant Program Director. Probation remediation plans become part of the permanent record will be filed in the students GC Program file and with the Associate Dean of the Graduate Division.

A student will remain on probation until the requirements of the remediation plan have been met and probationary status has been removed by a definitive action of the GGGC Executive Committee.

Dismissal

A student shall be eligible for dismissal from the GC Program if he/she:

1. fails to maintain a 3.0 cumulative grade point average during 2 out of 3 consecutive quarters, or
2. has a documented instance(s) of academic misconduct (as outlined in Section 1) and requires a Review Committee or
3. demonstrates a continued pattern of documented unprofessional behavior despite attempts at remediation or
4. has not completed all requirements for the Masters of Genetic Counseling degree within 5 years of the date he/she entered as a 1st-year student, with the exclusion of an approved leave of absence or
5. in accordance with the provisions of the GC Program and the Graduate Division, the behavior of a student is judged by competent authorities using established procedures, to be detrimental to the interests of the University community, or incompatible/inconsistent with the profession of genetic counseling.

Dismissal Review and Procedures

A student deemed eligible for dismissal will receive formal notice that his/her performance does not meet GC Program standards and s/he therefore is referred to a committee charged with an in-depth review of academic performance. This information will be transmitted in writing and conveyed electronically or in person. This notice will inform the student of his/her right to submit information for the committee's consideration. The notice will include the specific reasons for the referral, the rules and procedures

governing the committee's deliberations, the student's right to review and request a copy of his/her educational record, and the written information that will be provided by the school to the in-depth review committee.

The in-depth review committee shall undertake a comprehensive review of the entire academic performance of the student. The student may submit additional written information, including information from other individuals, and may address any aspect of his or her academic performance in writing to the review committee. The committee will carefully deliberate and review the student's entire academic record and professional performance.

Based on their review, the in-depth review committee shall make one of the following determinations:

1. Allow the student to continue in the program with specific conditions and a timeline for remediation, and establish dates for review of compliance with those conditions.
2. Offer or mandate a leave of absence with specific conditions and a timeline for return, and establish dates to review compliance with the conditions and timeline.
3. Confirm dismissal. More information can be found in the UCSF Academic Senate Divisional Procedure for Student Grievance in Academic Affairs

Appeal

There is **no** appeal of an in-depth review committee decision to continue the student in the program or mandate a leave of absence, or any conditions or timelines associated with those decisions.

There are only two grounds for a student to appeal a dismissal decision:

1. Factual errors in the record that were not identified at the in-depth review committee meeting, if such errors would have changed the committee's decision.
2. Failure of the committee to follow the procedure set forth in this section, if such failure would have changed the committee's decision.

For detailed and updated appeal process information, please see the Divisional Procedure for Student Grievance in Academic Affairs

Student Grievance Procedures

Grievance procedures are available to students who believe the University has violated their privacy rights, discriminated against the student or otherwise violated their rights as outlined in section 110.00 of the Policies Applying to Campus Activities, Organizations.

Grievance procedures related to academic issues are appropriate only in cases in which the student believes bias or wrongdoing by a faculty member has occurred. Grievances are not the same as disagreements. A student cannot grieve an assigned grade, for example, merely because the student disagrees with the grade.

Resources

The Office of the Ombuds is a resource for all members of the UCSF community. The office provides a confidential, neutral, informal and independent place to discuss campus-related problems and can help identify and evaluate options, provide information, facilitate conversations between conflicting parties and make referrals when necessary. The office offers assistance with:

- Conflicts (interpersonal, workplace, academic)
- Perceived unfair treatment
- Improving communication

- Understanding UCSF policies and procedures
- Navigating campus administration

Contact the Office of the Ombuds at at 415.502.9600 or visit ombuds.ucsf.edu for more information.

Ronald Bachman, M.D.

Curriculum Vitae

I. Education and Certification

University of California, Berkeley, CA; BA (1959)
Phi Beta Kappa, Kraft Scholarship Award
University of California, San Francisco, CA; MD (1963)
Alpha Omega Alpha, Mosby Scholarship Award
Pediatric Internship and Residency, University of California, San Francisco, CA (1963-1965)
Pediatric Residency, University of Washington, Seattle, WA (1965-1966)
Genetics Training – National Institute of Child Health and Human Development, NIH (1966-1968)

American Board of Pediatrics (1968)
American Board of Genetics (1982)

II. Kaiser Permanente Hospital, 1968 – 2007

Chief, Department of Genetics, Kaiser Permanente Hospital, Oakland, CA
Assistant Clinical Professor, Department of Pediatrics, University of California Medical School San Francisco, CA
Associate Clinical Professor, School of Public Health, University of California, Berkeley, CA

III. Responsibilities – 1968-2007 Management and Administration of:

- Genetics Department with more than 80 employees (physicians, genetic counselors, nurses, computer specialists, clerical). Includes day-to-day operation and projections for future.
- Comprehensive genetic services for more than 750,000 Health Plan Members. Includes day-to-day operation and projections for future: Prenatal Services, Genetic Screening, Fetal Diagnosis, Neonatal Services, Genetic Screening, Diagnosis, Pediatric and Adult Genetic Services, and Cancer Counseling; Multispecialty Clinics, including Spina Bifida, Craniofacial, Metabolic/Lipid, Skeletal Dysplasia, and Neurogenetics.
- Budget planning, management, and projection for Genetics Department with a budget > $10 million.
- Development of Oakland Genetics Department web site. www.dor.kaiser.org/genetics

IV. Development of Genetic Education Programs

- Train pediatric/obstetric/pathology residents
- Train graduate students (University of California, Genetic Counseling Program)
- Lectures on application of new genetic technologies in clinical medicine

V. Significant Past Experience

Assistant Chief, Department of Pediatrics, Kaiser Permanente Hospital, Oakland, CA (1973-1976)
Assistant Physician-in-Chief, Kaiser Permanente Hospital, Oakland, CA (1976-1981)

VI. Retirement - 2006 to Present

- Lecturer California State University at Stanislaus – (Genetic Counseling Program) Embryology of Birth Defects
- Lecturer Wayne State Medical School (Genetic Counseling Program) – Embryology of Birth Defects
- Lecturer University of California at Irvine (Genetic Counseling Program) – Embryology of Birth Defects
- Co- Medical Director – Genetic Counseling Program – California State University at Stanislaus

VII. Publications

1. Cuthbertson E., Gilfillan R., Bachman R. Spontaneous and induced variations in bone marrow pressure in the dog. *Angiology* (1964); 15:145.
2. Bachman R. Posterior urethral valves (letter). *American Journal of Diseases of Children* (1967); 114:216.
3. Bachman R. Chromosomal abnormalities in congenital rubella (letter). *New England Journal of Medicine* (1967).
4. Bachman R., De La Cruz F., Al-Aish M., Santell F. Short arm deletion of an X chromosome in a 19-year-old girl. *American Journal of Mental Deficiency* (1971); 75:435.
5. Bachman R. Peutz-Jeghers syndrome. *American Journal of Diseases of Children* (1973) 125:77.
6. Golbus M., Bachman R., Wiltse S., Hall B. Tetraploidy in a live born infant. *Journal of Medical Genetics* (1976); 13:329.
7. Johnson G., Bachman R. A 46,XY del(18)(pter--p1100) cebocephalic child from a 46,XX,t(12;18)(18pter--18p1100::12qter--12pter) normal parent. *Human Genetics* (1976); 34:103.
8. Johnson G., Bachman R., Roed T., Riddervold P. Partial trisomy 10p and familial translocation t(7;10)(p22;p12). *Human Genetics* (1977); 35:356.
9. Daentl D., Townsend J., Siegal R., Goodman J., Piel C., Wara D., Bachman R. Familial nephrosis, hydrocephalus, thin skin, blue sclerae syndrome: clinical, structural and biochemical studies. *Birth Defects: Original Article Series* (1978); Vol. XIV, number 6b, 315-339.
10. Kihara H., Fluharty A., Tsay K., Bachman R., Stephens J., Ng J. Prenatal diagnosis of pseudo arylsulfatase A deficiency. *Prenatal Diagnosis* (1983); 3:29.
11. Chen H., Blumberg B., Immken L., Lachman R., Rightmire D., Fowler M., Bachman R., Beemer F. The Pena-Shokeir syndrome: report of five cases and further delineation of the syndrome. *American Journal of Medical Genetics* (1983); 16:213.
12. Knight L., Lipson M., Mann J., Bachman R. Mosaic inversion duplication of chromosome 15 without phenotypic effect: occurrence in a father and daughter. *American Journal of Medical Genetics* (1984); 17:649.
13. Harlap S., Shiono P.H., Ramcharan S., Golbus M., Bachman R., Mann J., Lewis J.P. Chromosomal abnormalities in the Kaiser-Permanente birth defects study, with special reference to contraceptive use around the time of conception. *Teratology* (1985); 31:381.
14. Bachman, R., Schoen, E., Backstrom, M., Lee, R., Williams, S, Jurecki, E.:Phenylalanine embryopathy in three siblings: implications of maternal diet therapy. *Amer. J. Dis. Child* (1993); 147:22.
15. Bachman R., Schoen E., Stembridge A., Jurecki E., Imagire R. Compliance with Childhood Cholesterol Screening in a Prepaid Practice. *Amer. J. Dis. Child* (1993); 147:382.
16. Bachman R., Schoen E, Stembridge A, Jurecki E, Imagire R. Cholesterol: Myth vs Reality ?. *Arch. Pediatr. Adolesc. Med.* (1994); 148:330.
17. Bachman R., Schoen E. Managed genetic care in a large HMO. *HMO Practice* (June 1996).
18. Bachman R., Schoen E. Managed genetic care in the largest HMO: the challenge of providing genetic services to 2.7 million members. *The Permanente Journal* (1998); 2:10.
19. Wilcox W., Lucas B., Loebel B., Bachman R., Lachman R., Rimoin D. Pacman Dysplasia: Report of two affected sibs. *American Journal of Medical Genetics* (1998); 77:272.

20. Bachman R., Schoen E. Design and Implementation of Genetic Services within an HMO. *Managed Care Interface* (1998); 11:69.
21. Zneimer S., Ziel B., Bachman R. Partial Trisomy of Chromosome 6q: an Interstitial Duplication of the Long Arm. *American Journal of Medical Genetics* (1998); 80:133.
22. Hanley W.B., Platt LD, Bachman RP, Buist N., Geraghty MT, Issacs J., O'Flynn ME, Rhead WJ, Seidlitz G., Tishler B. Undiagnosed maternal phenylketonuria: The need for prenatal selective screening or case finding. *Am J Obstet Gynecol* (1999); 180:986.
23. Bachman R. and Schoen EJ. Johann Gregor Mendel in the 21st Century: Genetic Science Fiction is Alive Today. *Permanente Journal* (2001); 5:13-16.

Curriculum Vitae
Nicola J. Cadenas, MS, LCGC

EDUCATION

University of California at Berkeley *2000-2002*
Masters of Science in Genetic Counseling.

University of North Carolina at Chapel Hill *1992-1996*
Bachelor of Science in Biology

CERTIFICATION

Certified Genetic Counselor - American Board of Genetic Counseling, 2002
California Licensed Genetic Counselor – 2011 - current

PROFESSIONAL EXPERIENCE

- Cancer Genetic Counselor
  Cancer Genetics and Prevention Program
  Helen Diller Family Comprehensive Cancer Center
  University of California San Francisco
  San Francisco, CA Spring 2002-present

- Cancer Genetic Counselor (International Sabbatical)
  Programa de Cáncer Hereditario (ProCanHe)
  Hospital Italiano de Buenos Aires
  Argentina Fall 2007 – Spring 2008

- Genetic Counselor Volunteer
  Louisiana Family Assistance Center
  Hurricane Katrina DNA Identification Program
  Baton Rouge, LA – April 2006

TEACHING EXPERIENCE

- Supervisor for genetic counseling interns, 2003- present
- Residency supervisor for clinical nurse specialists masters in genomics, 2003-present
- Annual guest lecturer at UCSF School of Medicine, sessions on cancer and reproductive genetics.
- CSU Stanislaus - Hereditary Cancer Genetics Course for Masters in Genetic Counseling, 2009-present

SELECTED PRESENTATIONS

Endocrine Society Meeting (ENDO), San Francisco, 2002
An interactive genetics module providing mock counseling sessions to meeting participants

Annual Review in Family Medicine, San Francisco 2003
Hereditary breast and ovarian cancer: What the primary care provider needs to know

National Society of Genetic Counselors, Charlotte, 2003
Ethical issues regarding a sperm donor with a BRCA mutation

Bay Area Genetics Exchange, Oakland, 2005
Medical Genomics Clinic at the UCSF Cancer Risk Program: A clinic for families with a history of cancer and congenital anomalies.

Safeway Foundation, 2005
Hereditary Cancer, Embracing the Family Tree

San Antonio Breast Cancer Symposium, San Antonio, 2005
Characteristics of pre-menopausal invasive breast cancer and age-associated risk of breast cancer in BRCA1 and BRCA2 mutation carriers compared with non-carriers

American Society of Human Genetics, New Orleans, 2006 and
San Antonio Breast Cancer Symposium, San Antonio 2006
Genetic Services in satellite clinics, a model of delivery in 3 different communities

Grand Rounds at Hospital Italiano Buenos Aires March 2008
Cancer Hereditaro (in Spanish)

Jewish Film Festival August 2008
Q&A after the documentary, "In the Family" by Johanna Rudnick

Hereditary Cancer Oct 2009
Queen of the Valley Medical Center, Napa Valley

COMMUNITY OUTREACH

Hereditary Cancer Education sessions for:
- Cancer Risk Program
- Women's Cancer Awareness Group
- Ovarian Cancer Foundation for Living
- Taking our Daughters and Sons to Work Day

ASSOCIATIONS

National Society of Genetic Counselors, 2002-present
American Society of Human Genetics, 2006

PUBLICATIONS

Lee R, Beattie M, Crawford B, Mak J, Stewart N, Komaromy M, Esserman L, Shaw L, McLennan J, Strachowski L, Luce J, Ziegler J. Recruitment, genetic counseling, and BRCA testing for underserved women at a public hospital. Genet Test. 2005 Winter;9(4):306-12.

Scott R. May, Nicola J. Stewart, Wesley Chang and Andrew S. Peterson. A Titin mutation defines roles for circulation in endothelial morphogenesis. Developmental Biology, Volume 270, Issue 1, June 2004, 31-46

Zoltewicz JS, Stewart NJ, Leung R, Peterson AS. Atrophin 2 recruits histone deacetylase and is required for the function of multiple signaling centers during mouse embryogenesis. Development. 2004 Jan;131(1):3-14.

Delgado GA, Glazer RA, Stewart NJ. Predator-induced behavioral and morphological plasticity in the tropical marine Gastropod Strombus gigas. *Biol Bull.* 2002 Aug; 2003(1):112-20.

Julie Noel Harris-Wai, Ph.D. M.P.H.
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EDUCATION

Robert Wood Johnson Health and Society Scholars Program 2010
University of California (San Francisco and Berkeley)
Postdoctoral Research Fellowship in Population Health Sciences

University of Washington, Seattle 2008
Doctorate of Philosophy (Ph.D.) - Public Health Genomics
Dissertation: Understanding the role of context and communication on the utility of family history information in cancer prevention and screening.
Dissertation Advisors: Deb Bowen PhD (chair), Wylie Burke MD PhD, Kelly Fryer-Edwards PhD, Diane Magyary PhD

University of North Carolina, Chapel Hill 2003
Masters of Public Health (M.P.H.) - Health Behavior and Health Education
Thesis: BRCA1/2 genetic testing and family communication
Thesis Advisor: James Sorenson PhD

University of North Carolina at Wilmington 1998
Bachelor's of Science (B.S.) - Biology, Marine Biology

RESEARCH EXPERIENCE

Assistant Professor 2014-present
University of California, Institute for Health and Aging; San Francisco, CA

Director, Translational Research Core and Community Engagement 2016-2017
Kaiser Permanente Research Bank
Oakland, CA

Associate Director 2013-2017
KP/UCSF Center for Transdisciplinary ELSI Research in Translational Genomics (CT2G)

Staff Scientist 2010-2017
Kaiser Permanente, Division of Research; Oakland, CA

Robert Wood Johnson Health and Society Scholars Fellow 2008-2010
University of California at Berkeley and San Francisco

Project Coordinator 2006-2007
Fred Hutchinson Cancer Research Center

Predoctoral Research Fellow 2004-2008
Fred Hutchinson Cancer Research Institute and University of Washington
School of Public Health and Community Medicine

Project Director 2002-2004
Thurston Arthritis Cancer Research Center, University of North Carolina,
School of Public Health

Research Assistant 2001-2003
Department of Health Behavior and Health Education, University of North Carolina,
School of Public Health

Research Technician II 1999-2001
Howard Hughes Medical Institute, Duke University Department of Cell Biology

TEACHING EXPERIENCE

Invited Lecturer: Research Ethics for Medical Students Winter 2018
UCSF School of Medicine Inquiry Program

Invited Lecturer: Ethical Issues in Genomics Winter 2017, 2018
UCSF School of Nursing (Genomics Minor)
N294B: Implications of Genomics for Nursing Practice

Lecturer and Small Group Leader: Community Engaged Research 2017-present
UCSF Dissemination and Implementation Training Program

Director: Responsible Conduct of Research Required Training for 2017-present
Research Fellows

Curriculum Planning Committee for the UCSF Genetic Counseling 2017
Masters Program

Associate Director: Responsible Conduct of Research (Graduate Course) 2014-2015; 2017

Instructor: Epidemiology 296: Independent Study in Qualitative Research 2014-2015
Methods for Epidemiology and Translational Science (Graduate course)

Co-Director: Responsible Conduct of Research with Human Subjects 2014- 2015
Department of Epidemiology and Biostatistics, and Clinical Translational Science Institute,

University of California, San Francisco

Instructor: Ethical and Social Challenges of Genomic and Precision Medicine 2014
Coursera and University of California, San Francisco

Instructor: Community Based Participatory Research (Graduate course) 2006
Department of Medical History Ethics, University of Washington School of Medicine

Teaching Assistant: Genetic Epidemiology (Graduate course) 2007
Department of Epidemiology, University of Washington

Teaching Assistant: Genetics and the Law (Graduate course) 2005-2006
University of Washington Law School

Instructor, Theoretical Foundations of Health Behavior (Graduate course) 2001-2002
Department of Health Behavior and Health Education. University of North Carolina, School of Public Health

Teaching Assistant: Public Health Genomics (Graduate course) 2001
Department of Health Behavior and Health Education, University of North Carolina School of Public Health

PUBLICATIONS

Peer-Reviewed Journal Publications:

Wolf SM, Amendola LM, Berg JS, Chung WK, Clayton EW, Green RC, **Harris-Wai J,** Henderson GE, Jarvik GP, Koenig BA, Lehmann LS, McGuire AL, O'Rourke P, Somkin C, Wilfond BS, Burke W. Navigating the research-clinical interface in genomic medicine: analysis from the CSER Consortium. *Genetics in Medicine* 2017. August 31

Bowen DJ, Hyams T, Goodman M, West KM, **Harris-Wai J**, Yu JH. Systematic Review of Quantitative Measures of Stakeholder Engagement. *Clinical and Translational Sciences* 2017. May 29

Berg J, Bailey D, Beggs A, Brenner S, Brower A, Cakici J, Birsoy O, Chan K, Chen F, Currier R, Dukhovny D, Green R, **Harris-Wai J**, Holm I, *et.al*, Wise A. Newborn Sequencing in Genomic Medicine and Public Health. *Pediatrics* 2017. 139(2) January

Bowen DJ. Hay JL, Harris-Wai JN, Meischke H, Burke W. All in the Family? Communication of cancer survivors with their families. *Familial Cancer* 2017. April 3

Bowen DJ, Albrecht T, Hay J, Eggly S, **Harris-Wai JN**, Meischke H; Communication among melanoma family members. *Journal of Health Communication* 2017. February

Liang R, Meiser B, Smith S, Kasparian NA, Lewis CR, Chin M, Long GV, Ward R, Menzies AM, **Harris-Wai** JN, Kaur R; Advanced cancer patients' attitudes toward, and experiences with, screening for somatic mutations in tumours: A qualitative study *Eur J Cancer Care* 2016. Oct 11

Joseph G, Chen F, **Harris-Wai JN**, Puck JM, Young C, Koenig BA; Parental Views on Newborn Screening using Whole Genome Sequencing. *Pediatrics* 2016. Jan; 137(Suppl 1): S36-46

Lemke AA, **Harris-Wai JN;** Stakeholder engagement in policy development: Challenges and opportunities for human genomics. *Genetics in Medicine* 2015. 17(12): 949-957

Bowen DJ, Burke W, Hay JL, Meischke H, **Harris JN;** Effects of web-based interventions on risk reduction behaviors in melanoma survivors. *Journal of Cancer Survivorship* 2015. 9(2): 279-286

Harris JN, Liljestrand P, Alexander GL, Goddard KAB, Kauffman T, Kolveska T, McCarty C, O'Neill S, Pawloski P, Rahm A, Williams A, Somkin CP; Oncologists' attitudes towards KRAS testing: A multisite study. *Cancer Medicine 2013. 2(6): 881-888*

Bowen DJ, Hay JL, Mayer J, Kuniyuki A, Meischke H, **Harris J**, Asgari M, Shoveller J, Press N, Burke W. Predictors of recruited melanoma families into a behavioral intervention project. *Contemporary Clinical Trials* 2012. 33(1):85-92

Boehmer U, **Harris J,** Bowen DJ, Schroy PC 3rd. Surveillance after colorectal cancer diagnosis in a safety net hospital. *Journal for Health Care in the Poor and Underserved* 2010. Nov; 21(4): 1138-51

Harris J, Hay J, Kuniyuki A, Asgari MM, Press N, Bowen D. Using a family systems approach to investigate cancer risk communication within melanoma families. *Psychooncology* 2010. 19(10): 1102-1111

Bowen D, **Harris J**, Jorgensen C, Myers M, Kuniyuki A. Socioeconomic Influences on the Effects of a Genetic Testing Direct-to-Consumer Marketing Campaign*. Public Health Genomics;* 2010. 13(3):131-42

Harris J, Bowen D, Badr H, Hannon P, Hay J, Regan Sterba K. Family communication during the cancer experience. *Journal of Health Communication;* 2009 14(S1): 76-84

Harris J, A Kuniyuki, L McIntosh, E Ostrander, J Stanford, D Bowen*;* Interest in genetic testing among affected men from hereditary prostate cancer families and their unaffected male relatives. *Genetics in Medicine*; 2009. May 11(5):344-55

Hay J, **Harris J**, et al. Personal communication in primary and secondary cancer prevention: Evolving discussions, emerging challenges. *Journal of Health Communication* 2009. 14(S1): 18-29

James RD, Yu JH, Henrikson NB, Bowen DJ, Fullerton SM, **Health Disparities Working Group**. Strategies & stakeholders: minority recruitment in cancer genetics research. *Community Genetics* 2008. 11(4): 241-9

Henrikson N, **Harris J**, Bowen D. Predictors of self-referral into a cancer genetics registry. *Cancer Epidemiology, Biomarkers, and Prevention* 2007. July 16(7): 1387-1392

Veenstra DL, **Harris J,** Burke W, Gibson R, Rosenfeld M, Watts C; Pharmacogenomics and aminoglycoside-induced hearing loss in cystic fibrosis patients: An evaluation of potential clinical and economic outcomes. *Genetics in Medicine;* 2007. Oct 9(10):695-704

Other Publications:

Obasogie OO, **Harris-Wai JN**, Darling K, Levesque M**. (2015)** Race in the Life Sciences: An Empirical Assessment, 1950–2000. *Fordham Law Review.* Vol. 83 (6) pp. 3089-3314

Harris, Julie. "Genetic Testing and Screening: III. Population Screening." In *Bioethics, 4th Edition,* edited by Bruce Jennings et al. Detroit: Macmillan Reference, 2014. Pp. 1289-1298.

Harris, Julie. "Genetic Testing and Screening: IV. Public Health Context." In *Bioethics, 4th Edition,* edited by Bruce Jennings et al. Detroit: Macmillan Reference, 2014. Pp. 1298-1303.

Harris, Julie. "Whole Genome Sequencing." In *Bioethics, 4th Edition,* edited by Bruce Jennings et al. Detroit: Macmillan Reference, 2014.

Publications Under Review and In Process:

Harris-Wai JN, Bowen DJ, Eggly S, Albrecht TL, Penner LA. Understanding how physicians and patients communicate about family health history: an observational study. *[under review: Journal of American Board of Family Physicians]*

Harris-Wai JN, Hay J, Kuniyuki A, Asgari, M, Bowen D. What's the use of talking?: Familial cancer risk communication and melanoma risk reduction behaviors. *[under review: Family Systems and Health]*

PRESENTATIONS (selected)

Harris-Wai JN, Nelson, S, Carpten, J, Berman B, Paz H; Panel Discussion- Next Generation Sequencing based molecular diagnostics. *California Initiative to Advance Precision Medicine.* Los Angeles, CA. August, 26. 2016 (Invited Panelist)

Harris-Wai JN; Engaging Diverse Communities to Inform Newborn Screening and Biobanking Policies. *Newborn Screening Translational Research Network.* Washington DC. September 8-9, 2016 (Invited Speaker)

Harris-Wai JN, Lee S, Ho-Yu J; Invited Program Workshop Session: The Ethics of Assessing Group Benefits and Harms in the Age of Precision Medicine. *American Society of Bioethics and Humanities.* Washington D.C. October 6-9, 2016

Harris-Wai JN, Butte A, Haussler D, Yu P, Sim I; Precision Medicine: Interrogating the Promise. *Just Data? Justice, Knowledge and Care in an Age of Precision Medicine. University of Santa Cruz Science and Justice Research Center.* May 18-19, 2016 (Discussant and Organizer)

Harris-Wai JN; Discussion Panel: Explore the Ethical, Social, Policy and Legal Implications Impacting the Adoption of Genomics in Healthcare. *Front Line Genomics Festival of Genomics Conference.* Boston, MA. June 22-24, 2015 (Invited Discussant)

Harris-Wai JN and Koenig BA; Governance of State-Mandated Newborn Screening Programs: Engaging Communities to Inform the Use of Novel Genome Sequencing Technologies*. 3rd Annual Governance of Emerging Technologies Conference: Law, Policy and Ethics.* Scottsdale, AZ. May 26-28, 2015. (Invited Speaker)

Harris-Wai JN; Community Engagement in Genomics and Precision Medicine. *Medical World Americas Conference*. Houston, TX. April 27-29, 2015 (Invited Speaker)

Harris-Wai JN and Somkin CP; Engaging Diverse Communities in Biospecimen Research: Addressing Trust in an Uncertain Context. American Anthropological Association Annual Conference. Washington DC. December 2014

Kapustij C and **Harris-Wai JN**; Genomic sequencing of newborns: Are we ready? Addressing the ethical and policy implications of whole genome sequencing in state newborn screening programs. American Society of Bioethics and Humanities. San Diego, CA October 2014

Harris-Wai JN, Lemke AA, Burke W, Koenig B, Terry S, and Burgess M; Stakeholder Engagement in Genomics Policy Development: What Is It? Why Do It? How?. San Diego, CA October 2014 (Session Organizer and Discussant)

Harris J, Liljestrand P, Schaefer C, Somkin C; Stakeholders' attitudes towards benefit sharing & returning genetic research results within a population-based biobank. American Public Health Association Annual Meeting. Washington DC. November 2011

Somkin C, **Harris J**, Liljestrand P, Godard K; *Current use of KRAS testing in clinical practice.* HMO Research Network Conference. Washington DC. March 2011

Somkin C, **Harris J**, Liljestrand P, Schaefer C; *Multiple stakeholder views on data sharing: Implications for biobank governance.* Oxford International Data Sharing Conference. Oxford, UK. September 20-22 2010

Harris J; *Race and Genetics: Putting the debate in context.* Robert Wood Johnson Health and Society Scholars Program Annual Meeting. Washington DC. April 26-30 2010

Harris J, Eggly S, Bowen D**;** *Understanding how physicians and patients communicate about family health history.* 137th Annual meeting of American Public Health Association (APHA). Philadelphia, PA. November 2009

Harris J; *Pediatricians as Key Targets for Knowledge Dissemination and Integration; Breast Cancer and the Environment*. Sixth Annual Early Environmental Exposures Meeting; Sausalito, CA. November 2009

Harris J, Van Bebber S, Phillips K; *Factors affecting adoption of personalized medicine technologies: Case study of genome expression profiling tests for breast cancer.* 5th International DNA Sampling Conference. Banff, Alberta, CA. September 2009

Harris J; *Race and Genetics: An historical investigation.* Robert Wood Johnson Health and Society Scholars Program Annual Meeting. San Diego, CA. May, 2009

Bowen DJ, **Harris J**, Albrecht T, Eggly S. Convergence between patient and provider on screening for cancer. American Academy on Communication in Healthcare. November, 2008

Bowen, DJ, Hay, J, **Harris, J**, Meischke, H, Press, NA,Shoveller, JA, Asgari, M, Burke, W, Edwards, M; *What is a family?: Communication opportunities with Melanoma Families.* American Society of Preventive Oncology Annual Meeting. Houston, TX. February 2007
Harris J; *Interest in Genetic Testing Among Affected and Unaffected Men from HPC Families;* NCI Biobehavioral Cancer Prevention and Control Annual Fellows Conference. Seattle, WA. April 21 2006

Additional Poster Presentations not listed are available upon request

GRANT SUPPORT

U01 HG009599 (Koenig, Kwok, Slavotinek, Norton PI, Harris-Wai Co-I) 2017-2021
Genomic Sequencing to aid diagnosis in pediatric and prenatal practice
The UCSF Program in Prenatal and Pediatric Genome Sequencing (P3EGS) will study the effectiveness of sequencing as a tool for 1) diagnosing infants and children with serious developmental disorders, and, 2) providing genetic information to parents when a prenatal study reveals a fetus with a structural anomaly. Ethical, social and economic issues in the delivery of genomic sequencing results to diverse populations, such as underrepresented minorities and the medically underserved will also be investigated.

AHRQ R21 HS23547 (Harris-Wai PI) 2014-2017
Engaging Diverse Communities to Inform California's Newborn Screening Policies
Through a unique partnership with the California Department of Public Health, we propose to use innovative and tested public engagement methods to inform policy decisions about California's newborn screening program.

American Public Health Laboratories (Piper PI, Harris-Wai consultant) 2017-2018
Deliberative Community Engagement for Iowa's Newborn Screening Program
To use a deliberative community engagement strategy in order to obtain guidance from the public on how and when to add new genetic disorders to the Iowa Newborn Screening panel.

NHGRI P20HG007243 (Somkin/ Koenig); Harris-Wai PI (2017) 2013-2017

Center for Transdisciplinary ELSI Research in Translational Genomics (CT2G)
To develop a center of excellence in research on the ethical, legal, social, and policy implications of translational genomics.

PCORI Network Grant (McGlynn/Lieu PI); Harris Key Personnel
Kaiser Permanente & Strategic Partners Patient Outcomes Research To Advance Learning (PORTAL) Network 2014-2015
To develop a nationwide research network and establish patient-centered engagement strategies to inform and govern the research network.

NCI KR021077 (Bloom/Somkin); Harris Co-Investigator 2010-2015
NCI/ Univ. of California, Berkeley
Alameda County Network Project to Reduce Cancer Disparities
To develop a Regional Center for Reducing Cancer Disparities through Outreach, Research and Training based in Alameda County, California, focusing on religion using Faith Based interventions.

115-9062 (Chen/Somkin) 2010-2011
NCI/ UC Davis RC2 MD004797
Enabling Minority Participation in Clinical Trials (EMPaCT)
To collaborate with investigators at UCD to determine barriers to clinical trials accrual among minorities and ways to mitigate those barriers.

115-9584 (Goddard/ Kushi) 2009-2011
NCI/ KPNW
CRN Program of CER in Genomics & Personalized Medicine of Colorectal Cancer
This project, submitted under the auspices of the Cancer Research Network, has a major focus on genetic testing in colorectal cancer. There are several components, including an evidence synthesis piece, cost-effectiveness of Kras and Lynch syndrome testing, a study of utilization of Kras testing in different health plans, a comparative effectiveness study of Kras testing, examination of psychosocial aspects of Kras testing, and work to develop infrastructure to support studies of genomics and personalized medicine in cancer.

115-9888 (Schaefer) 2008-2011
Robert Wood Johnson Foundation
The Kaiser Permanente Research Program on Genes, Environment and Health (RPGEH): Creating a Unique Resource to Expedite Genomic and Gene-Environment Studies
This project helped to fund development of the RPGEH infrastructure, including development of a 100,000 sample biorepository and program infrastructure to support review and facilitation of collaborative research projects.

SERVICE TO THE PROFESSIONAL COMMUNITY

Associate Editor: American Journal of Bioethics: Empirical Research 2013-2016
(Taylor and Francis Journals)

Manuscript reviewer: 2008-present

Journal of General Internal Medicine
American Journal of Managed Care

Abstract Reviewer: 2010-present

Public Health Genomics section of American Public Health Association
Cancer Forum section of American Public Health Association

Facilitator, Special interest group session on Communication in Cancer Prevention and Control at Society of Behavioral Medicine (SBM) Annual Meeting, San Diego, CA. 2008

Doctoral Student Representative, Institute for Public Health Genetics 2005-2006
University of Washington

Student Liaison to Department of Health Behavior and Health Education, 2001-2003
University of NC

***Professional Association Memberships*:**

Committee Member, Policy and Translational Science section of the 2012-2014
Public Health Genomics section of American Public Health Association

Member, Robert Wood Johnson Foundation Alumni Network 2010-present

American Public Health Association (APHA): Genomics Forum, Cancer Forum, Ethics Special Interest Group 2008-present

Member, American Society of Human Genetics (ASHG) 2010-present

Alumni member, The Jackson Laboratory. Bar Harbor, ME 1992-present

SELECT SERVICE TO THE COMMUNITY

Board Member (co-Chair), The California Sperm Bank (501(c)(3) organization) 2011-present
Berkeley, CA
Provide oversight, advice, and decision-making on all aspects of the bank's operations.

Board Member (Chair), PREFund (501(c)(3) organization) 2016- present
San Francisco, CA
PREFund is a nonprofit board aimed at providing early childhood educational opportunities and ensuring that families can remain and thrive in San Francisco.

NIKI LOVICK, MS, LCGC

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EDUCATION

June 2012 **Master of Science, Genetic Counseling** San Francisco, CA
California State University, Stanislaus

June 2009 **Bachelor of Science, Specialization in Biology** Montreal, QC
Concordia University

- Graduated with distinction
- Recipient of the 'Outstanding Contribution to Society' award

CLINICAL EXPERIENCE

Nov 2015-Present **UCSF Hereditary Cancer Clinic,** *Genetic Counselor*
University of California San Francisco

- Involved in start-up and development of the Hereditary Cancer Clinic at UCSF, whose mission is to provide a central resource for families with a hereditary cancer syndrome to receive personalized care and planning for their long-term health and well-being
- Provide genetic counseling, primarily for individuals with a known hereditary cancer syndrome and their at-risk family members
- Provide psychosocial support and facilitate decision making regarding screening and/or risk reduction for patients with hereditary cancer syndromes
- Participated in a multi-disciplinary steering committee that developed program standard screening guidelines for individuals with different hereditary cancer gene mutations
- Supervise, train, and educate genetic counseling and medical students within the clinical setting
- Involved in multiple ongoing research projects as part of the UCSF Center for BRCA Research

Mar 2013-Nov2015 **Yale Cancer Genetics and Prevention Program,** *Genetic Counselor*
Yale New Haven Hospital/Yale University School of Medicine

- Provided comprehensive cancer genetic counseling for a diverse patient population
- Worked collaboratively as part of a multidisciplinary cancer prevention team
- Provided professional support services to referring healthcare providers, including phone consultations and preparing referral guidelines, tools, and protocols
- Developed content for physician and patient newsletters
- Served as a representative from cancer genetic counseling at multidisciplinary tumor boards
- Co-led a young women's hereditary breast cancer support group

Jul 2011-Jul 2012 **Genetic Counseling Student Intern**

- Completed 40 weeks of clinical training in cancer, prenatal, pediatric, adult, and metabolic genetics; demonstrated flexibility and adaptability in new clinic settings
- Clinical settings included high volume community hospitals, academic institutions, private clinics, as well as experience in phone and web-based genetic counseling
- Extensive experience utilizing Spanish, Cantonese, and Mandarin phone interpreters

Professional Memberships and Certifications

2015-Present Licensed by the state of California

2012-Present Diplomate of the American Board of Genetic Counseling

2010-Present National Society of Genetic Counselors

Selected Academic Teaching and Invited Lectures

2017-Present **Adjunct Professor**
California State University Genetic Counseling Program, Cancer Genetics course

Nov 2017 **Invited Speaker**
SLO Oncology Breast Cancer Symposium
"Genetic Counseling and Testing for Inherited Cancers"

2013-Present **Supervisor, Genetic Counseling Students**

2013-Present **Workshop Leader**
Led small group case discussions for second year medical students for the Yale University School of Medicine and UCSF Medical Genetics course

Feb 2014 **Invited Speaker**
Academic-Community Partnerships: Science for Everyone
"Genetic Testing for Cancer Predisposition and the SCOTUS Decision"

Nov 2012 **Invited Speaker**
American Society of Human Genetics Annual Meeting
"The Impact of Mandatory Genetic Testing in the NCAA"

Related Activities

2015 **Make-A-Wish Foundation**
Wish Granter

2014-2016 **Special Olympics Connecticut**
Events volunteer

Publications

Jhaveri, A., Zuckerman, K., Deshpande, H., **Lovick, N**., Rath, K., Boffa, D., Singh, D., Schwartz, P., Bale, A., Hofstatter, E. (2015). The Benefit and Burden of Cancer Screening in Li-Fraumeni Syndrome: A Case Report. *Yale Journal of Biology and Medicine,* 88(2), 181-5.

Bonadies, D., Brierley, K., Barnett, R., Baxter, M., Donenberg, T., Ducaine, W., Ernst, M., Homer, J., Judkins, M., **Lovick, N.**, Powers, J., Stanislaw, C., Stark, E., Stenner, R., Matloff, T. (2014). Adverse Events in Cancer Genetic Testing: the Third Case Series. *The Cancer Journal*, 20(4), 246-53.

Ernst, M & **Lovick, N.** (2014). What is the Difference Between Clinical and Direct to Consumer Testing? *Generations: Yale Cancer Genetic Counseling Program (Community Newsletter).*

Lovick, N. (2013). Updates in Ovarian Cancer and BRCA1/2. *Advances: Yale Cancer Genetic Counseling Program (Provider Newsletter).*

Kelsey J. McClelland
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Education

California State University, Stanislaus
M.S. Genetic Counseling — Jun 2014

University of Denver
B.A. Biology - Cognitive Neuroscience Concentration — Nov 2011
B.A. Psychology

Clinical Experience

Genetic Counselor — Oct 2014- Present
University of California, San Francisco Biochemical Genetics

- Provide individual counseling and case management with UCSF Biochemical Genetics Clinic. Focus on children and adults with genetic disorders of metabolism. Provide ongoing education and ensure patient compliance with recommended medical treatments
- Counsel and coordinate cases with CA State Newborn Screen Program (public health program to identify infants with treatable genetic disorders). Communicate critical medical information to physicians and families of newborns with positive screen results
- Completed a Lysosomal Disease Fellowship with clinical focus on Lysosomal storage disorders, including patient registry database management, working with pharmaceutical companies, and coordinating treatment

Cardiovascular Genetic Counseling Intern — Mar 2014-Jun 2014
Stanford Medical Center for Inherited Cardiovascular Disease

- Provided genetic counseling, assistance in coping with diagnosis, and psychosocial assessments and interventions in a specialty clinic
- Interpreted rare and novel genetic variants using analysis tools and population databases: UCSC Genome Browser, ClinVar, ExAC, dbSNP, IGSR

Prenatal Genetic Counseling Intern — Jan 2014-Mar 2014
Kaiser Permanente, San Francisco

- Assessed risk factors for pregnancy including abnormal ultrasounds, abnormal analyte screening, teratogenic exposures, and family history to determine potential underlying genetic etiology

Cancer Genetic Counseling Intern — Sept 2013-Dec 2013
University of California, San Francisco and San Francisco General Hospital

- Provided pretest counseling, result review, and assessment of familial cancer risk

Teaching Experience

UCSF Faculty, Clinical Instructor — Oct **2**014-Present
University of California, San Francisco

- Instructor of Reproductive Genetics, Developmental Delay Genetics, Neurogenetics and Dementias, and Genetics of Common Disease for Small Groups component of UCSF medical student curriculum
- Lecturer for Advanced Medical Genetics and Molecular Genetics courses on congenital heart defects, inherited cardiac diseases, bleeding disorders, complex inheritance and recurrence risk

Course Director — Jan 2016-Present
California State University, Stanislaus

- Designed and instructed Biochemical Genetics course for core M.S. Genetic Counseling curriculum. Topics include: inborn errors of metabolism, newborn screening, biochemical and molecular lab testing, and therapeutics.

Research Experience

Masters of Science Research Project Aug 2012-Jun 2014

University of California, San Francisco Biochemical Genetics

- Built clinical study of 25-member family affected by mitochondrial disease for M.S. thesis. Used ANOVA statistical analysis to assess predictive ability of mitochondrial heteroplasmy levels for severity of symptoms

Research Assistant Jan 2013-Jan 2014

Kaiser Permanente, Oakland

- Studied pregnancy outcomes from patients who screened positive on newborn screening for Smith-Lemli-Opitz

Research Assistant Jun 2011-Jun 2012

Child Development Lab, Department of Psychology, University of Denver

- Studied factors that influence children's health and development, performed developmental and stress assessments in a pre-school setting

Research Assistant Jan 2009-Jun 2012

Gene Emotion Mood (GEM) Lab, Department of Psychology, University of Denver

- Studied factors that increase the vulnerability of adolescents to mood disorders
- Interviewed subjects and their families, administered stress tasks, and was responsible for genetic and cortisol sample collection

Professional Experience

Caregiver Jan 2012-Aug 2012

Touching Hearts at Home, Denver, CO

- Provided at-home care to adults with mental or physical disabilities
- Focused on communication and service during end of life care

Volunteer Experience

Weekend Trip and Respite Care Volunteer Aug 2015- Present

Camping Unlimited: Boulder Creek, CA

- Facilitate day trips and overnight camping trips with children and adults with disabilities

Crisis Hotline Worker Oct 2011- Aug 2012

Rape Assistance and Awareness Program (RAAP): Denver, CO

- Intensive crisis management and counseling training

Publications/Presentations

Poster Presentation Oct 2014

American Society of Human Genetics Conference

- "Mitochondrial Heteroplasmy and Clinical Variability in a MELAS family"

Presentation Apr2014

Children's Hospital, Oakland - Foster parent educational group

- "Autism: Current Knowledge and Genetic Testing"

Poster Presentation May 2014

Bay Area Genetic Counseling Conference

- "MELAS within a Family: Mitochondrial Heteroplasmy and Clinical Variability"

Certifications/Associations

American Board of Genetic Counseling - Certified Genetic Counselor Feb 2015-Present
American Society of Human Genetics – Member Jun 2014-Present
National Society of Genetic Counselors – Member Jan 2013-Present

Cynthia S. Morgan

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Experience:

6/17 – present: University of California, San Francisco, San Francisco, CA

- Director, Master's Program in Genetic Counseling
  Serve as lead in development of a new educational program for a master of science degree in genetic counseling. Designed brand new educational program to be in compliance with UCSF Graduate Council regulations and standards for professional accreditation set by the Accreditation Council for Genetic Counseling. Development included designing contemporary curriculum, recruitment of instructional faculty, formulation of a budget to fund a self-supporting program, recruitment and commitment for active participation by the Fresno branch campus, development of bylaws for the newly formed Graduate Group in Genetic Counseling that will govern the program, creation of program regulations that are compliant with the UCSF Graduate Council, design of a student handbook, eliciting support for the new program from within and outside UCSF. These materials have been incorporated into an application to seek institutional and campus-wide approval.
- Medical Genetics Curriculum Committee member for UCSF Medical school

3/15 – 5/17 Invitae

Genetic Counselor, Clinical Genomics (50% employment)

Laboratory genetic counselor at a commercial laboratory offering diagnostic testing through next generation sequencing. Lead genetic counselor on the metabolic team involved in training and educating scientists and other genetic counselors about inborn errors of metabolism, including the underlying biochemistry, clinical features and laboratory findings. Active participant in the launch of two metabolic disease testing products, with the initial product being a new clinical area for the company. Product development included planning of gene panels for clinically relevant content, curation and creation of clinical content for reports, development of public facing content for company web site, strategizing commercial and marketing targets, development of promotional materials and training of sales staff. Served on the Clinical Consult service answering client questions about the company, test results, assay sensitivity, variant interpretation, company policies and appropriate tests to order for a given clinical presentation. Involved in the refinement of variant interpretation by helping to create a pathognomonic category that utilizes the high specificity of certain metabolic laboratory studies to award points towards variant pathogenicity.

3/13 – 5/17: University of California, San Francisco, San Francisco, CA

Genetic Counselor, special projects (10% employment)

This position exists to advance the academic component of the Biochemical Genetics service. Includes administration and maintenance of clinical research projects comprising both industry-sponsored clinical trials and investigator-initiated studies. IRB protocol submissions, modifications, liaising with industry contacts and training of current UCSF staff on existing protocols and IRB procedures. Creation of a recharge system within the UCSF billing system to enable investigator initiated study billing. Creation of Department of Pediatrics genetic counselor Operational Protocol to increase genetic counselor functionality within the

University. Co-authoring academic publications related to clinical research performed in the Biochemical Genetics service. Ongoing training of Medical Genetics fellows, genetic counselors and nutritionists.

3/12 – 2015: HS Assistant Clinical Professor, Department of Physiologic Nursing, University of California San Francisco

Instructor "Genetics and the Family History"

Practicum quarter long course for masters candidate nursing students seeking a genomics minor. Course addressed importance and relevance of conventional family history taking, proper pedigree construction, pedigree analysis, and risk assessment. Use of predesigned questionnaires, internet resources and advantages and disadvantages of such tools. Course also included discussion of unexpected issues revealed in family history taking, using the pedigree as a psychosocial tool, ethical considerations, and appropriate referral resources. Comparison of traditional family history taking versus emerging technologies such as SNP analysis and genome/exome sequencing; and what practicing nurses can anticipate when patients utilize these technologies. Coordination and recruitment of guest lectures in specialty topics.

01/08 – 6/16: Assistant Adjunct Professor, California State University, Stansilaus. MS Genetic Counseling Program.

Instructor "Biochemical Genetics"

Designed new semester long course for masters candidate students in genetic counseling (30 instructional hours). Course design included development of syllabus, creation of lecture material, selection of course readings, development of student assignments and exams, recruitment and coordination of guest lecturers for specific topics and procurement of materials from outside vendors for lectures. Using commonly encountered inborn errors of metabolism as models the course covered basic medical biochemistry, disease clinical presentation, establishment of a differential diagnosis, genetic etiology, molecular genetics, case management, treatment and psychosocial issues. Topics include amino acidopathies, carbohydrate disorders, fatty acid oxidation disorders, urea cycle disorders, lysosomal storage disease, organic acidemias, cofactor disorders, expanded newborn screening, psychologic aspects of chronic metabolic disease, nutritional therapies and conventional and biochemical laboratory studies. Goals were to simplify complex material into easily understood components while engaging students, raising awareness of metabolic disease and removing the fear many professionals feel when encountering inborn errors of metabolism.

2/02 – 3/13 University of California, San Francisco, San Francisco, CA

- Genetic Counselor (part-time status as of 10/04)
  Provide genetic counseling and ongoing case management for individuals and families with known or suspected inborn errors of metabolism.
- Genetic Counselor & Clinical Coordinator, Neurometabolic Clinic
  Coordinate over 45 metabolic clinics per year including triaging referrals, maintaining continuity of care for patients, ensuring patients have proper specialty providers from clinic staff (geneticists, nutritionists, neurologist, genetic counselors), coordinating clinical exposure for biochemical genetics trainees (clinical fellows, laboratory fellows, neurology fellows, residents, medical students, genetic counseling students), ensuring adequate staffing for clinics, communicating with all clinic providers, liaison with medical center staff, and managing an administrative assistant.
- Co-Principal Investigator and Study Coordinator, 2 separate Phase III Clinical Trials sponsored by Genzyme Corporation: Eliglustat for the Treatment of Gaucher Disease. (2010-2012)
  IRB submissions and modifications; GCRC submissions and modifications, in-service to nursing staff; creation of physician and pharmacy treatment orders; recruitment of subjects;

management and monitoring of study subject's clinical course and evaluation schedules; electronic data management and entry; liaison with study sponsor.

- Genetic Counselor, Lysosomal Disease Center
  Genetic counseling and case and treatment management for individuals and families affected with Gaucher disease, Pompe and all MPS conditions.
- Study Coordinator, Phase III Clinical Trial Enzyme Replacement Therapy for Mucopolysaccharidosis I. 2002-2004.
- Regional Clinical Coordinator, MS/MS Expanded Newborn Screening Program

7/99 – 2/02 Kaiser Permanente, Northern California, San Jose, CA
Genetic counselor, Metabolic clinic coordinator

- Genetic counseling - provided genetic counseling for prenatal, pediatric and adult patients for a variety of indications including: prenatal diagnosis, pediatric and adult diagnostic evaluations.
- Metabolic Clinic Coordinator – Coordinate bi-monthly metabolic clinic for adults and children with metabolic diseases in the South Bay. Clinic included genetic, nutrition and psychology services and provided on-going care for the entire family unit.
- Other – supervision and training of new genetic counselors and OB/GYN residents. Creation of 7 department Practice Protocols for various chromosome and ultrasound abnormalities. Creation of 2 informational patient brochures

2/00 – 6/00 Familial Breast Cancer Research Unit at The Centre for Research in Women's Health Toronto, Ontario, Canada
Research Study Coordinator, Genetic Counselor

- Research Study Coordinator – Recruitment of participants for a research study searching for non-founder BRCA I or BRCA II mutations and/or polymorphisms/markers in the Ashkenazi Jewish population. Enrolling BRCA I and BRCA II mutation negative breast and ovarian cancer probands in a research study looking for BRCA III.
- Genetic Counselor – provided genetic counseling for all new probands and family members participating in BRCA I & II mutation testing.

Education: University of California, Berkeley, CA
Master of Science, Health and Medical Sciences, May 1999
University of Washington, Seattle, WA
Bachelor of Science, Zoology, June 1992

Certification / License:
Licensed Genetic Counselor, State of California, Expires 9/2020
American Board of Genetic Counseling, Expires 12/2022

Other Employment:
9/97 – 5/99 University of California at Berkeley & California Department of Health, Genetic Disease Branch, Berkeley, CA
Research Clerk

- Responsible for gathering data from Prenatal Diagnosis Centers (PDC's) and individual physicians on pregnancy outcome in women who received an abnormal prenatal diagnosis result
- Data collection, compilation and organization for use in statistical analysis

10/92 – 7/97 Fred Hutchinson Cancer Research Center, Seattle, WA
Research Technician

- Studied drug resistance in human cancers through analysis of the Multi-Drug Resistance gene (MDR) and the effects of cellular drug processing in a three-dimensional tissue culture model.
- Responsible for numerous tissue culture and molecular and cellular biology projects
- Trained and supervised new employees and visiting students

Other Counseling Experience:

9/97 – 4/98 Castro Valley Unified School District, Castro Valley, CA
Counseling Intern

- Provided individual counseling to seven elementary school children on a weekly basis
- Utilized play therapy and reflective listening techniques during counseling
- Developed behavior modification program for an individual student
- Provided weekly assistance in a special day class for significantly mentally and physically disabled students

4/96 – 8/97 Domestic Abuse Women's Network (DAWN), Renton, WA
Volunteer Crisis Counselor

- Responsible for answering crisis hotline and providing crisis intervention to victims of domestic violence
- Provided emotional counseling and support to female victims of domestic violence
- Provided social assessment and referrals to appropriate support organizations and social services

Teaching:

- Small group discussion leader, UCSF first year medical students 2017-present
- Small group discussion leader, Life Cycle Genetics; UCSF first year medical students. 2016
- Supervisor, Genetic Counseling Interns, Stanford University Masters Program in Genetic Counseling. Summer 2010
- Reviewer, Course in Biochemical Genetics, Stanford University Masters Program in Genetic Counseling. 2010
- Co-coordinator Regional Lysosomal Disease Patient Advocacy meeting "The Holistic Approach to Living with A Chronic Disease" 2007
- Coordinator, Educational Breakout Session, New and Emerging Therapies in the Treatment of Phenylketonuria. National Society of Genetic Counselors Educational Annual Education Conference, 2006.
- Coordinator West Coast Regional Mucopolysaccharidosis Patient Advocacy meeting "The Educational Process: A 180 day journey that doesn't have to be uphill for children with MPS" 2006
- Coordinator West Coast Regional Mucopolysaccharidosis Patient Advocacy meeting "Orthopedic Issues in Mucopolysaccharidosis" 2004
- Small group discussion leader, Life Cycle Genetics; UCSF second year medical students. 2003
- Small group discussion leader, Life Cycle Genetics; UCSF second year medical students. 2002
- Kaiser Permanente Medical Center, Santa Teresa: Patient education classes on prenatal diagnosis and hereditary breast and colon cancer, 1999-2002.
- Supervisor, OB/GYN resident, Medical Genetics rotations; Kaiser Permanente Medical Center, 2000.

Professional Presentations and Invited Lectures:

- Invited lectures: Genetics and the Family History, Risk Assessment in Family Histories, Issues in Family Histories. 2017. UCSF Nursing School, masters degree candidates, genomics minor. Recorded lectures to be used for subsequet classes
- Invited lectures: Genetics and the Family History, Risk Assessment in Family Histories, Issues in Family Histories. UCSF Nursing School, masters degree candidates, genomics minor September 2015 and September 2016
- Invited Presentation: Consequences of an R463C Mutation in Gaucher Disease. Northern California Genetics Exchange. May 2011.
- Invited Presentation: Eliglustat Clinical Trials for the Treatment of Gaucher Disease. Northern California Health Care Advocates meeting. December 2010.
- Invited Presentation: Eliglustat Clinical Trials for the Treatment of Gaucher Disease. Gaucher Patient Advocacy Meeting, August 2010.
- Invited Presentation: Multiple Myeloma and Gaucher Disease: Case Presentation. Health Care Advocates Meeting for the Treatment of Lysosomal Storage Diseases. Dallas, TX, May 2010.
- Invited Lecture: Psychology and Genetics. Pacific Graduate School of Psychology, January 2010.
- Invited Speaker: Psychosocial Aspects of Gaucher Disease. Amicus Pharmaceuticals, December 2009.
- Invited lecture: Expanded Newborn Screening. Faculty Obstetric and Gynecology Group, University of California San Francisco, September 2004.
- Invited Lecture: Inborn Errors of Metabolism. UCSF nursing masters degree candidates. February 2004
- Invited Lecture: Expanded Newborn Screening. OB/GYN Grand Rounds, University of California San Francisco, January 2003.
- Invited Lecture: Family History Taking in Pediatric Cases. UCSF nursing masters degree candidates. February 2002.
- Invited Lecture: Expanded Newborn Screening. Pediatric Grand Rounds, University of California San Francisco, September 2002.
- Invited Lecture: Expanded Newborn Screening: Garrod Redux. Pediatric Grand Rounds, California Pacific Medical Center, August 2002.

Publications:

- Needham M, Packman W, Rappoport M, Quinn N, Rappoport M, Aoki C, Bostrom A, Cordova M, Macias S, **Morganc C**, Packman S. Health-Related Quality of Life in Patients with MPS II. Journal of Genetic Counseling. 2014 Nov 14. [Epub ahead of print].
- Needham M, Packman W, Rappoport M, Quinn N, Cordova M, Macias S, **Morganc C**, Packman S. MPS II: Adaptive Behavior of Patients and Impact on the Family System. Journal of Genetic Counseling. (2014) 23: 330-338.
- Poster: Consequences of a R463 Mutation in Gaucher Disease. Society of Inherited Metabolic Disorders Conference. March 2011.
- "Genetic Counseling for Lysosomal Storage Diseases: Mucopolysaccharidosis Type I" in Lysosomal Storage Disorders. Editors John Barranger, Mario Cabrera 2007
- VanZutphen KH, Packman W, Sporri L, Needham MC, **Morgan C**, Weisiger K, Packman S. Executive functioning in children and adolescents with phenylketonuria. Clin Genet. 2007 Jul;72(1):13-8.
- Maurer BJ, Ihnat MA, **Morgan C**, Pullman J, O'Brien C, Johnson SW, Rasey JS, Cornwell MM. Growth of human tumor cells in macroporus microcarriers results in p53-independent, decreased cisplatin sensitivity relative to monolayers. Molecular Pharmacology. 1999 May; 55(5):938-47.

Professional Memberships & Activities:

National Society of Genetic Counselors (NSGC), 1999- present
NSGC Education Special Interest Group, 2012-present
NSGC Biochemical Genetic Special Interest Group, 2002- present
NSGC Clinical Supervisors Special Interest Group, 2008-2012
NSGC Pediatrics Special Interest Group, 2002-2010
NSGC Annual Education Conference, Logistics Committee, 1999
UC Berkeley Admissions Committee, Genetic Counseling Program, 2000
NSGC Student Mentor, 2000 - 2001
NSGC Education Committee, 2001

Marta Sabbadini, Ph.D., M.S., L.C.G.C.

Clinical Instructor
Biochemical Genetics, Personalized Genomics and Preventive Genomics
University of California San Francisco
550 16th Street - Box 0706 San Francisco, CA 94143
marta.sabbadini@ucsf.edu
(415) 476-8342

Education

2009 - 2011	**M.S.** Genetic Counseling, California State University, Stanislaus
2000 - 2005	**Ph.D.** (Molecular Genetics)**,** University of Brescia, Italy
1994 - 2000	**B.S., M.S.** (Biological Sciences: 110/110 cum laude), University of Milano, Italy

Clinical Experience

August 2017 - Present

Genetic Counselor III – UCSF Preventive Genomics Clinic
Department of Pediatrics, University of California San Francisco

- Established clinic for healthy adults interested in learning about their genetic risk in conjunction with Dr. Mendelsohn.
- Pre- and post-test counseling and testing coordination for patients in the Preventive Genomics clinic

Apr 2013 - Present

Genetic Counselor III – UCSF Biochemical Genetics Clinic and Lysosomal Storage Disease Center
Department of Pediatrics, University of California San Francisco

- Management and counseling of new and established patients with inborn errors of metabolism (IEMs) with a focus on the counseling and management of patient with lysosomal storage diseases, counseling for in-house genetics consults, and counseling and coordination of patients with positive newborn screening results.
- UCSF Lysosomal Storage Disease Center – Clinical coordinator and international LSD registries (Gaucher disease, Fabry disease, Pompe disease, MPSI) coordinator
- Supervision and training of medical genetics fellows and genetic counseling students

Aug 2013 - Present

Genetic Counselor III – UCSF Personalized Genomics Clinic
Department of Pediatrics, University of California San Francisco

- Established clinic in 2013 together with clinic director (Anne Slavotinek, MD, PhD) and co-director (Joseph Shieh, MD, PhD)
- Clinic coordinator and sole clinical genetic counselor providing pre- and post-test counseling, testing coordination and ensuring long-term follow-up for families identified as possible candidates for Whole Exome Sequencing (WES)
- Active member of the UCSF Genomic Medicine Initiative (GMI) group that launched the in-house clinical whole exome sequencing in June 2017
- Reviewer for in house exome sequencing variant interpretation and member of the UCSF genomic board
- Supervision and training of medical genetics fellows and genetic counseling students

Jul 2012 - Mar 2013 **Prenatal Genetic Counselor**
UCSF Clinical Laboratory Cytogenetics / San Francisco Perinatal Associates

- Full time position fulfilling all responsibilities required by the clinic, including ultrasound and diagnostic abnormalities and California Prenatal Screening Program counseling
- Supervision of genetic counseling students

Dec 2011 - Jun 2012 **Prenatal Genetic Counselor**
California Pacific Medical Center - Prenatal Diagnosis Center

- Full time position fulfilling all responsibilities required by the clinic, including ultrasound and diagnostic abnormalities and California Prenatal Screening Program counseling
- Supervision of genetic counseling students

Certifications and Licensure

2011 - Current American Board of Genetic Counseling Certification

2011 - Current California Genetic Counselor License

Teaching Experience and Positions

2015 - Present **Medical Genetics Curriculum Planning Committee Member**
UCSF School of Medicine

2016 - Present **Genetics Small Group Discussion Leader**
Bridges UCSF Medical School

- Ground school (inheritance of Genetic Disorders)
- ABC (Genetics Common Disease)
- H and I (Genetics and Identity)
- H and S (Genetic Testing , and Pharmacogenetics)

2016 **Invited small group session co-creator:** *Health and Society: Impact of Genetic Testing on Individuals, Families and Society*
Bridges UCSF medical school

2015 - 2016 **Genetics Small Group Discussion Leader**
UCSF Medical School

- Neurogenetics
- Developmental delay
- Reproductive Genetics

2015 - 2017 **Genomics and Precision Medicine Elective Lecturer**
UCSF medical school

2013 - Present **Medical Genetics Lectures and Journal Clubs**
UCSF Pediatric Genetics

2015 - Present **Principles of Human Genetics Course Director**
Genetic Counseling M.S. Program, California State University, Stanislaus

2013 - Present **Advanced Medical Genetics and Biochemical Genetics Lecturer**
Genetic Counseling M.S. Program, California State University, Stanislaus

2011	**Clinical Cytogenetics and Molecular Biology Course Director** Genetic Counseling M.S. Program, California State University, Stanislaus
2015 - Present	**Thesis Committee Member for Genetic Counseling Students** Genetic Counseling M.S. Program, California State University, Stanislaus
2001 - 2003	**Laboratory Instructor** ("The polymorphism of DNA" and "Molecular cloning") for Biology and Genetics course Department of Biology and Genetics, School of Medicine, University of Milano-Bicocca, Italy

Research Experience

2010 - 2011	**Masters Research Project**: "International genetic counseling students' perspective on their training experience in the United States" (*advisor*: Jon Weil, Ph.D.)
2007 - 2009	**Postdoctoral Fellow** (*advisor*: C. Spencer Yost, M.D.) Department of Anesthesia and Perioperative Care, University of California San Francisco
2003 - 2006	**Visiting Ph.D. Student / Postdoctoral Fellow** (*advisor*: David E. Levy, Ph.D.) Department of Pathology, New York University
2000 - 2003	**Ph.D. Student** (*advisor*: Prof. Raffaella Meneveri) Department of Experimental, Environmental Medicine and Biotechnology, University of Milano-Bicocca, Italy
1998 - 2000	**Masters Student** (*advisor*: Prof. Paola Comi) Department of Biomedical Sciences and Technologies, University of Milano, Italy

Fellowships and Grants

Apr 2013 - Jan 2015	Recipient of the Genzyme Lysosomal Storage Disease Fellowship
Spring 2011	Recipient of the CSU Stanislaus Biology Research Committee (BRC) grant in support of the Masters research project
2004 - 2005	Recipient of the Italian Federation for Cancer Research "Leonino Fontana and Maria Lionello" Fellowship
2000 - 2004	Recipient of the MIURST (Ministero dell'Universita' e della Ricerca Scientifica e Tecnologica) Ph.D. fellowship

Professional Memberships

2017 - Present	Member, American College of Medical Genetics and Genomics
2016 - Present	Member, American Society of Human Genetics
2010 - 2014	Member, National Society of Genetic Counselors

Languages

Fluent spoken and written Italian; intermediate spoken Spanish

Invited Speaker

How Do I Decide Which Clinical Trial is Right for Me? FOP Family Gathering. December 1-3, 2017

The Importance of the X in eXome. ACMG Genomic Case Conferences. Hosted by the University of California, San Francisco. April 20, 2016

Challenges in Disease Monitoring – A Pediatric Fabry Patient Example. *In "Registry Data Life Cycle: from Patient Assessments to Registry Publications" session.* Genzyme 15th National Rare Disease Registries Meeting. Chicago, IL, November 12-13, 2015

Cardiac Disease in Female Patients with Fabry Disease. Genzyme Rare Disease Registries Regional Meeting. San Francisco, CA, May 1-2, 2014

Publications

Pociot F, Larsen ZM, Zavattari P, Deidda E, Nerup J, Cattaneo M, Chiaramonte R, Comi P, **Sabbadini M**, Zollo M, Biunno I, Cucca F. No evidence for SEL1L as a candidate gene for IDDM11-conferred susceptibility. Diabetes Metab Res Rev 2001 Jul-Aug;17(4):292-5

Chiaramonte R, **Sabbadini M**, Balordi F, Comi P, Sherbet GV. Allele frequency of two intragenic microsatellite loci of SEL1L gene in Northern Italian population. Mol Cell Biochem 2002 Mar;232(1-2):159-61

Chiaramonte R, Calzavara E, Balordi F, **Sabbadini M**, Capello D, Gaidano G, Serra A, Comi P, Sherbet G V. Differential regulation of notch signal transduction in leukaemia and lymphoma cells in culture. J Cell Biochem 2003;88(3):569-77

Sabbadini M, Barisani D, Conforti E, Marozzi A, Ginelli E, Miserocchi G, Meneveri R. Gene expression analysis in interstitial lung edema induced by saline infusion. Biochim Biophys Acta 2003 Jul 14;1638(2):149-56

Sabbadini M, Yost CS. Molecular biology of background K channels: insight from K2P knockout mice. J Mol Biol 2009 Feb 6;385(5):1331-44

Yoo S, Liu J, **Sabbadini M**, Au P, Xie GX, Yost CS. Regional expression of the anesthetic-activated potassium channel TRESK in the rat nervous system. Neurosci Lett. 2009 Nov 6;465(1):79-84

Chae YJ, Zhang J, Au P, **Sabbadini M**, Xie GX, Yost CS. Discrete Change in Volatile Anesthetic Sensitivity in Mice with Inactivated Tandem Pore Potassium Channel TRESK. Anesthsiology 2010 Dec;113(6):1326-37

Sabbadini M, Naldi M, Packman W, Youngblom J, Weil J. International Genetic Counseling Students' Perspective on Their Training Experience in the United States. J Genet Couns. 2013 Dec;22(6):817-29

Slavotinek A, Pua H, Hodoglugil U, Abadie J, Shieh J, Van Ziffle J, Kvale M, Lee H, Kwok PY, Risch N, **Sabbadini M**. Pierpont syndrome associated with the p.Tyr446Cys missense mutation in TBL1XR1. Eur J Med Genet. 2017 Jul 4. pii: S1769-7212(17)30245-8 [Epub ahead of print]

Abstracts and Poster Presentations

R Chiaramonte, **MGM Sabbadini**, F Balordi, P Comi, I Biunno, M Zollo, ZM Larsen and F Pociot. Studio del coinvolgimento del gene *SEL1L* nella suscettibilità al diabete insulino dipendente. II congresso FISV, Riva del Garda (TN), Italy, September 30–October 4, 2000. Abstract book, page 60 (4.8)

Sabbadini M, Barisani D, Conforti E, Miserocchi G, Meneveri R. IL1β, IL-6 and TNFα mRNA expression in mild pulmonary interstitial edema. Experimental Biology 2002, New Orleans, LA, April 20-24, 2002. FASEB J. 2002 Mar, 16(5):A1146 (861.4)

Barisani D, **Sabbadini M**, Conforti E, Marozzi A, Ginelli E, Miserocchi G, Meneveri R. Modulation of cytokine mRNA levels is the first event in pulmonary interstitial edema. 53° Congresso Nazionale della Società Italiana di Fisiologia, Ferrara, Italy, September 16-19, 2002. Abstract Book, page 88

K Schlessinger, A Corlett, **M Sabbadini** and D Levy. STAT3 and its role in cell transformation. Keystone Symposia: Jaks and stats: Development to Disease, Whistler, British Columbia, Canada, April 15-20, 2004. Abstract Book page 71 (309)

Sabbadini M, Naldi M, Packman W, Youngblom J, Weil J. International genetic counseling students' perspective on their training experince in the United States. Transnational Alliance for Genetic Counseling Meeting, Montreal, Canada, October 11, 2011

Sabbadini M, Naldi M, Packman W, Youngblom J, Weil J. International genetic counseling students' perspective on their training experince in the United States. NSGC Annual Education Conference, San Diego, CA, October 27-30, 2011

Sabbadini M, Alhariri A, Lee C, Muller E, Oglesbee D, Segal S, Packman S. Gaucher disease and Langerhans cell histiocytosis. European Society of Human Genetics Conference, Milan, Italy, May 31 - June 3, 2014

Sabbadini M, Shieh J, Madou M, Alsadah A, Sherr E, Slavotinek A. Exome Sequencing and Counseling in a Personalized Genomics Clinic. ACMG Annual Clinical Genetics Meeting, Salt Lake City, UT, March 24-28, 2015

Sabbadini M, Oglesbee D, Foster-Barber A, Segal S, Alhariri A, Lee C, Muller E, Packman S. *De Novo* Mutations on Maternal Alleles in Two Patients with Neuronopathic Gaucher Disease. Society for Inherited Metabolic Disorders 38th Annual Meeting, Salt Lake City, UT, March 28-31, 2015

Sabbadini M, Shieh J, Slavotinek A. Personalized Genomics Clinics: A Model for Delivery of Genetics Care. ASHG Annual Meeting, Vancouver, Canada, October 18-22, 2016

Iacoboni D, Goldberg D, **Sabbadini M**, Quintana R, Erhard K, Michalski S, Esplin E, Shieh J, Ouyang K. Contiguous 2p16.3p21 Gene Deletion Inclusive of *EPCAM*, *MSH2*, and *MSH6* Identified with Next-Generation Sequencing. ACMG Annual Meeting, Phoenix, AZ, March 21-25, 2017

Sabbadini M, Pua H, Hodoglodil U, Abadie J, Shieh J, Van Ziffle J, Kvale M, Lee H, Kwok PY, Risch N, Slavotinek A. Further evidence for Pierpont syndrome associated with a specific missense mutation in *TBL1XR1*. ACMG Annual Meeting, Phoenix, AZ, March 21-25, 2017

CURRICULUM VITAE

PERSONAL DATA

Name:	Allyson Marie Scott, MS, LCGC
Address:	3063 Sacramento Street #21 San Francisco, CA, 94115 Phone: (415) 828-8158
Email:	allyson.scott@gmail.com
Citizenship:	United States
Birth Date:	May 9, 1978
Birth Location:	San Jose, CA

EDUCATION

2000	University of California, San Diego San Diego, California Bachelor of Science, Biology Minor, Healthcare and Social Issues
2005	Northwestern University Chicago, Illinois Masters of Science, Genetic Counseling Thesis: The Genetic and Embryology Basis of Abnormal Fetuses in the Arey-Krantz Collection

BOARD CERTIFICATION AND LICENSURE

2007	American Board of Genetic Counseling
2011	California Department of Public Health Licensed Genetic Counselor

EMPLOYMENT

2005-present	Genetic Counselor University of California, San Francisco Prenatal Diagnosis Center

PROFESSIONAL SOCIETY MEMBERSHIPS

Intermittent dates	National Society of Genetic Counselors
Intermittent dates	American College of Medical Genetics
Intermittent dates	American Society of Human Genetics

PROFESSIONAL AND SCIENTIFIC SERVICE

Service to the Community

2006	Monta Vista High School AP Biology Careers in Genetics
2007 – present	Monta Vista High School Health Sciences Career Night Genetic Counseling

TEACHING

Teaching Responsibilities

2006 – present	Clinical Supervisor, Genetic Counseling Students Multiple Graduate Programs
2005 – present	Clinical Supervisor, Residents in Obstetrics and Gynecology Department of Obstetrics and Gynecology University of California, San Francisco School of Medicine
2005 – present	Clinical Supervisor, Medical Students University of California, San Francisco School of Medicine

PUBLICATIONS

Clinical Guidelines for Advanced Practice Nursing
Prenatal Screening and Diagnosis
Chapter Reviewer, **Scott, A**.

LECTURES AND PRESENTATIONS

"Life Cycle: Prenatal Diagnosis" Small Group Session for Medical Students, University of California, San Francisco School of Medicine. 2005-present, annually

"Life Cycle: Down syndrome" Family Interview, University of California, San Francisco School of Medicine. 2015 – present, annually

"Hemoglobinopathies" Residents in Obstetrics and Gynecology, University of California, San Francisco, School of Medicine, 2016

"Hemoglobinopathies" Fellows in Perinatology and Genetics, University of California, San Francisco, School of Medicine, 2016

"Genetic Counseling" Midwifery Students, University of California San Francisco, School of Nursing, 2016

"Unremarkably Remarkable", Commencement Speaker, Northwestern University Graduate Program in Genetic Counseling, 2016

CURRICULUM VITAE

Name: **Summer Segal, PhD, MS, LCGC**

Position: HS Clinical Instructor
Genetic Counselor III
Division of Medical Genetics
Department of Pediatrics
University of California, San Francisco

Grief Support Specialist
Integrated Pediatric Pain & Palliative Care (IP3) Program
UCSF Benioff Children's Hospital

Office Address: 550 16th Street, 4th Floor, Mail Code 0706
San Francisco, CA 94143
Telephone: (415) 476-4674
Fax: (415) 476-9976
E-mail: summer.segal@ucsf.edu

EDUCATION

1995-1999 Pennsylvania State University, State College, PA
B.S., Biobehavioral Health

2000-2002 University of California**,** Berkeley, CA
M.S., Genetic Counseling

2013-2018 Saybrook University, Oakland, CA
Ph.D., Psychology
Concentration: Existential, Humanistic & Transpersonal Psychology

Clinical Internships

2000-2001 We Care Services for Children, Concord, CA
Child and Family Therapy Intern

May 2001-Aug 2001 Genetics Division, University of California, San Francisco, CA
Genetic Counseling Intern

Aug 2001-Nov 2001 Biochemical Genetics, University of California, San Francisco, CA
Genetic Counseling Intern

Nov 2001-Feb 2002 Genetics Department, Kaiser Permanente, Oakland, CA
Genetic Counseling Intern, Prenatal Diagnosis

Certification Courses

2012 POLST: Beginning the Conversation for Pediatrics
Coalition for Compassionate Care of California & Children's Hospice and Palliative Care Coalition. Sacramento, CA

2014 Supporting Dying and Grieving Children and Their Families

The Dougy Center. Concord, CA

2015 Being With Dying: Professional Training Program for Clinicians in Compassionate Care of the Seriously Ill and Dying
Upaya Institute. Santa Fe, NM

2014-2016 Certificate Program: Foundations of Existential-Humanistic Practice
Existential Humanistic Institute. Oakland, CA

2016 Compassionate Bereavement Care Certification in Traumatic Grief Counseling
MISS Foundation & Elizabeth Kubler-Ross Family Trust. Sedona, AZ

2017 Resolve Through Sharing Bereavement CoordinatorTraining in Neonatal & Pediatric Death
Gunderson Health System. Walnut Creek, CA.

LICENSURE & CERTIFICATION

2007-present Certified, American Board of Genetic Counseling

2012-present License, State of California Department of Public Health GC000346

PRINCIPAL POSITIONS HELD

2002-2009 UCSF Benioff Children's Hospital Oakland
Pediatric Genetic Counselor
Division of Medical Genetics

- Medical management, psychosocial assessments, and counseling of individuals/families in Genetics Clinic, Craniofacial Clinic, and Intensive Care Nursery
- Coordinator, Northern California Skeletal Dysplasia Clinic
- Advisory Board, Northern California Skeletal Dysplasia Clinic (2002-2007)

2009-present University of California, San Francisco
Genetic Counselor III
Biochemical Genetic Medicine Service

- Clinical: Medical management, psychosocial assessments, and counseling of individuals/families with inborn errors of metabolism
- Teaching: Educational programs and lectures to community medical personnel, post-doctoral genetics fellows, medical students, genetic counseling graduate students, psychology graduate students, and patient groups
- Research: Co-principal investigator of research protocols funded by private sector and public sources
- Clinical supervisor of genetic counseling interns
- Coordinator, UCSF Lysosomal Disease Center (2009-2012)
- Coordinator, California Newborn Screening Program Area Service Center (2009-2012)

2012-present UCSF Benioff Children's Hospital, San Francisco
Grief Support Specialist
Coordinator, perinatal palliative care & grief support services

Integrated Pediatric Pain and Palliative Care (IP3) Program

- Clinical: Grief counseling for individuals experiencing perinatal loss, loss of a child, or losses associated with life-shortening medical conditions in inpatient and outpatient setting
- Teaching: Educational programs and lectures in perinatal palliative care & grief/loss support

AWARDS

1995-1999	Schreyer Scholar, Pennsylvania State University
2001	Health and Medical Sciences Fellowship, University of California Berkeley
2013-2016	President's Scholarship, Saybrook University

RESEARCH

1996-1999	Pennsylvania State University, State College, PA - Research Assistant, Behavioral Endocrinology Laboratory
2011-2013	University of California, San Francisco, CA - Co-PI/Study coordinator: Phase 3 clinical trial on oral chaperone therapy for Fabry disease - Study coordinator: Phase 3 clinical trial on oral substrate reduction therapy for Gaucher disease

GRANTS

Complex Care Program: Patient and Family Education and Support

Genzyme Corporation	1/3/12-12/20/12 $40,000
Shire Human Genetic Therapies, Inc.	7/1/12-6/30/13 $37,000

Development of the Complex Care Program. This pilot program served as a collaboration between Child Neurology, Medical Genetics, and Integrated Pediatric Pain & Palliative Care (IP3), aiming to provide symptom management, case management and psychosocial support services to children and families affected by complex and potentially life-limiting neurologic and neurodegenerative disorders. The program emphasized a family-centered approach to facilitate adaptation to illness-related losses and maximize quality of life.
Role: Co-Investigator and Clinician

PROFESSIONAL ORGANIZATIONS

Memberships

2002-	National Society of Genetic Counselors
2002-	American Society of Human Genetics
2012-	American Academy of Hospice and Palliative Medicine
2016-	Association for Death Education and Counseling
2016-	Association for Humanistic Psychology

SERVICE ACTIVITIES

2014 - present	Northern California Collaborative of Pediatric Palliative Care	Member
2016	Genetic Disease Screening Program, California Department of Public Health: Adrenoleukodystrophy Newborn Screening	Consultant
2016 - 2017	Palliative Care Leadership Center (PCLC), UCSF: Perinatal Palliative Care	Presenter
2016 - present	UCSF Perinatal Palliative Care Task Force	Chair
2017 - present	UCSF Genetic Counseling Program Steering Committee	Member
2017 - present	Bereavement Task Force of the UCSF BCH Family Advisory Council	Co-Chair

PUBLICATIONS

Waterson J, Stockley TL, Segal S, Golabi M. (2010). Novel duplication in glypican-4 as an apparent cause of Simpson–Golabi–Behmel syndrome. *American Journal of Medical Genetics Part A,* 152A(12): 3179-3181.

Weber S, Segal S, Packman W. (2012). Inborn errors of metabolism: Psychosocial challenges and proposed family systems model of intervention. *Molecular Genetics and Metabolism,* 105: 537-541.

Bugescu N, Alioto A, Segal S, Cordova M, Packman W. (2015). The neurocognitive impact of Fabry disease on pediatric patients. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, 168(3): 204-210.

INVITED PRESENTATIONS – NATIONAL

2017	*Working with Grief as a Genetic Counselor*. Symposium for the National Society of Genetic Counselors (NSGC) Annual Education Conference Columbus, OH

INVITED PRESENTATIONS – REGIONAL

2011-2016	*Counseling in Biochemical Genetics*. Annual lecture in the California State University Stanislaus Genetic Counseling Masters' Program, Biochemical Genetics Course
2012-2016	*Genetic Disease: Psychosocial Considerations*. Annual lecture in the Pacific Graduate School of Psychology, Palo Alto University, Pediatric Medical & Health Psychology Course
2012	*Pediatric Palliative Care Comes of Age*. Lecture to UCSF Medical Genetics Division
2013	*Facilitating Familial Adaptation to Chronic Illness*. Lecture to UCSF Medical Genetics Division
2014-present	*Navigating Difficult Conversations*. Annual lecture to UCSF Medical Genetics Fellowship
2014	*Death & Dying: Clinical Considerations*: Lecture in the California State University Stanislaus Genetic Counseling Masters' Program, Principles & Practices of Genetic Counseling Course

2014	*Hope and Resilience*: Lecture in the California State University Stanislaus Genetic Counseling Masters' Program, Principles & Practices of Genetic Counseling Course
2015	*Applying a Family Systems Lens to Pediatric Palliative Care*. Lecture to the UCSF Integrated Pediatric Pain & Palliative Care Service
2015	*Applying a Family Systems Lens to the Practice of Medical Genetics*. Lecture to the UCSF Medical Genetics Division
2016	*Loss, Grief, & Bereavement*. Lecture in the Pediatric End-of-Life Nursing Education Consortium Training (ELNEC), UCSF Benioff Children's Hospital Oakland
2016	*Perinatal Palliative Care: Defining the Scope of Practice*. Lecture for the UCSF Palliative Care Leadership Center (PCLC)
2017-present	*Caring for Grieving Families*. Semiannual lecture in the UCSF Perinatal Palliative Care Seminar

CONFERENCE ABSTRACTS

1. Segal S, Root M, Hocker W, Jacobson O, Foster-Barber A, Bogetz J. A Pediatric Palliative Care Program to Meet the Needs of Children with Severe Neurological Impairment and Their Families. Poster Presentation. American Academy of Pediatric, Section on Hospice and Palliative Medicine, San Francisco, CA, October 2016.

PUBLIC SERVICE

1996-2000	The AIDS Project, State College, PA HIV Test Counselor, Certified by the Department of Health

AREAS OF INTEREST

Pediatric and perinatal palliative care; grief and loss; medical genetics; inborn errors of metabolism; existential-humanistic psychology; relationship-centered care; contemplative care; medical education; transformative learning; communication skills; professional development

University of California San Francisco

CURRICULUM VITAE

Name: **Anne Michele Slavotinek**

Position: Professor of Clinical Pediatrics, Step 3
Division of Genetics
Department of Pediatrics
School of Medicine

Address: 1550 4th St, Room RH384C,
University of California, San Francisco
San Francisco CA 94143-2711
Voice: (415) 514-1783
Fax: (415) 476-9305
Email: anne.slavotinek@ucsf.edu

EDUCATION:

Degrees:

1981-1986	Medical School, University of Adelaide, Australia	MB.BS	Medicine
1988-1995	Royal Australasian College of Physicians, Australia	FRACP	Medicine/Genetics
1991-1995	Flinders University, Australia	Ph.D	Cell Biology
1992-1998	The Open University, U. K.	BA Hons	Art History

Training Positions:

01/1987-01/1988	Royal Adelaide Hospital, South Australia	Intern	Medicine
02/1988-02/1991	Flinders Medical Centre, South Australia	Resident	Medicine
05/1991-02/1994	MRC Human Genetics Unit, Edinburgh, U.K.	Scientist	Cell Biology
02/1994-09/1995	Churchill Hospital, Oxford, U.K.	Registrar	Genetics
10/1995-12/1998	St Mary's Hospital, Manchester, U.K.	Senior Registrar	Genetics
12/1998-06/2000	NHGRI, NIH Bethesda	Visiting Fellow	Biology
07/2000-06/2002	National Institutes of Health, Bethesda	Clinical Fellow	Genetics

LICENSES, CERTIFICATION:

USA Medical Licenses:

1999	ECFMG certification
2001-2004	Connecticut Medical License 040008
2002-now	California Medical License A79866

Board Certification in Clinical Genetics:

1997-now	Consultant Clinical Geneticist, Human Genetics Society of Australasia
1998-now	Certification of Specialist Training, Clinical Genetics, United Kingdom

2002-now American Board of Medical Genetics. Certified in Clinical Genetics

PRINCIPAL POSITIONS HELD:

2002-2003	University of California, San Francisco	Clinical Instructor	Pediatrics
2003-2006	University of California, San Francisco	Assistant Professor	Pediatrics
2006-2012	University of California, San Francisco	Associate Professor	Pediatrics
2012-now	University of California, San Francisco	Professor	Pediatrics

OTHER POSITIONS HELD CONCURRENTLY:

2003-now	Stanford University School of Medicine	Adjunct Clinical Instructor
2008-now	Institute of Human Genetics, UCSF	Faculty
2008-now	Sturge Weber Foundation Center of Excellence	Clinical Geneticist
2009-now	Pathway to Discovery in Molecular Medicine (MMP)	Faculty

HONORS AND AWARDS:

2000	Fellows Award for Research Excellence (FARE), NIH
2004	Hellman Family Award
2007	Mentored Career Development award, NICHD, NIH
2008	European Society for Human Genetics-Nature award
2011	Nomination for Kaiser teaching award
2014	Haile T. Debas Academy of Medical Educators Excellence in Teaching Award
2017	Pediatric Fellow Leadership Award, UCSF

KEYWORDS/AREAS OF INTEREST:

Dysmorphology; Malformations and birth defects; Multiple congenital anomaly syndromes; Exome sequencing; Personalized genomics; Anophthalmia, microphthalmia, coloboma; Bardet-Biedl syndrome; Multiple congenital anomaly syndromes

CLINICAL ACTIVITIES

CLINICAL ACTIVITIES SUMMARY:

I attend in General Genetics clinic each week, in Craniofacial clinic each month and at several multidisciplinary clinics as described above. I am the director of the Personalized Genomics clinic, the first of its kind at UCSF. I also attend on service for a minimum of three to four months per year. As an Attending for the above clinics, I supervise Genetics Fellows and Genetic Counselors and oversee residents, medical students, Molecular Genetics Fellows and Cytogenetics Fellows that rotate through our service.

CLINICAL SERVICES:

Attending, General Genetics Clinic, UCSF: I attend at General Genetics Clinic for six half days every month. In this clinic, patients are referred for all types of Genetics consultations, including

intellectual disability/autism, multiple congenital anomalies, chromosome abnormalities and family history of a genetic disorder.

Attending, Personalized Genomics Clinic, UCSF: I am the director of a personalized genomics clinic that takes place on four afternoons each month. In this clinic, patients are seen for provision of exome sequencing as a clinical or research test, with consent, results provision and follow up visits.

Attending, Clinical Genetics Service, UCSF: I attend on service for a minimum of 3 months per year. On service, I cover all in-house consults from General genetics, including from the Neonatal and Pediatric Intensive Care Units.

Attending, Craniofacial Anomalies Clinic, Department of Dentistry, UCSF: I attend at Craniofacial Anomalies Clinic for a half morning once per month. This is a multidisciplinary clinic in which patients with craniofacial anomalies receive genetic evaluation and counseling.

Attending, Dermatology Genetics Clinic, Department of Dermatology, UCSF: I attend at Dermatology Genetics Clinic for one morning every four months. This is a multidisciplinary clinic in which patients receive concurrent dermatology and genetics evaluations.

Attending, Ophthalmology Genetics Clinic, Department of Pediatric Ophthalmology, UCSF: I attend at Ophthalmology Genetics Clinic for one morning every two months. This is a multidisciplinary clinic in which patients receive concurrent ophthalmology and genetics evaluations.

Attending, ENT Genetics Clinic, Department of Audiology, UCSF: I attend at Ophthalmology Genetics Clinic for one morning every month. This is a multidisciplinary clinic in which patients with hearing impairment receive concurrent audiology and genetics evaluations.

Attending, Endocrinology Genetics clinic, Department of Pediatrics, UCSF: I attend at Endocrinology Genetics Clinic for one morning every two months. This is a multidisciplinary clinic in which patients receive concurrent endocrinology and genetics evaluations.

Other Attending Duties

Attending, Autism Neurogenetics Clinic, Department of Psychiatry, UCSF: I attended at Autism Genetics Clinic for one morning every one to two months from 2008-2009 and from 2013-2014. This was a multidisciplinary clinic in which patients with autism receive concurrent pediatric neurology and genetics evaluations.

Attending, Disorders of Sexual Development clinic, Department of Urology, UCSF: I represented Genetics at the Disorders of Sexual Development clinic in 2014. This multidisciplinary clinic was held once per month and cares for patients with complex genitourinary presentations.

Clinical Geneticist, International Anophthalmia conference (ICAN), held every second year.
Jules Stern Eye Institute, UCLA June 2009; University of Illinois, July 2013; Wills Eye Institute, Philadelphia, July 2015, UCSF, July 2017.

PROFESSIONAL ACTIVITIES

MEMBERSHIPS:

1998-1999	Association of European Cytogeneticists
1994-1998	The Genetical Society, United Kingdom
1994-2001	Skeletal Dysplasia Society, United Kingdom
1994-2002	British Society of Human Genetics
2006-2009	Society for Craniofacial Genetics
1997-now	American Society of Human Genetics
2003-now	Diabetes Center, UCSF
2003-now	American College of Medical Genetics and Genomics
2004-now	Western Society for Pediatric Research
2008-now	Society for Pediatric Research
2013-now	European Society for Human Genetics

SERVICE TO PROFESSIONAL ORGANIZATIONS:

2003	Moderator, 53rd American Society for Human Genetics Annual Meeting, Clinical Genetics II; Los Angeles, CA
2003-now	Gorlin Syndrome Support Group Regional Advisor
2003-now	Curbstone Consults, Dysmorphology advisor, American Society for Human Genetics Annual meetings
2004	Moderator, WSPR Western Regional Meeting, Genetics, Carmel, CA
2004	5th Northern California Genetics Exchange, UCSF, Program Organizer and Chair
2007	8th Northern California Genetics Exchange, UCSF, Program Organizer and Chair
2007	Lead Facilitator, Curbstone Consults, American Society for Human Genetics Annual Meeting. Session 2, San Diego, CA
2007	Moderator, David Smith Meeting, Gastroschisis Session, Williamsburg, VA
2008	Moderator, WSPR Western Regional Meeting, Morphogenesis and Malformations Carmel, CA
2008	Moderator, American College of Medical Genetics Annual Meeting, Clinical Genetics I, Phoenix, AZ
2008	Moderator, David Smith Meeting, Cilia II, Mont-Tremblant, Quebec
2008	Moderator, American Society for Human Genetics Annual Meeting, Clinical Genetics II, Philadelphia, PA
2009	Moderator, New Technologies Session, American College of Medical Genetics Annual Meeting, Clinical Genetics, Tampa, FL
2010	Reviewer of Workshop Proposals for 2011 meeting, Pediatric Academic Societies
2010	Moderator, Molecular basis of disease session, 31st Annual David Smith Workshop on Malformations and Morphogenesis, Union, WA
2010	Moderator, American Society for Human Genetics Annual Meeting, Invited Session: Developmental eye disorders: In sight of progress?
2011	Moderator, American College of Medical Genetics Annual Meeting, Clinical Genetics I, Vancouver, Canada
2011	12th Northern California Genetics Exchange, UCSF, Program Organizer
2011	Moderator, Cortical Dysplasia session, 32nd Annual David Smith Workshop on Malformations and Morphogenesis, Union, WA
2012	Moderator, American College of Medical Genetics Annual Meeting, Clinical Genetics I, Charlotte, NC

2012 Moderator, American College of Medical Genetics Annual Meeting, Developmental Eye Disorders, Seeing the Light, Charlotte, NC
2012 Moderator, American Society for Human Genetics Annual Meeting, Clinical Genetics: Mutations, Mutations and Syndromes, San Francisco, CA
2012 Reviewer, Pediatric Academic Society workshops for 2013 meeting
2013 Reviewer and abstract judge, 34th Annual David Smith Workshop on Malformations and Morphogenesis, Lac Tremblant, Canada
2013 Moderator, Syndromes II, 34th Annual David Smith Workshop on Malformations and Morphogenesis, Lac Tremblant, Canada
2014 Reviewer and abstract judge, Development, Pediatric Academic Societies meeting, San Diego 2015
2015 Moderator, Connecting the Dots: Hard and Soft Tissue Syndrome, American Society for Human Genetics Annual Meeting, Baltimore, MD
2016 Abstract reviewer, David Smith Workshop on Malformations and Morphogenesis
2016 Moderator, Insights into the Genetic Basis of Eye Syndromes, American Society for Human Genetics Annual Meeting, Vancouver, Canada
2017 Moderator, Genetics/Inborn Errors of Metabolism, Pediatric Academic Societies meeting, San Francisco, CA
2017 International Society for Prenatal Diagnosis Organizing Committee
2017 Moderator, Genetic testing for Fetal Anomalies, International Society for Prenatal Diagnosis, San Diego, CA
2017 Moderator, Gene Discovery and Functional Models of Intellectual Disability, American Society for Human Genetics Annual Meeting, Orlando, FL

Program Committee, American College of Medical Genetics and Genomics

2007-2014 Member, Program Committee for Annual Meeting, American College of Medical Genetics
2008-2011 Leader of Clinical Genetics section, Program Committee, American College of Medical Genetics Annual Meeting
2010 Leader of Molecular Genetics section, Program Committee, American College of Medical Genetics Annual Meeting
2011-2012 Vice-Chair, Program Committee for Annual Meeting, American College of Medical Genetics
2012-2013 Chair, Program Committee for Annual Meeting, American College of Medical Genetics

Education Committee, American College of Medical Genetics and Genomics

2015- 2016 Member, Education Committee, American College of Medical Genetics
2017- Vice Chair, Education Committee, American College of Medical Genetics

American Board of Medical Genetics and Genomics (ABMGG)

2015 Writer for Part II activities
2017- Board member, American Board of Medical Genetics and Genomic
2017 ABMGG item writer, Clinical Genetics, for certification exam

American Society of Human Genetics

2015 Genetics Education Outreach Network, member

Other committees: American College of Medical Genetics and Genomics

2009 Faculty, Advocates Advisory Program
2012, 2017-now Member, Committee Chairs
2014, 2016-now Faculty mentor, Faculty trainee lunch

SERVICES TO PROFESSIONAL PUBLICATIONS:

Editorial Boards

2009-now Editorial Board, Clinical Dysmorphology
2011-2012 Editorial Board, Case Reports in Genetics
2012-now Editorial Board, Molecular Genetics and Genomic Medicine
2013-now Editorial Board, American Journal of Medical Genetics
2014-now Editorial Board, Orphanet Journal of Rare Diseases
2015-now Editorial Board, Molecular Syndromology

Associate Editorships

2008-now Associate Editor, BMC Medical Genetics
2010-2014 USA Editor, Journal of Pediatric Genetics
2016-now Associate Editor, European Journal of Medical Genetics
2017-now Associate Editor, American Journal of Medical Genetics

Papers Reviewed for Peer Reviewed Journals

2004-2007 Ad hoc referee for Nat Genet (1 paper in 2006), Am J Hum Genet (1 paper in 2007), J Peds (1 paper in 2006), Trends in Genetics (1 paper), J Med Genet (11 papers in last 3 years; 5 in 2006, 2 in 2007), Am J Med Genet (12 papers in last 2 years; 6 in 2006, 2 in 2007), Clin Genet (4 papers in last 3 years; 2 in 2006), Eur J Med Genet (2 papers in last two years), Clin Dysmorphol (2 papers in 2006), Int J Radiat Biol (1 paper), Brit J Cancer (1 paper), Cleft Palate Craniofac J (1 paper), Brit J Neurosurg (1 paper, Int J Oral Maxillofac Surg (1 paper), Int J Peds Otorhinolaryngol (2 papers in 2006), Prenat Diag (1 paper in 2006), Gene Clinics 1 entry in 2006; Ped Dermatol (1 paper in 2006, 1 in 2007), BMC Genetics (1 paper in 2007), Neonatal-Perinatal Medicine (1 paper in 2007)

2008 Am J Med Genet 5 papers, Hum Mol Genet 2 papers, J Med Genet 3 papers, Clinc Genet 3 papers, Hum Genet 1 paper, Am J Perinatol 1 paper, Int J Oral Maxillofac Surg 1 paper, Expert Reviews OB/GYN, 1 paper, Gene Clinics, 2 entries. Lung Cell Mol Physiol 1 paper

2009 Am J Med Genet 1 paper, Eur J Med Genet 4 papers, J Autism Dev Dis 1 paper, Hum Mutat 2 papers, Birth Defects Research 1 paper, Clin Dysmorphol 3 papers, PLoSOne 1 paper, Genetics in Medicine 1 paper, Am J Pernatol 1 paper, Eur J Hum Genet 1 paper, J Med Genet 2 papers, Cleft Palate Craniofac J 1 paper, Am J Hum Genet 1 paper, Clin Genet 1 paper, World J Peds 1 paper, Neonatology 1 paper

2010 J Pediatr Pathol 1 paper, Am J Med Genet 7 papers, Clin Genet 2 papers, Hum Genet 2 papers, Eur J Hum Genet 1 paper, PLoSGenet 2 papers, Eur J Med Genet 3 papers, J Med Genet 1 paper, Prenatal diagnosis 1 paper

2011 Case reports in Genetics 4 papers, Clin Dysmorphol 4 papers, Hum Genet 1 paper, Mol Vision 1 paper, Am J Med Genet 2 papers, Eur J Med Genet 1 paper, Hum Mutat 2 papers, Prenatal Diagnosis 1 paper, Congenital anomalies 1 paper; J Med Genet, 1 paper, PLoSOne 1 paper; J Exp Med 1 paper, Am J Hum Genet 1 paper, PLoSGenet 1 paper

2012 Am J Med Genet 4 papers; Hum Mutat 1 paper, Eur J Hum Genet 1 paper, Gene 1 paper, J Med Genet 3 papers, BMC Med Genet 4 papers, PloSOne 1 paper, Case Reports in Genetics 4 papers, Hum Mol Genet 2 papers, Nat Genet 2 papers, Clin Invest Med 1 paper, Genet Med, 1 paper, Mol Syndromol 1 paper, Eur J Med Genet 1 paper, Annals Neurology 1 paper, J Pediatr Genet 1 paper, Clin Genet 1 paper.

2013 Am J Hum Genet 1 paper, Eur J Hum Genet 1 paper, J Med Genet 1 paper, Hum Genet 1 paper, Clin Genet 2 papers, Clin Dysmorphol 1 paper, Am J Med Genet 2 papers, J Pediatr Genet 1 paper.

2014-2017 I have continued to review papers for journals, largely confined now to those for which I am on the Editorial Board or an Associate editor. Am J Med Genet 4 papers, Am J Hum Genet 4 papers, Orphanet Journal of Rare Diseases 4 papers, BMC Medical Genetics 3 papers, Journal of Clinical Investigation 1 paper, Hum Mol Genet 2 papers.

Material Reviewed for Support Groups

2008 Unique, Chromosome support group, U.K.

2012 Unique, Chromosome support group, U.K. Trisomy 8 mosaicism

2013 Unique, Chromosome support group. U.K. 15q26 deletions

INTERNATIONAL INVITED PRESENTATIONS:

2006 European Society of Human Reproductive Endocrinology, Prague, CZ. Invited talk: declined.

2010 Society of Pediatric Research. Novel microdeletion syndromes detected by chromosome microarrays. Vancouver, Canada. Invited talk.

2017 Dysmorphology course. 'What I know best – Fraser syndrome' Rome, Nov 2017

2017 4th SIAMG conference, INDO-US conference, Short stature. Kerala, India, Dec 2017

NATIONAL INVITED PRESENTATIONS:

2000 Seminar, National Human Genome Research Institute, NIH, Bethesda

2001 Seminar, Department of Genetics, University of Wisconsin, Madison

2002 Seminar, Department of Genetics, Johns Hopkins University, Baltimore

2002 Seminar, Department of Genetics, University of Chicago, Chicago

2002 Seminar, Division of Genetics, University of San Francisco, San Francisco, CA

2005 Grand Rounds, Department of Pediatrics, AI Dupont Hospital for Children, Wilmington, DE

2006 American College of Medical Genetics Annual meeting, San Diego, CA. Invited talk: Fryns Syndrome. Declined.

2006 American Society for Human Genetics Annual meeting, New Orleans, LO. Invited talk: Syndromes with Congenital Diaphragmatic Hernia.

2007 American Society for Human Genetics Annual meeting, San Diego, CA. Invited talk: Array CGH – Uncovering Novel Microdeletion Syndromes.

2007 CDH Study Group Biannual meeting, Houston TX. Invited talk: Gene Identification in Birth Defects – Congenital Diaphragmatic Hernia.
2007 Research Presentation, NIH Fifth Birth Defects Conference, Baltimore, MD
2008 Research Presentation, NIH Sixth Birth Defects Conference, Baltimore, MD
2009 American College of Medical Genetics Annual meeting, Tampa, FL. Invited talk: Cardinal Signs, De Barsy Syndrome
2009 Research Presentation, NIH Seventh Birth Defects Conference, Washington, DC
2010 Seminar, Division of Genetics, SickKids, Toronto, Canada
2010 American Society for Human Genetics Annual meeting, Washington, DC. Invited talk: Eye Development Genes and Known Syndromes
2011 Research Presentation, NIH Eighth Birth Defects Conference, Washington, DC
2012 Professors Rounds, Department of Pediatrics, Weill Cornell Medical College, New York, NY
2012 Seminar, Department of Genetics and Genomic Sciences, Mt Sinai School of Medicine, New York, NY
2013 Research Presentation, NIH Ninth Birth Defects Conference, Washington, DC
2014 American College of Medical Genetics Annual meeting, Nashville TN. Invited talk: Impact of Recent Advances in Genetics and Genomics on Neonatal Genetics
2015 Seminar, Transforming care through personalized genomics, Nemours Children's Health System, Wilmington, DE
2015 Seminar, Next-generation sequencing and CRISPR for gene discovery in birth defects, Nemours Alfred I. DuPont Hospital for Children, Wilmington DE
2016 Invited speaker, 4th Annual Symposium Clinical Applications of Genome-Wide Testing, UCLA, Feb 2016

REGIONAL AND OTHER INVITED PRESENTATIONS:

2002 Grand Rounds, Endocrine Genetics, NIH, Bethesda, MD
2002 Grand Rounds, Department of Genetics, Stanford University, Palo Alto, CA
2003 Grand Rounds, Department of Oral and Maxillofacial Surgery, UCSF, San Francisco, CA
2003 Seminar, Joint Genome Institute, Walnut Creek, CA
2003 Seminar, Stickler syndrome support group, San Jose, CA
2003 Seminar, Genetic Epidemiology Group, UCSF, San Francisco, CA
2003 Grand Rounds, Department of Genetics, Stanford University, Palo Alto, CA
2004 Grand Rounds, Department of Pediatrics, UCSF, San Francisco, CA
2004 Seminar, Diabetes Center, UCSF, San Francisco, CA
2004 Grand Rounds, Department of Pediatrics, Kaiser Permanente, San Francisco, CA
2004 Support group talk, Gorlin syndrome support group, San Francisco, CA
2005 Seminar, Neonatology Division, UCSF, San Francisco, CA
2005 Grand Rounds, Department of Neurology, UCSF, San Francisco, CA
2005 Seminar, Department of Pediatric Audiology, UCSF, San Francisco, CA
2005 Seminar, Genetic Epidemiology Group, UCSF, San Francisco, CA
2006 Human Genetics/Oral and Craniofacial Disease workshop, UCSF, San Francisco, CA
2007 Teaching rounds, Division of Pediatric Surgeons, UCSF San Francisco, CA
2007 Genetics Grand Rounds, UCSF, San Francisco
2007 Seminar, Program in Human Genetics, UCSF, San Francisco, CA

2007 CME presentation, Genetics in Medicine, Sequoia Hospital, CA
2008 Seminar, Program in Human Genetics, UCSF, San Francisco, CA
2008 Grand Rounds, Department of Pediatrics, SFGH, San Francisco, CA
2009 Seminar, Division of Neonatology, Dept. Pediatrics, UCSF
2009 Teaching Rounds, Department of Pediatrics, SFGH, San Francisco, CA
2009 Grand Rounds, Department of Pediatrics, Kaiser Oakland, CA
2009 Seminar, Program in Human Genetics, UCSF, San Francisco, CA
2010 Grand Rounds, Department of Pediatrics, UCSF, San Francisco, CA
2010 Grand Rounds, Marin General Hospital, Marin, CA
2011 Teaching, Neonatology Core Curriculum Series, UCSF, San Francisco, CA
2012 Teaching, Neonatology Core Curriculum Series, UCSF, San Francisco, CA
2012 Teaching: Facing up to the Dysmorphic Newborn, Neonatology Core Curriculum Series, UCSF, San Francisco, CA
2013 Grand Rounds, Department of Pediatrics, UCSF, San Francisco, CA
2013 Seminar, Program in Human Genetics, UCSF, San Francisco, CA
2013 Pediatric Neurology Rounds, UCSF, San Francisco, CA
2014 Seminar for Ophthalmology trainees, UCSF San Francisco, CA
2014 Grand Rounds, Department of Neurology, UCSF, San Francisco, CA
2014 Grand Rounds, Department of Pediatrics, UCSF, San Francisco, CA
2014 Grand Rounds, Department of Pediatrics, Marin General Hospital, Marin, CA
2014 Neurodevelopmental Case Conference, Department of Psychiatry, UCSF San Francisco, CA
2015 Seminar for Nephrology Division, Department of Pediatrics, UCSF
2015 Invited speaker, Genetics of hearing loss, Multi-Disciplinary Evaluation and Management of Permanent Pediatric Hearing Impairment conference, Walnut Creek, CA
2015 Invited speaker, Dysmorphology, 45th Annual Fall Conference-UCSF Benioff Children's Hospital Oakland
2015 Invited speaker, Genetics, Genetics 101, 45th Annual Fall Conference-UCSF Benioff Children's Hospital Oakland
2016 HMGGP Seminar, Colorado Children’s Hospital, Aurora, CO, Jan 2016
2016 Keynote speaker, Pediatric bone disease, CCMBM P30 Spring Half-Day Symposium, UCSF Mar 2016
2016 Grand rounds, Dept. of Ophthalmology, Genetic causes of anophthalmia, microphthalmia and coloboma, UCSF Mar 2016
2016 ACMG Genomics Case Conferences, April 2016
2016 RUN seminar, Division of Nephrology, UCSF, April 2016
2016 Grand rounds, Dept. of Child and Adolescent Psychiatry, UCSF, April 2016
2016 The role of genetics in disease. One Medical group, San Francisco, Aug 2016
2016 Grand rounds, Dept. Medicine, UCSF, October 2016
2017 RUN seminar, Division of Nephrology, UCSF, April 2016
2017 Institute of Human Genetics Symposium, UCSF, June 2017
2017 International Children’s Anophthalmia Network, July 2017
2017 Grand rounds, Dept. Dermatology, UCSF, August 2017

CONTINUING EDUCATION and PROFESSIONAL DEVELOPMENT (last 5 years):

2012 American College of Medical Genetics Annual Clinical Genetics Meeting, Charlotte, NC
American Society of Human Genetics 62nd Annual Meeting, San Francisco, CA
2013 American College of Medical Genetics Annual Clinical Genetics Meeting, Phoenix, AZ
European Society of Human Genetics Annual Meeting, Paris, France
32nd Annual David W. Smith Workshop on Malformations/Morphogenesis, Lac Tremblant, Canada
American Society of Human Genetics 63rd Annual Meeting, Boston, MA
2014 American College of Medical Genetics Annual Clinical Genetics Meeting, Nashville, TN
European Society of Human Genetics Annual Meeting, Milan, Italy
American Society of Human Genetics 64th Annual Meeting, San Diego, CA
10th Birth Defects conference, Rockville, MD.
2015 American College of Medical Genetics Annual Clinical Genetics Meeting, Salt Lake City, UT
European Society of Human Genetics Annual Meeting, Glasgow, U.K.
34th Annual David W. Smith Workshop on Malformations/Morphogenesis, St. Michaels, MD
2016 American College of Medical Genetics Annual Clinical Genetics Meeting, Charlotte, NC
34th Annual David W. Smith Workshop on Malformations/Morphogenesis, Lake Arrowhead, CA
American Society of Human Genetics 65th Annual Meeting, Vancouver, Canada
2017 American College of Medical Genetics Annual Clinical Genetics Meeting, Phoenix, AZ
European Society of Human Genetics Annual Meeting, Copenhagen, Denmark
35th Annual David W. Smith Workshop on Malformations/Morphogenesis, Stowe, VT
American Society of Human Genetics 66th Annual Meeting, Orlando, FL

GOVERNMENT and OTHER PROFESSIONAL SERVICE:

Grant reviews

2008	Study section, International and Cooperative Projects, (ICP1), National Institutes of Health
2009	Royal College of Obstetrics and Gynecology, Wellbeing of Women's Research Advisory Committee. Grant Reviewer
2009	Estonian Science Foundation. Grant Reviewer
2010-2011	Telethon, Italy, Grant Reviewer
2010	Stage 1 reviewer, NIH RC4 applications - Recovery Act Limited Competition: Director's Opportunity for Research in Five Thematic Areas (RC4), RFA OD10-005, National Institutes of Health
2013	CHARGE syndrome foundation, grant reviewer
2013	NIGMS Loan Repayment Program, grant reviewer
2013	Telethon, Italy, grant reviewer
2014	Ophthalmic Research Institute of Australia (ORIA), grant reviewer
2014	MRC, UK Peer Review Request Biomedical Catalyst DPFS/DCS grant reviewer
2014	AFM-Telethon Scientific Council France, grant reviewer
2015	Reviewer, Study section, U01 Pediatric Cardiac Genomics Consortium (PCGC), NHLBI, NIH
2015	German Federal Ministry for Education and Research (BMBF)

2015 Ophthalmic Research Institute of Australia (ORIA), grant reviewer
2015 Reviewer, Study section U01, Sudden Cardiac Death in the Young: Population Based Studies, NHLBI, NIH
2016 CHARGE syndrome foundation, grant reviewer
2017 CHARGE syndrome foundation, grant reviewer

UNIVERSITY AND PUBLIC SERVICE

SERVICE ACTIVITIES SUMMARY:

In 2015, I completed my terms as Chair of the University of California Systemwide Committee for Rules and Jurisdiction and Parliamentarian for the Academic Senate at UCSF. I was a reviewer for two study sections at National Heart Lung Blood Institute, National Institutes of Health in 2015. In 2016-2017, I have served as the Chair of a search committee in Pediatric Genetics. I have also served on the promotions committee for the Department of Pediatrics.

UC SYSTEM and MULTI-CAMPUS SERVICE:

2012 University Committee on Rules and Jurisdiction (UCR&J), At Large member
2013-2015 University Committee on Rules and Jurisdiction (UCR&J), Chair

UCSF CAMPUS-WIDE:

Committee for Human Research (CHR)
2008-2011 Member, CHR committee, UCSF Parnassus campus

UCSF Academic Senate Executive Committee
2010-2015 Parliamentarian

UCSF Academic Senate, Rules and Jurisdiction Committee
2006-2008 Member, UCSF Academic Senate Rules and Jurisdiction Committee
2008-2009 Vice Chair, UCSF Academic Senate Rules and Jurisdiction Committee
2009-2010 Chair, UCSF Academic Senate Rules and Jurisdiction Committee
2011-2015 Ex-Officio member, Academic Senate Rules and Jurisdiction Committee

UCSF Academic Senate, Coordinating Committee
2009-2015 Member, UCSF Academic Senate Coordinating Committee

UCSF Academic Senate Task Force on Membership
2012 Member

UCSF Academic Senate Task Force on Bylaws Review
2012 Chair

Other UCSF Academic Senate Committees
2015 APB Administrative Initiatives Subcommittee

UCSF Faculty Search Committees

2007	Faculty Search Committee, Department of Orofacial Sciences
2007	Interview Panel, Assistant Director of Cytogenetics Laboratory, UCSF
2008	Search Committee, Assistant Professor, Dept. Laboratory Medicine, UCSF
2012	Search Committee, Deborah Hoyt and Creig S. Hoyt, M.D., Chair in Pediatric Ophthalmology, UCSF
2015	Search Committee, Michal Vilensky Endowed Chair for Research in Ophthalmology, UCSF
2015	Search Committee, Clinical Geneticist, Dept. Pediatrics, Fresno
2015-2017	Chair, Search Committee, Clinical Geneticist, UCSF and Children's Hospital Oakland
2016	Member, Faculty Search Committee, Division of Genetics, Dept. Pediatrics

UCSF Institute of Human Genetics

2012	Genomic Medicine Work Group member

SCHOOL OF MEDICINE:

Medical Genetics Curriculum

1998-1998	Specialty Training Subcommittee in Clinical Genetics, Department of Postgraduate Medicine and Dentistry, University of Manchester
2004-2006	Medical Genetics Curriculum Committee, UCSF, Co-Chairman

DEPARTMENTAL SERVICE:

2003-2009	Department of Pediatrics	Pediatric Resident Interviews
2003-now	Department of Pediatrics	Division of Genetics, Resident/Fellow Interviews
2005-2006	Department of Pediatrics	Division of Cardiology, Faculty Search Committee
2005-2007	Department of Pediatrics	Housestaff Advising Program
2006-2006	Department of Pediatrics	Resident Matching Program
2006	Department of Pediatrics	Division of Genetics, T32 Grant Search Committee
2012- 2017	Department of Pediatrics	Academic Senate Merit and Promotions Committee
2013-2014	Department of Pediatrics	Ambulatory Care Operations Committee
2014	Department of Pediatrics	Division of Genetics, Faculty Search Committee
2015	Department of Pediatrics	Interview panel, Chief of Pediatric Pulmonary Medicine
2015-now	Department of Pediatrics	Pediatric Ambulatory Improvement Group member

OTHER SERVICE

2008	Application reviewer, UCSF Biomedical and Health Sciences Internship program
2008-2011	American Society of Human Genetics Education Programs Associate, Essay reviewer
2011	Participant at 'Bringing the Vision Together' conference, Eunice Kennedy Shriver National Institute of Child Health and Development, Washington DC, June 2011
2013	Ambassador, UCSF 2.0
2015 - now	Fetal Surgery Oversight committee, UCSF

Consulting

2009-2014	Member, Scientific Advisory Committee and Congenital Malformations Adjudication Panel, Nplate Pregnancy Exposure Registry, Amgen.

2010 Member, Scientific Advisory Committee, Dmab Pregnancy Exposure Registry, Amgen
2012-now Section Editor in Genetics, Up to Date, Inc.
2013-2014 Scientific Advisor, Etanercept Exposure Register, Amgen
2013-2014 Scientific Advisor, Botox Pregnancy Register, Allergan
2017 Consultant, OptumRx,

COMMUNITY AND PUBLIC SERVICE:

2013-now I have continued to volunteer at last 20 hours per year at the German International School of Silicon Valley, San Francisco campus. I have been the lead for the food and drink booth for Laternenfest, volunteered at the library and served food at the Weihnachtsmarkt.

CONTRIBUTIONS TO DIVERSITY:

2015-2016 Together with other members of the T32 program directors, I have helped to organize and attend the ASHG Diversity Breakfast. This breakfast is offered to students with underrepresented minority backgrounds who attend the American Society for Human Genetics Annual meetings.

TEACHING AND MENTORING:

TEACHING SUMMARY:

In 2017, I received a Pediatric Fellow Leadership Award at UCSF. I provide lectures on hearing loss, intellectual disability, eye defects and short stature to genetics trainees and other residents each year. I have continued to precept for the PISCES (Parnassus Integrated Student Clerkship Experiences) program and to participate as a small groups leader for medical student teaching in the School of Medicine. I have continued as the UCSF faculty member for the ACMG Foundation Summer Genetics Scholars Program.

SUMMARY OF TEACHING HOURS:

2015-2016 300 total hours of teaching (including preparation)
Formal class or course teaching hours: 40 (including preparation)
Informal teaching hours: 220
Mentoring hours: 40

2016-2017 300 total hours of teaching (including preparation)
Formal class or course teaching hours: 40 (including preparation)
Informal teaching hours: 220
Mentoring hours: 40

2017-2018 Anticipated 300 total hours of teaching (including preparation)
Anticipated Formal class or course teaching hours: 40 (including preparation)
Anticipated Informal teaching hours: 220
Anticipated Mentoring hours: 40

FORMAL TEACHING:

Qtr	Academic Year	Course No. & Title	Teaching Contribution	Units	Class Size
F	2003	UCSF Medical School 1st year	Genetics in Review, Integration/Consolidation Block; 1 one hour lecture	1 lecture	150
S	2003-now	School of Dentistry, UCSF	Craniofacial anomalies; 1 one hour session	1 lecture	15
F	2005	UCSF Medical School 1st year	Genetics of Heart Disease, Organs block; 1 one hour lecture	1 lecture	150
F	2005-2009	UCSF Medical School 1st year	Small group discussion leader, Prologue Block; 1 two hour session	1 session	15
F	2005-2009, 2014	UCSF Medical School 1st year	Small group discussion leader, Organs Block; 1 two hour session	1 session	15
W	2004; 2007-2010, 2013-2014	UCSF Medical School 2nd year	Small group discussion leader, Life Cycle Block; 1 two hour session	1 session	15
S	2007-2010	UCSF Medical School 2nd year	Small group discussion leader, Brain, Mind Behavior Block; 1 two hour session	1 session	15
S	2009-2013	UCSF Medical School 3rd year	Small group discussion leader Intersession; 3 two hour sessions	3 sessions	6
F	2016-2017	UCSF Medical School 1st year	Small group discussion leader H and I; Genetics and Identity	1 session	15
F	2016-2017	UCSF Medical School 1st year	Small group discussion leader H and I; Stress and Resilience	1 session	15
S	2016-2017	UCSF Medical School 2nd year	Small group discussion leader BMB: Neurogenetics	1 session	15
F	2017-	UCSF Medical School 1st year	Small group discussion leader Life Stages	2 sessions	15

POSTGRADUATE AND OTHER COURSES:

1995-1998 Tutorials to Year 5 Medical Students, University of Manchester

1996-1997 Tutor for Problem Based Learning Groups, Year 3, University of Manchester Medical Undergraduate Curriculum

1996-1998 Lectures to MSc Students, MSc course, Department of Medical Genetics, St Mary's Hospital, Manchester

2006 Breakout Session Leader, The NIH Alphabet Soup of Grants form K to R, Clinical and Translational Sciences Training (CTST) Workshop, June 2006

2006-2007 Tutorial to Neonatology Fellows. Dysmorphology of the Newborn.

2006 Tutorial to Plastic Surgeons, UCSF. Embryology of the Head/Neck and Common Syndromes and Genetic Counseling, November 2006.

2007 Fellows Board Review Course, Division of Genetics, UCSF. I organized and lectured in a 10 lecture course designed to help the Fellows with preparation for the Clinical Board Exams

2007 Tutorial to Genetics Fellows. Array CGH and novel microdeletion syndromes

2009-now Tutorial to Masters students in GENE 274, Stanford. A Case-based Approach to Human Genetics, at Stanford. Congenital Adrenal Hyperplasia and Ambiguous Genitalia
2009 Fellows Board Review Course, Division of Genetics, UCSF. I organized and lectured in a 10 lecture course designed to help the Fellows with preparation for the Clinical Board Exams
2010 Tutorials to Masters students training in Genetic counseling

UCSF Genetic Counseling Student Program
2017 Genetic counseling program steering committee

INFORMAL TEACHING:

Division of Medical Genetics:

2002-now Medical Genetics Conference, Division of Genetics (weekly with four residents)
2002-now General Genetics Clinic (weekly with four to six residents)
2002-2007 Dysmorphology Genetics Clinic (weekly with one to two residents)
2002-now Attending Rounds, Genetics Service (2-5 months per year, one resident per month)
2004-now Dermatology Genetics Clinic (3-4 times a year with three to four residents)
2004-now Ophthalmology Genetics Clinic (3-4 times a year with one to two residents)
2008-2010 Autism Genetics Clinic (monthly with one to two residents)
2011-now UCSF Faculty for ACMG Foundation Summer Genetics Scholars Program

Teaching Seminars for Fellows in Medical Genetics:

2015 Short stature
2015 Hearing loss
2016 Intellectual disability
2016 Deformations, disruptions, malformations
2017 Hearing loss
2017 Approaches to eye defects

Department of Pediatrics:

2004-2005 Chairmans Rounds, presentations on Noonan syndrome and Trisomy 21
2006 Pediatrics Teaching Rounds – VATER syndrome
2007 Chairman's Rounds

School of Nursing:

2008 Dysmorphology Examination, 1st year nursing students

MENTORING SUMMARY:

I am currently on the Scholarship Oversight Committee of Dr. Daniah Beleford and mentor to Dr. Aya Abu El-Haijja, two Fellows in our division. In 2016, I was a member of the Scholarship Oversight Committee for Dr. Victoria Berger and in 2015, I served on the Scholarship Oversight Committee for Dr. Teda Arunrut. I have helped to mentor Dr. Jessica Tenney, an Assistant Professor who is a new faculty member in our Division. I am also acting as an informal mentor to Dr. Aya Abu El-Haijja, a genetics resident in our Division.

Mentoring
2006- 2007 Women's Medical Student Association, Mentor
2007- now MTSP program, Mentor
2008- 2011 Research Mentor, Dr. Jake Hogue

PREDOCTORAL STUDENTS SUPERVISED OR MENTORED:

Dates	Name	Program or School	Role	Current Position
2005	Catherine Li	High School Student	Research Advisor, Summer student	NA
2005-2007	Elena Hsieh	Medical Student, 3rd year, UCSF	Research Advisor	Medical Student, UCSF
2006	André Landin Malt	Visiting Scientist	Research Advisor, Summer Student	Ph.D Student
2006	Jeffrey Leong	4th Year Dental Student, UCSF	Research Advisor	Resident
2006	Erica Wu	Medical Student, 1st year, UCSF	Research Advisor, Summer student	Medical Student, UCSF
2007	Vanessa Wu	4th Year Dental Student, UCSF	Research Advisor	Dental Student, UCSF
2007	Ben West	High School Student	Research Advisor, Summer Student	Student, Berkeley University
2007-2009	Ryan Chao	Berkeley University, BSc	Research Supervisor	Staff Research Associate
2007	Kelly Steiglitz	1st year, Baylor University, Dallas	Research Advisor, Summer Student	Student, Baylor University, Dallas
2008	Alexandra Aminoff	Medical Student, 4th year, UCSF	Research Advisor, Research Project	Medical Student, UCSF
2008	Anu Ramachandran	High School Student	Research Advisor, Summer Student	NA
2009	Ryan Powers	High School Student	Research Advisor, Summer Student	University of Pennsylvania
2009-2010	James Huang	Berkeley University, BSc	Research Supervisor	Staff Research Associate
2010	Sam Brondfield	Medical Student, 3rd year, UCSF	PISCES Supervisor	Medical Student, UCSF
2010-2011	Erica Sanford	Medical Student, 4th year, UCSF	Research Supervisor	Medical Student, UCSF
2011	Jared Nathanson	4th year, Berkeley University	Research Supervisor	Student, Berkeley University
2011	Jessica Wickland	1st year, Wayne State	ACMG Summer Student	2nd year, Wayne State
2011-2012	Sirina Keesara	Medical Student, 3rd year, UCSF	PISCES Supervisor	Medical Student, UCSF
2011-2012	Mochi Liu	Berkeley University	Research Supervisor	Berkeley University

		Student		Student
2012	Faren Clum	1st year, UCSF	ACMG Summer Student	2nd year, UCSF
2013-2014	Caitlin Kakigi	Medical Student, 3rd year, UCSF	PISCES Supervisor	Medical Student, UCSF
2013	Sanjin Tunovic	Tulane University School of Medicine	ACMG Summer Student	Tulane University School of Medicine
2013-2014	Kyle Umeda	San Francisco State University student	Research Supervisor	San Francisco State University
2014	Eric Cho	Temple University School of Medicine	ACMG Summer Student	Temple University School of Medicine
2014-2015	Sai Duriseti	Medical Student, 3rd year, UCSF	PISCES Supervisor	Medical Student, UCSF
2015	Vanessa Su	Berkeley University Student	Research Supervisor	Berkeley University Student
2015	Varsha Gupta	2nd year, Case Western University	ACMG Summer Student	2nd year, Case Western University
2015-2016	Angela Suen	Medical Student, 3rd year, UCSF	PISCES Supervisor	Medical Student, UCSF
2016	Sarah Eppley	Medical Student, 2nd year, UC Berkeley program	ACMG Summer Student	Medical Student, 2nd year, UC Berkeley program
2016-2017	Alison Rustagi	Medical Student, 3rd year, UCSF Medical Student, 3rd year, UCSF	PISCES Supervisor	Medical Student, 3rd year, UCSF
2017	Juan Ramos	2nd year, Edward Via College of Osteopathic Medicine, Sparatanburg, SC	ACMG Summer Student	2nd year, Edward Via College of Osteopathic Medicine, Sparatanburg, SC
2017-2018	Abby Wang	Medical Student, 3rd year, UCSF	PISCES Supervisor	Medical Student, 3rd year, UCSF

POSTDOCTORAL FELLOWS AND RESIDENTS DIRECTLY SUPERVISED OR MENTORED:

Dates	Name	Fellow	Faculty Role	Current Position
2002-2003	Melinda Scully, MD	Clinical Fellow	Clinical Supervision	Attending, CPMC
2002-2003	Sabrina Cheng, MD	Clinical Fellow	Clinical Supervision	Research Fellow, CDC

2002-2003	Xiao-Dong Han, MD, Ph.D	Biochemical Genetics Fellow	Clinical Supervision	Fellow in Genetics, UCSF
2002-2004	Xiao-Wei Fu, Ph.D	Ph.D Fellow	Clinical Supervision	Lab. Director, Baylor University, Dallas
2002-2004	Renius Owen, Ph.D	Ph.D Fellow	Clinical Supervision	Director, QUEST Diagnostics
2003-2004	Ophir Klein, MD, Ph.D	Clinical Fellow	Clinical Supervision	Assistant Professor, UCSF
2003-2005	Petra Swidler, MD	Clinical Fellow	Clinical Supervision	Assistant Professor, St Louis University
2003-2007	Indira Mehta, Ph.D	Ph.D Fellow	Clinical Supervision	Fellow in Genetics, UCSF
2004-2007	Madelena Martin, MD	Clinical Fellow	Clinical Supervision	Assistant Professor, University of Massachusetts
2004-2006	John Tsai, MD	Clinical Fellow	Clinical Supervision	Fellow, Johns Hopkins University
2005-2007	John Holt, MD	Clinical Fellow	Clinical Supervision	Bioinformatics Fellow, Stanford
2005-2007	Susan Tran, MD	Clinical Fellow	Clinical Supervision	MFM Fellow, UCSF
2006-2008	Katherine Bianco, MD	Clinical Fellow	Clinical Supervision	Fellow and Resident in Medical Genetics
2006-2007	Hatem Zayed, Ph.D	Postdoctoral Fellow	Research Supervision	Ph.D Fellow, Medical Genetics
2007-2009	Brian Shaffer, MD	Clinical Fellow	Clinical Supervision	Attending, UCSF
2007-2009	Suma Shankar, MD, Ph.D	Clinical Fellow	Clinical Supervision	Attending, Emory University
2007-2008	Cecily Fitzgerald, MD	Clinical Fellow	Clinical Supervision	Fellow and Resident in Medical Genetics
2008	David Sun, Ph.D	Postdoctoral Fellow	Research Supervision	Ph.D Fellow
2008-2010	Nelson LopezJimenez, MD, Ph.D	Postdoctoral Fellow	Research Supervision	Postdoctoral Fellow
2008-2011	Jacob Hogue, MD	Clinical Fellow	Clinical Supervision	Clinical Fellow
2009-2011	Divya Vats, MD	Clinical Fellow	Clinical Supervision	Faculty, LA Children's Hospital
2009-2011	Angie Jelin, MD	Clinical Fellow	Clinical Supervision	Clinical Fellow
2009-2011	Karla Bermudez-Wagner, MD	Clinical Fellow	Clinical Supervision	Clinical Fellow
2009-2010	Adebola Olarewaju	Pediatric Nurse Resident	Clinical Supervision	Pediatric Nurse Resident

2010-2011	Rashmi Jain, MD	Clinical Fellow	Clinical Supervision	Internist
2010-2012	Mani Yahyavi, BA	Staff Research Associate	Research Supervision	Medical Student
2011-now	Ben Li, MD	Clinical Fellow	Clinical Supervision	MFM Fellow
2011-2013	Chung Lee, MD	Clinical Fellow	Clinical Supervision	Faculty, Oregon Health Sciences
2011-2013	Swetha Krishna-murthi, MD	Clinical Fellow	Clinical Supervision	Faculty, Greenwood Genetics center
2012-2013	Bryce Mendelsohn, MD	Clinical Fellow	Clinical Supervision	Fellow
2013-2014	Shyamali Mandal, Ph.D	Staff Research Associate	Research Supervision	Employee at Genentech
2014	Ehsan Ullah	Graduate Student	Research Supervision	Graduate Student
2013-2015	Ahmad Alhariri, MD	Clinical Fellow	Clinical Supervision	Clinical Fellow
2013-2015	Marwan Ali, MD	Clinical Fellow	Clinical Supervision	Clinical Fellow
2013-2015	Theresa Sparks, MD	Clinical Fellow	Clinical Supervision	Clinical Fellow
2013-2015	Adnan Alsadah, MB.BS	Clinical Fellow	Clinical Supervision	Clinical Fellow
2014	Ashley Brynn	Pediatric Nurse Resident	Clinical Supervision	Pediatric Nurse Resident
2015-2015	Teda Arunrut, MD	Clinical Fellow	Clinical Supervision	Clinical Fellow
2015-2017	Victoria Berger, MD	Clinical Fellow	Clinical Supervision	Clinical Fellow
2016-now	Aya Abu-El-Haijja, MD, MPH	Clinical Fellow	Clinical Supervision	Clinical Fellow
2016-now	Daniah Beleford, MD, Ph.D	Clinical Fellow	Clinical Supervision	Clinical Fellow
2017 - now	Anne Mardy, MD	Clinical Fellow	Clinical Supervision	Clinical Fellow
2017 - now	Thoa Ha, MD	Clinical Fellow	Clinical Supervision	Clinical Fellow

Thesis committees:

2014 Paul Brady, University of Leuven, Belgium
2016 Akela Kurosawa, UCSF

FACULTY MENTORING:

Dates	Name	Position while Mentored	Mentoring Role	Current Position
2006-2012	Sneha Oberoi, DDS	Assistant Clinical Professor, Craniofacial Anomalies	Research Advisor	Associate Clinical Professor, Craniofacial Anomalies

VISITING FACULTY MENTORED:

2011 David Mowat Sydney Children's Hospital, Sydney, Australia
2012 Wen-Hann Tan Boston Children's Hospital, USA
2014 Teresa Neuhann Medizinisch Genetisches Zentrum, Muenich, Germany

RESEARCH AND CREATIVE ACTIVITIES:

RESEARCH and CREATIVE ACTIVITIES SUMMARY:

Genomic Medicine

In the last two years, my research focus has shifted towards next-generation sequencing and personalized medicine due to my involvement in the Genomics Medicine Initiative (GMI) at UCSF. Together, our group of clinical geneticists, counselors, bioinformaticians, statisticians, pathologists and ethicists established whole exome sequencing (WES) as a clinical test at UCSF in 2017. We have also been successful in obtaining funding and have a U01 grant, Genomic sequencing to aid diagnosis in pediatric and prenatal practice: examining clinical utility, ethical implications, payer coverage, and data integration in a diverse population. This grant and our center are part of Clinical Sequencing Exploratory Research (CSER) 2 consortium that will study the clinical utility of whole exome sequencing in patients and biological parents from underrepresented minority and underserved populations. In this grant, I am one of four PIs and will be responsible for recruitment and study of 800 Pediatric patients at three clinical sites during the four years of the grant, with an annual budget for my component of Aim 1 of $437,306; the grant has a total annual budget of $3,045,425 (total direct costs).

Genetic Etiology of Birth Defects

I have continued to ascertain patients with rare patterns of congenital anomalies and to use both clinical and research WES to identify new causative genes. We have described a pleiotropic intellectual disability syndrome with ear anomalies, renal anomalies, heart defects, diaphragmatic defects and disordered sexual development in association with heterozygosity for de novo *PBX1* sequence variants (see Significant Publications below). We have also described developmental delays, cataracts and dysmorphic features in patients with biallelic sequence variants in *INTS1* (paper in preparation).

I have continued to run a basic science laboratory supported by a Research Allocation Program (RAP) grant and departmental funds. The goal of my research is to study the genetic causes and mechanisms underlying birth defects, including anophthalmia, microphthalmia, and coloboma. I have collaborated with Dr. Anthony Moore and Dr. Farrah Islam to recruit subjects with isolated or syndromic microphthalmia and coloboma. We are currently using single nucleotide polymorphism (SNP) arrays, WES and whole genome sequencing to study these families for the underlying causative genes. My laboratory also uses zebrafish as an animal model to study eye defects. We have used CRISPR/Cas9 to target *foxe3*, creating biallelic indel mutations in this gene that has resulted in fish with lens defects. We have also targeted other genes that are involved in eye development, including *vax1* and *ints1*. We have used immunohistochemistry to characterize the eye defects in the *foxe3* mutant fish and qRT-PCR and RNA-Seq to determine the effects of loss of *foxe3* expression on the genes expressed in the lens. We are currently preparing a paper on this work and will use our results to apply for grant funding.

I am also interested in nonsense suppression therapy and we have used PTC124 (Ataluren) to rescue the ventral fin defects in a *bmp4* mutant zebrafish with a nonsense mutation.

CRB2-related syndrome

After describing mutations in the *CRB2* gene associated with elevated α-feto-protein, congenital nephrosis, Finnish type, and cerebral ventriculomegaly, we are planning to study the

mutations that we reported in vitro and in vivo, using mutagenesis and transfection and siRNA to determine if loss of CRB2 perturbs ciliary function.

RESEARCH GRANTS - CURRENT:

1 UO1 HG009599 (Kwok PI) 08/04/17-05/31/22; 3 calendar months
NHGRI, NIH $3,045,425 (total direct)
Genomic sequencing to aid diagnosis in pediatric and prenatal practice: examining clinical utility, ethical implications, payer coverage, and data integration in a diverse population
This project will perform whole exome sequencing in 1100 patients and parents who are from underrepresented minorities or underserved in order to evaluate the clinical utility of exome sequencing in this population.
The grant has shared PIs and I am the PI for Aim 1, although Dr Kwok is the corresponding PI.

1U01DE024440-01 Spritz (PI) 05/16/14 – 04/30/19; 0.12 calendar months
NIH/University of Colorado $709,333 (total direct)
Subcontract to UCSF $179,330 (total)
Developing 3D Craniofacial Morphometry Data and Tools to Transfer Dysmorphology

Team science award, Slavotinek (PI) 06/01/16-04/30/18
UCSF Research Allocation Program total $70,000 yr 1
Genomic Variation in Structural Eye Defects
This project will perform detailed phenotyping and whole genome sequencing in patients with structural eye defects.

Grants with Effort as needed:
IHG Exploratory grant, Phillips (PI) 01/01/17-12/31/17
Institute of Human Genetics, University of California, San Francisco total $25,000
Reimbursement of Next Generation Sequencing Based Gene Panel Tests for Pediatric Patients.

CIAPM grant, Martin/Bofelli (PIs) 01/01/17-12/31/17
California Institute for Advancing Precision Medicine total $1,000,000
Investigating the utility of whole genome sequencing in pediatric care

RESEARCH GRANTS - SUBMITTED:

1R21 1R21NS099580-01 Slavotinek (PI) 10/01/16-09/30/18
NIH, NINDS total $250,000 yrs 1-2
Mechanisms for Hydrocephalus and Ocular Defects Associated with Sequence Variants in CRB2
This project will determine the mechanism for the hydrocephalus caused by CRB2 mutations.
Role: PI

RESEARCH GRANTS - PAST:

Oxfordshire Health Authority (PI) 1995
Chromosome painting of radiation-induced micronuclei £2900 direct/yr 1

Royal College of Pediatrics (PI) 1996
Child Health Allen and Hanbury Research Awards £2100 direct/yr 1
Chromosome microdeletions in idiopathic mental retardation

Central Manchester NHS Trust (PI) 1997
Chromosomal causes of idiopathic mental retardation £1500 direct/yr 1

Trust Endowment Grant, Central Manchester Healthcare NHS Trust (PI) 1998
The detection of chromosome microdeletions in children with idiopathic £5663 direct/yr 1
learning difficulties using comparative genomic hybridization (CGH)

REAC grant 36248-52409-430000 (PI) 2003-2004
School of Medicine, UCSF $25,000 direct/yr 1
Molecular Genetic Analysis of Fryns syndrome.

Academic Senate Grant, 401/37334/504204 and 436000/37334/504204 (PI) 2004
School of Medicine, UCSF $35,000 /yr 1
Array comparative hybridization in Fryns syndrome

DERC study feasibility award #P30 DK63720 (PI) 05/01/04-01/31/07
Diabetes Center, UCSF. $25,000/yr 1
The role of genetic variations in Bardet-Biedl syndrome genes $50,000/yrs1-2
in common human obesity

PGA grant (Co-Investigator) IUT 6719625, Dr Len Pennachio (PI) 02/01/05-01/31/07
NHLBI, NIH $16,000/yr 1
Comparative Genomic Analysis of CV gene regulation $32,000/yrs1-2

R03 HD049411-01 (PI) 03/15/05-03/14/07
NICHD, NIH $50,000 direct/yr 1
Genetic analysis of congenital diaphragmatic hernia $100,000 direct/yrs1-2

Hellman Family Award for Early Career Faculty (PI) 01/01/05-12/31/07
Hellman Foundation $50,000 direct /yr 1
Genetic Analysis of Congenital Diaphragmatic Hernia

1K08 HD053476-01A1 Slavotinek (PI) 04/1/07-03/31/13
NIH, NICHD $114,437 direct/yr1
Molecular Genetic Analysis of Congenital Diaphragmatic Hernia $578,562 direct/yrs1-5

1R21 EY019999-01 Slavotinek (PI) 08/01/2010-07/31/2012
NIH, NEI total $424,875 direct/yrs1-2
Anophthalmia Spectrum Disorders

A119241 Bird, Lynne (PI) 03/01/2013-02/28/2014

Angelman Syndrome Foundation — total $48,272 direct/yr 1
Levodopa/Carbidopa Treatment of Children with Angelman syndrome

5R01 FD003523-02 Tan, W-H (PI) — 08/01/2013-07/31/2014
Children's Hospital Corp., US Food and Drug Administration — total $29,000 direct/yr1
A Phase II Trial of Levodopa in Angelman Syndrome

Research Allocation Program, UCSF Slavotinek (PI) — 09/01/2012-08/31/2014
Clinical Application of Exome Sequencing to — total $50,000 direct/yr1
Developmental Eye Disorders

1R21 EY022779-01 Slavotinek (PI) — 08/28/12-08/27/14
NIH, NEI — total $234,875 direct/yrs1-2
Gene Discovery in Human Anophthalmia/Microphthalmia

5T32 GM007085-35 Slavotinek (PI) — 01/01/2014-06/30/2015
NIH, NIGMS — total $190,778/yr
Postdoctoral Training in Medical Genetics and Genomics

1U01 HG007437-01 Berg et al. (PI) — 02/01/2013-7/31/2016 0.6 calendar
NIH/NHGRI — $5,475,219 (total direct)
Subcontract to UCSF $18,510 (total)
Clinically Relevant Variants Resource

PEER REVIEWED PUBLICATIONS (from a total of >160 peer reviewed publications):

1. **Slavotinek A**, Thomson A, Eynaud P, Perry P, Steel CM, and Eden OB. The frequency of micronuclei in bone marrow erythroblasts during the treatment of childhood acute lymphoblastic leukaemia. Mutat Res. 303: 11-8, 1993.

2. **Slavotinek A**, Perry PE, and Sumner AT. Micronuclei in neonatal lymphocytes treated with the topoisomerase II inhibitors amsacrine and etoposide. Mutat Res. 319: 215-22, 1993.

3. **Slavotinek A**, McMillan TJ, and Steel CM. A comparison of micronucleus frequency and radiation survival in lymphoblastoid cell lines. Mutagenesis. 8: 569-75, 1993.

4. **Slavotinek A**, McMillan TJ, and Steel CM. The measurement of radiation survival using the MTT assay. Eur J Cancer. 30A: 1376-82, 1994.

5. **Slavotinek A**, Miller E, Taylor GM, Nüsse M, and van Heyningen V. Micronucleus frequencies in lymphoblastoid cell lines measured with the cytokinesis-block technique and flow cytometry. Mutagenesis. 10: 439-45, 1995.

6. Cummings J, Sumner AT, **Slavotinek A**, Meikle I, Macpherson JS, and Smyth JF. Cytogenetic evaluation of the mechanism of cell death induced by the novel anthracenyl-amino acid topoisomerase II catalytic inhibitor NU/ICRF 500. Mutat Res. 344: 55-62, 1995.

7. **Slavotinek A**, Pike M, Mills K, and Hurst JA. Cataracts, motor syndrome disorder, short stature, learning difficulties, and skeletal abnormalities - a new syndrome? Am J Med Genet. 62: 42-7, 1996.

8. **Slavotinek A**, Hellen E, Gould S, Coghill SB, Huson SM, and Hurst JA. Three infants of diabetic mothers with malformations of left-right asymmetry - further evidence for the aetiological role of diabetes in this malformation spectrum. Clin Dysmorphol. 5: 241-7, 1996.

9. **Slavotinek A**, Sauer-Nehls S, Braselmann H, Taylor GM, and Nüsse M. Chromosome painting of radiation-induced micronuclei. Int J Radiat Biol. 70: 393-401, 1996.

10. Müller W-U, Nüsse M, Miller BM, **Slavotinek A**, Viaggi S, and Streffer C. Micronuclei: a biological indicator of radiation damage. Mutat Res. 366: 163-9, 1996.

11**. Slavotinek A**, Huson SM and Fitchett M. Interstitial deletion of band 3q25. J Med Genet. 34: 430-2, 1997.

12. **Slavotinek A**, Clayton-Smith J, and Super M. Familial patent ductus arteriosus - a further case of CHAR syndrome. Am J Med Genet. 71: 229-32, 1997.

13. **Slavotinek A,** and Kingston H. Interstitial deletion of chromosome bands 4q12→q13.1: case report and review of proximal 4q deletions. J Med Genet. 34: 862-5, 1997.

14. **Slavotinek A**, Maher E, Gregory P, Rowlandson P, and Huson SM. The phenotypic effects of chromosome rearrangement involving bands 7q21.3 and 22q13.3. J Med Genet. 34: 857-61, 1997.

15. **Slavotinek A**, Stahlschmidt J, and Moore L. Transverse limb defects, holoprosencephaly and neuronal heterotopia - a new syndrome ? Clin Dysmorphol. 6: 365-70, 1997.

16. **Slavotinek A**, Gaunt L, and Donnai D. Paternally derived duplications of 11p15.5 and Beckwith-Wiedemann syndrome. J Med Genet. 34: 819-26, 1997.

17. **Slavotinek A**, and Donnai D. A boy with severe manifestations of type 1A brachydactyly. Clin Dysmorphol. 7: 21-7, 1998.

18. **Slavotinek A**, Hurst JA, Dunger D, and Wilkie AOM. ACTH receptor mutation in a girl with familial glucocorticoid deficiency. Clin Genet. 53: 57-62, 1998.

19. Powell J, Wojnarowska F, Dawber R, **Slavotinek A**, and Huson S. Childhood vulval lichen sclerosus in a patient with ectodermal dysplasia and uncombable hair. Pediatr Dermatol, 15: 446-9. 1998.

20. **Slavotinek A**, Rosenberg M, Knight S, Gaunt L, Fergusson W, Killoran C, Clayton-Smith J, Kingston H, Campbell RHA, Flint J, Donnai D, and Biesecker L. Screening for submicroscopic chromosome rearrangements in children with idiopathic mental retardation using microsatellite markers for the chromosome telomeres. J Med Genet. 36: 405-11, 1999.

21. **Slavotinek A**, Schwarz C, Getty JF, Stecko O, Goodman F, and Kingston H. Two cases with interstitial deletions of chromosome 2, and sex reversal in one. Am J Med Genet. 86: 75-81, 1999.

22. **Slavotinek A**, and Clayton-Smith J. Brachydactyly type B - case report and further evidence for clinical heterogeneity. Clin Dysmorphol. 8: 165-71, 1999.

23. **Slavotinek A**, Shaffer LG, and Shapiro SK. Monosomy 1p36. Review. J Med Genet. 36: 657-63, 1999.

24. **Slavotinek A**, Clayton-Smith J, and Kerr B. Unilateral tibial aplasia, pre-axial polysyndactyly, vertebral anomalies and imperforate anus. Clin Dysmorphol. 8: 223-5, 1999.

25. **Slavotinek A**, and Clayton-Smith J. A girl with ectodermal dysplasia, choanal atresia and polysyndactyly. Clin Dysmorphol. 8: 287-9, 1999.

26. Stone D*, **Slavotinek A***, Bouffard GG, Banerjee-Basu S, Baxevanis AD, Barr M, and Biesecker LG. Mutations in a putative chaperonin cause the McKusick-Kaufman syndrome. Nat Genet. 25: 79-82, 2000. * These authors contributed equally to this work.

27. **Slavotinek A**, Stone, EM, Heckinlively, JR, Green, JS, Heon, E, Musarella, MA,. Parfrey, PS, Sheffield, VC and Biesecker, LG. *Mutations in *MKKS* cause Bardet-Biedl syndrome. Nat Genet. 26: 15-6, 2000.

28. **Slavotinek A**, Kingston H. Punctate calcification of the epiphyses, visceral malformations and craniofacial dysmorphism in a female baby. J Med Genet. 37: 796-8, 2000.

29. **Slavotinek A**, Chen X-N, Jackson A, Gaunt L, Campbell A, Clayton-Smith J, and Korenberg J. Tetrasomy 21 in a male infant. J Med Genet. 37: E10, 2000.

30. **Slavotinek A,** Vacha SJ, Peters KF, and Biesecker LG. Sudden death caused by pulmonary thromboembolism in Proteus syndrome. Clin Genet. 58: 386-9, 2000.

31. **Slavotinek A**, and Biesecker LG. Phenotypic overlap of McKusick-Kaufman syndrome with Bardet-Biedl syndrome - a literature review. Am J Med Genet. 95: 208-15, 2000.

32. **Slavotinek A**, and Biesecker LG. Unfolding the role of chaperonins in human disease. Review. Trends Genet. 17: 528-35, 2001.

33. **Slavotinek A**, Dubovsky, E, Dietz, HC, and Lacbawan F. Report of a child with aortic aneurysm, orofacial clefting and features of Marfan syndrome – possible PHACES syndrome. Am J Med Genet. 110: 283-8, 2002.

34. **Slavotinek AM**, Searby, C, Al-Gazali, L, Hennekam, RCM, Schrander-Stumpel, C, Orcana-Losa, M, Pardo-Reoyo, S, Kumar, D, Cantani, A, Capellini, Q, Neri, G, Zackai, E, and Biesecker, LG. Mutation analysis of the *MKKS* gene in McKusick-Kaufman syndrome and selected Bardet-Biedl syndrome patients. Hum Genet. 110; 561-7, 2002.

35. **Slavotinek AM**, Tifft C. Fraser syndrome and cryptophthalmos – review of the diagnostic criteria and evidence for phenotypic modules in complex malformation syndromes. J Med Genet. 39: 623-33, 2002.

36. **Slavotinek A**, Poyser L, Wallace A, Martin F, Gaunt L, and Kingston H. Two unusual cases of trisomy 18 mosaicism with molecular marker studies. Am J Med Genet. 117A: 282-8, 2003.

37. **Slavotinek AM**, Collins T, and Muenke M. Non-syndromic hemihyperplasia in a male and his mother. Am J Med Genet. 121A: 47-51, 2003.

38. **Slavotinek AM**, and Lacbawan F. Large interstitial deletion of chromosome 13q and severe short stature: clinical report and review of the literature. Clin Dysmorphol. 12: 195-6, 2003.

39. **Slavotinek AM**, Boles-Koffler D, and Lacbawan F. A female infant with an inverted duplication of chromosome 2q33 to 2q37.3. Clin Dysmorphol. 12:251-6, 2003.

40. **Slavotinek AM**, and Biesecker LG. Genetic modifiers in human development and malformation syndromes, including chaperone proteins. Hum Mol Genet. 12: R45-50, 2003.

41. Kozma C, **Slavotinek A**, and Meck J. Segregation of a t(1;3) translocation in multiple affected family members with both types of adjacent-1 segregants. Am J Med Genet. 124A: 118-128, 2004

42. **Slavotinek A**. Fryns syndrome – a review of the phenotype and diagnostic guidelines. Am J Med Genet. 124A: 427-33, 2004.

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SIGNIFICANT PUBLICATIONS (five since last review):

1. **Slavotinek A**, Kaylor J, Pierce H, Cahr M, DeWard SJ, Schneidman-Duhovny D, Alsadah A, Salem F, Schmajuk G, Mehta L. CRB2 Mutations Produce a Phenotype Resembling Congenital Nephrosis, Finnish type, with Cerebral Ventriculomegaly and Raised Maternal Serum and Amniotic Fluid Alpha-Fetoprotein. Am J Hum Genet. 96: 162-169, 2015

This paper describes the identification of a new syndrome comprising elevated alpha feto-protein, congenital nephrosis, Finnish type, and cerebral ventriculomegaly together with the identification of the causative gene, *CRB2*. I coordinated the clinical findings from three families, initiated the protein studies and wrote the paper.

2. Lamont RE, Tan W-H, Innes AM, Parboosingh JS, Schneidman-Duhovny D, Rajkovic A, Pappas J, Altschwager P, DeWard S, Fulton A, Gray KJ, Krall M, Mehta L, Rodan LH, Saller Jr. DN, Steele D, Stein D, Yatsenko SA, Bernier FP, **Slavotinek, AM**. Expansion of Phenotype and Genotypic Data in *CRB2*-Related Syndrome Eur J Hum Genet 24:1436-1444, 2016

This paper expands the phenotype by reporting new cases with *CRB2* mutations and severe hydrocephalus. I coordinated the clinical findings from these six patients and wrote the paper.

3. Ullah E, Saqib MAN, Sajid S, Shah N, Zubair M, Ahmad Khan M, Ahmed I, Ali G, Kumar Dutta A, Danda S, Lao R, Ling-Fung Tang P, Kwok P-Y, Ansar M, **Slavotinek A**. Genetic Analysis of Consanguineous Families Presenting with Congenital Ocular Defects. Exp Eye Research 146:163-171, 2016

This paper describes the results of Ehsan Ullah' visit as a doctoral student to my laboratory. He used Sanger sequencing and exome sequencing to find causative mutations in five out of eight consanguineous families with eye defects from Pakistan.

4. **Slavotinek A**, Pua H, Hodoglugil U, Abadie J, Shieh J, Van Ziffle J, Kvale M, Lee H, Kwok PY, Risch N, Sabbadini M. Pierpont syndrome associated with the p.Tyr446Cys missense mutation in TBL1XR1. Eur J Med Genet. 2017 Jul 4. pii: S1769-7212(17)30245-8. doi: 10.1016/j.ejmg.2017.07.003.

This paper describes our success using the UCSF bioinformatics pipeline to re-analyze an exome and reach a molecular genetic diagnosis – this is the first publication on a solved exome case by the sequencing group of the Genomics Medicine Initiative at UCSF. I saw the patient and wrote the paper.

5. **Slavotinek A***, Risolino M*, Losa Llabata M, Cho MT, Monaghan KG, Schneidmn Duhovny D, Parisotto S, Herkert JC, Stegmann, APA, Miller K, Shur N, Chui J, Mueller E, DeBosse S, Szot, JO, Chapman G, Pachter NS, Winlaw DS, Mendelsohn BA, Dalton J, Sarafoglou K, Karachunski PI, Lewis JM, Pedro H, Dunwoodie S, Selleri L+, Shieh J+. *De novo*, deleterious sequence variants that alter the transcriptional activity of the homeoprotein PBX1 are associated with intellectual disability and pleiotropic developmental defects. Hum Mol Genet 2017 Sep 22. doi: 10.1093/hmg/ddx363. * = The first two authors should be regarded as joint First Authors + = The last two authors should be regarded as joint Senior Authors. Hum Mol Genet 26:4849-4860, 2017

This paper is the first to describe *PBX1* variants that cause a broad range of organ malformations. I collated the details from eight patients and co-wrote the paper in association with the other first and last authors.

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41. Chao R, Agarwal P, West B, Bove K, **Slavotinek AM**. Anophthalmia, diaphragmatic defects and vitamin A metabolism. 29th Annual David W. Smith workshop on Malformations and Morphogenesis, Lac Tremblant, August 2008.

42. Hogue J, **Slavotinek AM**. Chromosome 17q21.31 deletion syndrome: A report of two new patients and review of the literature. Western Society for Pediatric Research, Carmel. January 2009. Presented by Dr Hogue.

43. Hogue J, **Slavotinek AM**. Escobar Syndrome: A mild presentation associated with ileal atresia. Genetics Exchange, UC Davis, May 2009. Presented by Dr Hogue.

44. Shankar S, **Slavotinek AM**. RHYNS syndrome. Genetics Exchange, UC Davis, May 2009. Presented by Dr Shankar.

45. JimenezLopez N, Gerber S, Popovici V, Mirza S, Coppen K, Ta L, Trueb B, **Slavotinek AM**. *Fgfrl1* null mice have reduced expression of *Tpm3* and other sarcomere genes in the diaphragm. 30th Annual David W. Smith workshop on Malformations and Morphogenesis, Philadelphia, August 2009.

46. Hogue J, Hudgins L, Chen E, Gripp K, Bird L, **Slavotinek AM**. Branchio-oto-renal syndrome: A review of the phenotypic spectrum based on 18 patients. 30th Annual David W. Smith workshop on Malformations and Morphogenesis, Philadelphia, August 2009. Presented by Dr Hogue.

47. Vats D, Alazami A, **Slavotinek AM**. A new family with camptodactyly, arthropathy, coxa vara, pericarditis (CACP) syndrome and a predominantly rheumatological presentation. Western Society for Pediatric Research, Carmel, CA, January 2010.

48. Bermudez-Wagner K, **Slavotinek AM**. The importance of behavioral and attention disorders in individuals with 8p23.1 deletions. Western Society for Pediatric Research, Carmel, CA, January 2010. Presented by Dr Bermudez-Wagner.

49. Hogue J, **Slavotinek AM**, Wat M, Danhaive O, Scott D, Rauen K. Chromosome 16p11.2 deletion: Expansion of the phenotype to include diaphragmatic hernia. Western Society for Pediatric Research, Carmel, CA, January 2010. Presented by Dr Hogue.

50. Bermudez-Wagner K, **Slavotinek AM**. The association of developmental delay and hypotonia with microdeletions of chromosome 17q12. Western Society for Pediatric Research, Carmel,CA, January 2010. Presented by Dr Bermudez-Wagner.

51. **Slavotinek AM**, Vats D. GAPO Syndrome – a new case with atypical features including thumb hypoplasia. Genetics Exchange, Stanford University, May 2010.

52. Knoth A, Nash K, Cox V, **Slavotinek AM**. Expanding the 3q29 microdeletion phenotype: dysfluency in the proband. Genetics Exchange, Stanford University, May 2010. Presented by Ms Knoth.

53. **Slavotinek AM**, Madireddy L, Chao R, Musone S, Wheatley A, Kwok P-Y, Marles S, Baranzini S, Chudley AE, Zenker M. A new family with Manitoba-Oculo-Tricho-Anal (MOTA) and mutations in *FREM1*. 31st Annual David Smith Workshop on Malformations and Morphogenesis, Union, WA, August 2010.

54. Homozygosity for a FBN1 missense mutation in an adult patient with atypical features of Marfan syndrome. Hogue J, Strecker M, Cox V, **Slavotinek AM**. 31st Annual David Smith Workshop on Malformations and Morphogenesis, Union, WA, August 2010. Presented by Dr Hogue.

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56. **Slavotinek A**, Li J, Bardakjian T, Tonkin L, Schneider A, Sherr E, LopezJimenez N. Targeted 'Next Generation' Sequencing in Anophthalmia Patients reveals an *OTX2* Mutation. Oral presentation, 60th American Society of Human Genetics Annual Meeting, Washington DC, November 2010.

57. Vats D, Jelin A, Campbell K, Moore S, **Slavotinek A**. A case report of Walker-Warburg syndrome and review of the literature. Genetics Exchange, UCSF, May 2011. Presented by Dr Vats.

58. Sanford E, **Slavotinek A**. CHAOS review. Genetics Exchange, UCSF, May 2011. Presented by Ms Sanford.

59. Jeng LJB, Bermudez-Wagner K, **Slavotinek AM**, Sanford EF. Congenital Diaphragmatic Hernia in a Patient with a Partial Deletion of Neurexin-1. Signature Genetics Annual conference, June 2011. Presented by Dr Jeng.

60. Bijlmsa EK, Schanze D, Breuning MH, Zenker M, **Slavotinek AM**. Three patients with eye abnormalities: MOTA syndrome and Fraser syndrome. Oral presentation at the 22nd European Meeting on Dysmorphology, Strasbourg, September 2011. Presented by Dr Bijlsma.

61. **Slavotinek A**, Chao R, Abouzeid H, Bardakjian T, Schneider A, Sherr EH, Youssef M, Lemke G, Schorderet DF. *VAX1* mutation associated with microphthalmia, corpus callosum agenesis and orofacial clefting – the first description of a *VAX1* phenotype in humans. 32nd Annual David Smith Workshop on Malformations and Morphogenesis, Lake Arrowhead, September 2011.

62. Champion KJ, Pickler L, Bermudez Wagner K, **Slavotinek A**, Champaigne NL, Curtis Rogers R, Yim D, Jones JR, Tsai AC. A distinctive form of Noonan syndrome: A clinical description of the *SHOC2* phenotype. 32nd Annual David Smith Workshop on Malformations and Morphogenesis, Lake Arrowhead, September 2011. Presented by Dr Champion.

63. **Slavotinek A**, Chao R, Yahyavi M, Abouzeid H, Bardakjian T, Schneider A, Sherr EH, Youssef M, Lemke G, Schorderet DF. *VAX1* mutation associated with microphthalmia, corpus callosum agenesis and orofacial clefting – the first description of a *VAX1* phenotype in humans. 61st American Society of Human Genetics Annual Meeting, Montreal, Canada, October 2011.

64. Krishnamurthi S, Miyamoto J, **Slavotinek A**, Shieh JTC. 17q12 Deletion and Risk for Multiorgan System Disease. Western Society for Pediatric Research, Carmel, 2012. Presented by Dr Krishnamurthi.

65. Li B, Hogue J, **Slavotinek A**. A Patient with Atelosteogenesis type I Caused by a Novel Missense Mutation in *FLNB* and Tracheal Hypoplasia. Western Society for Pediatric Research, Carmel, 2012. Presented by Dr Li.

66. Li B, **Slavotinek A**. Two siblings with Adducted Thumbs-Clubfoot Syndrome (ATCS), an under-diagnosed condition with distal arthrogryposis. Genetics Exchange, Kaiser Oakland, May 2012. Presented by Dr Li.

67. Li B, **Slavotinek A**. Two siblings with Adducted Thumbs-Clubfoot Syndrome (ATCS), a rare cause of distal arthrogryposis. Western Society for Pediatric Research, Carmel, 2013. Presented by Dr Li.

68. Chandratillake G, Garcia S, Tirch J, Harris J, Patwardhan A, Chervitz S, Mendelsohn B, West J , Chen R, **Slavotinek A**. Revised Diagnosis Through Exome Sequencing of an Infant With Congenital Cataracts Expands Phenotypic Spectrum of *COL4A1-A*ssociated Disorders. National Society of Genetic Counselors Annual Meeting, New Orleans, LO, Sept 2014. Presented by Dr Chandratillake.

69. Gonzaga-Jauregui C, Harel T, Gambin T, Kousi M, Griffin LB, Bainbridge MN, Lawson KS, Pehlivan D, Okamoto Y, Withers M, Mancias P, **Slavotinek A**, Reitnauer PJ, Shy M, Crawford TO, Koenig M, Goksungur MT, Jhangiani S, Willer J, Flores BN, Wiszniewski W, Antonellis A, Katsanis N, Muzny DM, Boerwinkle E, Gibbs RA, Lupski JR. Exome sequencing unveils novel

disease-causing variation in Charcot-Marie-Tooth disease and suggests genetic burden contributes to phenotypic variability and complex neuropathy. American Society of Human Genetics 64th Annual Meeting, San Diego, Oct 2014. Presented by Dr Gonzaga-Jauregui.

70. Brin MF, Kirby R, **Slavotinek A**, Miller-Messana M, Parker L, Yushmanova I, Yang H. Pregnancy outcomes following exposure to onabotulinumtoxinA. IBRCC'14. Presented by Dr Brin.

71. Alsadah A, **Slavotinek A**, Kaylor J, Pierce H, Cahr M, DeWard SJ, Schneidman-Duhovny D, Salem F, Schmajuk G, Mehta L. CRB2 Mutations Produce a Phenotype Resembling Congenital Nephrosis, Finnish type, with Cerebral Ventriculomegaly and Raised Maternal Serum and Amniotic Fluid Alpha-Fetoprotein. American College of Medical Genetics and Genomics Annual meeting, Mar 2015. Presented by Dr. Alsadah.

72. **Slavotinek A**, Gray K, Rodan L, Chaudhari B, Rajkovic A, Steele D, Vanderwall R, Tan W-H Congenital nephrosis, cerebral ventriculomegaly and heterotopias – expanding the phenotype associated with *CRB2* mutations. 34th Annual David W. Smith Workshop on Malformations/Morphogenesis, St. Michaels, MD.

73. Ruzhnikov MRZ, Alsadah A, Mendelsohn BA, Alhariri A, Cilio MR, Wu YW, Marco EJ, Hsiao E, Sullivan J, Shieh J, **Slavotinek A**, Sherr EH. Diagnostic Outcomes and Relative Cost of Clinical Whole Exome Sequencing. Western Society for Pediatric Research, Carmel, Jan 2016. Presented by Dr Ruzhnikov.

74. Arunrut T, Sabbadini M, Jain M, Scaglia F, **Slavotinek A**. Ehlers-Danlos syndrome, progeroid type, caused by a novel mutation, p.(Cys324Ser) in *B4GALT7* in a child with joint laxity, growth retardation, dysmorphic facial features and novel eye findings including bilateral colobomas. Western Society for Pediatric Research, Carmel, Jan 2016. Presented by Dr Arunrut.

75. Lamont RE, **Slavotinek AM**, Tan W-H, Innes AM, Parboosingh JS, Schneidman-Duhovny D, Rajkovic A, Pappas J, Altschwager P, DeWard S, Fulton A, Gray KJ, Krall M, Mehta L, Rodan LH, Saller Jr. DN, Steele D, Stein D, Yatsenko SA, Bernier FP. Expansion of phenotype and genotypic data in CRB2-related syndrome. American College of Medical Genetics and Genomics Annual Meeting, Mar 2016, Tampa FL.

76. Juusola J, Copenheaver D, Retterer K, Marth A, Butler E, Deardorff M, Krantz I, Zackai E, Medne L, Bedoukian E, Wilkins, A,Lehman A, McKinnon M, Van Allen M, Clarke L, Van Karnebeek C, Niyazov D, Graham J, Kucuk Z, Nalepa G, Willing M, Bernat J, Vats D, Massingham L, Sorrentino S, Stoler J, Chung W, Hamosh A, Slavotinek A, Richard G, Bale S. WES in a week: Rapid exome testing for critical care. American College of Medical Genetics and Genomics Annual Meeting, Mar 2016, Tampa FL. Presented by Dr Juusola.

77. Tan WH, Bird LM, Sadhwani A, Barbieri-Welge RL, Skinner, SA, Horowitz LT, Bacino CA, Noll LM, Fu C, Hundley RJ, Wink LK, Erickson CA, Barnes GN, Slavotinek A, Jeremy R, Rotenberg A, Kothare SV, Olson HE, Poduri A, Nespeca MP, Chu HC, Willen JM. Levodopa in Angelman Syndrome – Results of a Multicenter Randomized Controlled Trial. 35th Annual David W. Smith Workshop on Malformations/Morphogenesis, Aug 2016, Lake Arrowhead, CA. Presented by

Dr. Tan.

78. **Slavotinek A**, Lessel D, Innes M, Krall M, von Hove J, Baillat D, Wagner E, Mancini G. Biallelic sequence variants in *INTS1* in patients with developmental delays, cataracts and dysmorphic features. 35th Annual David W. Smith Workshop on Malformations/Morphogenesis, Aug 2016, Lake Arrowhead, CA.

79. **Slavotinek A**, Lessel D, Innes M, Krall M, von Hove J, Baillat D, Wagner E, Mancini G. Biallelic sequence variants in *INTS1* in patients with developmental delays, cataracts and craniofacial anomalies. American Society of Human Genetics 65th Annual Meeting, Vancouver, Canada.

80. Kievit A, Tessadori F, Douben J, Jordens I, Maurice M, Hoogeboom A, Hennekam R, Nampoothiri S, Kayseri H, Castori M, Whiteford M, Motter C, Melver C, Massink M, van Gassen K, Savelberg S, Duran K, Bakkers J, Gil-da Silva Lopes V, **Slavotinek A**, Martinez-Glez V, de Klein A, van Haaften G, van den Boogaard M-J. Blepharo-Cheilo-Dontic syndrome patients show mutations in genes of the cadherin-catenin complex. American Society of Human Genetics 65th Annual Meeting, Vancouver, Canada.

81. **Slavotinek A**, Risolino M, Losa Llabata M, Cho MT, Monaghan KG, Schneidmn Duhovny D, Parisotto S, Herkert JC, Stegmann, APA, Miller K, Shur N, Chui J, Mueller E, DeBosse Z, Mendelsohn B, Pedro H, Selleri L, Shieh J. *De novo*, deleterious sequence variants in *PBX1* are associated with intellectual disability and ear, branchial arch, renal, cardiac and diaphragmatic abnormalities. American College of Medical Genetics Annual Clinical Genetics Meeting, Phoenix, AZ.

Poster presentations:

1. **Slavotinek A**, McMillan TJ, Steel CM. The measurement of radiation survival using the MTT assay. 23rd Annual Meeting of European Environmental Mutagen Society, Barcelona, Sept 1993.

2. **Slavotinek A**, Fantes J, Miller E, Thomson EJ. Micronucleus formation in human-mouse somatic cell hybrids - a possible mechanism for the loss of segregant chromosomes. 23rd Annual Meeting of European Environmental Mutagen Society, Barcelona, Spain Sept 1993.

3. MacPherson JS, Cummings J, Sumner AT, **Slavotinek A**, Meikle I, Miller E, Smyth JF. Studies on the mechanism of cell kill by anthracenyl-peptides - novel inhibitors of topoisomerase I and II. BACR/ACP meeting, Birmingham, U.K. Mar 1994. Published in: Br J Cancer 1994;69:SXXI 42.

4. **Slavotinek A**, Miller E, Taylor GM, Nüsse M, van Heyningen V. Spontaneous and radiation induced micronucleus frequencies in lymphoblastoid cell lines measured by the cytokinesis block technique and flow cytometry. UKEMS Annual Meeting, University of Hertford, U.K. Jul 1994.

5. **Slavotinek A**, Gregory P, Maher E, Rowlandson P, Huson SM. Further evidence for an ectrodactyly locus on 7q. 27th Annual Meeting of the European Society of Human Genetics, Berlin, Germany, May 1995.

6. **Slavotinek A**, Clayton-Smith J, Super M. Familial patent ductus arteriosus - a further case of CHAR syndrome. British Human Genetics Conference, York, U.K. Sept 1996. Published in: J Med Genet 1996;33:S29.

7. Martin F, **Slavotinek A**, Kingston H. Two cases of unusual trisomy 18 mosaicism. British Human Genetics Conference, York, U.K. Sept 1996. Published in: J Med Genet 1996;33:S18.

8. **Slavotinek A**, Knight SJL, Tassabehji M, Clayton-Smith J, Kingston H, Gaunt L, Donnai D. Screening for subtelomeric chromosome deletions in children with idiopathic mental retardation. British Human Genetics Conference, York, U.K. Sept 1997. Published in: J Med Genet 1997;34:S72.

9. **Slavotinek A**, Schwarz C, Getty JF, Fennell SJ, Kingston H. Interstitial deletions of chromosome 2q24-2q31 and chromosome 2q31-2q33. British Human Genetics Conference, York, U.K. Sept 1997; Published in: J Med Genet 1997;34:S43.

10. **Slavotinek A**, Jackson A, Gaunt L, Donnai D. Tetrasomy 21 in a five month old male. The American Society of Human Genetics 47th Annual meeting, Baltimore, MD, Oct 1997. Published in: Am J Hum Genet 1997;61:A140.

11. **Slavotinek A**, Rosenberg M, Knight S, Fergusson W, Gaunt L, Clayton-Smith J, Kingston H, Flint J, Donnai D, Biesecker L. The detection of submicroscopic chromosome rearrangements in children with idiopathic mental retardation and physical differences. 30th Annual Meeting of the European Society of Human Genetics, Lisbon, Portugal. May 1998.

12. **Slavotinek A**, Clayton-Smith J, Donnai D. Brachydactyly Type B - further evidence for marked variability in clinical presentation. British Society for Human Genetics Conference, York, U.K. Sept 1998. Published in: J Med Genet 1998;35:S65.

13. **Slavotinek A**, Gaunt L, Donnai D, Clayton-Smith J. 1p deletion syndrome - report of a case and review. British Society for Human Genetics Conference, York, U.K. Sept 1998. Published in: J Med Genet 1998;35:S79.

14. **Slavotinek A**, Gaunt L, Fergusson W, Turner H, Clayton-Smith J. Cryptic chromosome translocation between chromosomes 5q and 7q, holoprosencephaly and congenital cardiac disease. Second European Cytogenetic Conference, Vienna, Austria, July 1999. Cytogenet Cell Genet 1999;85:165.

15. **Slavotinek A**, Lacbawan F. A girl with a large, proximal interstitial deletion of chromosome 13q. American College of Medical Genetics Annual Meeting, Miami, FL, Mar 2001.

16. **Slavotinek A**, Elizabeth Dubovsky, Hal Dietz, Felictas Lacbawan. PHACES syndrome – report of a patient with aortic dissection and review of previously reported cases. 22th Annual David W. Smith workshop on Malformations and Morphogenesis, Lake Arrowhead, Sept 2001.

17. **Slavotinek A**, Tifft C. Fraser syndrome and cryptophthalmos – review of the phenotypic manifestations and diagnostic criteria. American College of Medical Genetics Annual Meeting, New Orleans, Mar 2002.

18. Khozma C, **Slavotinek AM**, Meck J. Segregation of a t(1;3) translocation resulting in different recombinant chromosomes in multiple family members. European Society of Human Genetics Annual Meeting, Strasbourg, May 2002.

19. Lee JS, Fridrich K, Reichenberger E, Tartaglia M, Gelb BD, Sachs S, Stratakis C, Muenke M, Collins MT, Robey PG, **Slavotinek A**. Phenotypic and genotypic characterization of Noonan-like/multiple giant cell lesion syndrome. American Association of Oral and Maxillofacial Surgeons Annual Meeting, Chicago, Oct 2002.

20. **Slavotinek, AM**. Phenotypic diversity in human malformation syndromes – are modifier genes important? 52nd American Society of Human Genetics Annual Meeting, Baltimore, MD, Oct 2002.

21. Tanaka J, Winder A, Frieden I, Vargervik K, **Slavotinek A**. ADULT (Acro-Dermato-Ungual-Lacrimal-Tooth) Syndrome. American College of Medical Genetics Annual meeting, San Diego, CA, Mar 2003.

22. **Slavotinek AM**. Molecular genetic analysis of Fryns syndrome. American College of Medical Genetics Annual meeting, San Diego, CA, Mar 2003.

23. **Slavotinek, AM**. Fryns syndrome: Five new cases and a review of the diagnostic criteria. 24th Annual David W. Smith workshop on Malformations and Morphogenesis, Vancouver, Canada Aug 2003.

24. Lin AE, **Slavotinek AM**. Cardiovascular malformations in Fryns syndrome: Utility of a mechanistic classification. 25th Annual David W. Smith workshop on Malformations and Morphogenesis, Snowbird, UT Aug 2004.

25. Greer Z, Mullaney B, Mora-Blanco L, **Slavotinek A**, Ashrafi K. WAR meeting, Santa Barbara, CA, Aug 2004.

26. **Slavotinek AM,** dela Cruz M, Lee SS, Davis R, Shrit A, Rhim J, Carlson EJ, Albertson D, Pinkel D. A new microdeletion syndrome associated with congenital diaphragmatic hernia at chromosome 15q26. 54th American Society of Human Genetics Annual Meeting, Toronto, Canada Oct 2004.

27. Li C, **Slavotinek A**, van de Kamp J, Marles S, Greenberg C, Chodirker B, Chudley A. Exclusion of Fras1 gene in patients with MOTA syndrome and report of 8 new cases in Manitoba aboriginal and a Dutch patient. 54th American Society of Human Genetics Annual Meeting, Toronto, Canada Oct 2004.

28. Skjei K, Martin M, **Slavotinek AM**. KBG syndrome: case report of identical male twins and delineation of diagnostic criteria. American College of Medical Genetics Annual Meeting, Dallas, TX, Mar 2005.

29. Van Westen LM, Krahn K, Mach A, Bullard S, Bader P, Beck A, Braddock S, Clark R, Cunningham ML, McCarrier J, Miller M, Murray J, Nino M, **Slavotinek A**, Lidral AC. Craniofrontonasal dysplasia syndrome. American Association of Dental Research, Mar 2005.

30. Hsieh E, Yeh R-F, **Slavotinek AM**. Opitz G/BBB Syndrome: A Clinical Retrospective Study of Orofacial Clefting Frequency in Different Ethnic Populations. Department of Pediatrics' Spotlight on Pediatrics Symposium, UCSF, San Francisco, CA Jun 2006.

31. **Slavotinek AM**, Winder A, Vargevik K. Expanded Spectrum of Hemifacial Microsomia with Imperforate Anus is Distinct from Townes-Brocks Syndrome. 27th Annual David W. Smith workshop on Malformations and Morphogenesis, Lake Arrowhead, CA, Aug 2006.

32. Leong J, Oberoi S, **Slavotinek A**, Vargervik K. Phenotypic Features of Non-Syndromic Familial Hypodontia. UCSF Research Day, San Francisco, CA Oct 2006.

33. **Slavotinek AM**, Bogert B, Moshrefi A, Skhiri M, Landin-Malt A, Vaisse C, Ashrafi K. Sequencing of *BBS2*, *BBS4* and *BBS5* genes in non-syndromic obesity patients reveals a small contribution of these genes to the obesity phenotype that is likely to involve a multifactorial model. 56th American Society for Human Genetics Annual Meeting, New Orleans, LO, Oct 2006.

34. Bleyl SB, Moshrefi A, Shaw G, Saitoh Y, Schoenwolf GC, Pennacchio LA, **Slavotinek AM**. Candidate genes for congenital diaphragmatic hernia from animal models: Mutation screening of *FOG2*, *SIX1* and *PDGFRA* in 96 patients reveals rare variants. 56th American Society for Human Genetics Annual Meeting, New Orleans, LO, Oct 2006.

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36. Hsieh EWY, Yeh R-F, Oberoi S, Vargervik K, **Slavotinek AM**. A Clinical Retrospective Study of Orofacial Clefting Frequency in Different Ethnic Populations from the UCSF Craniofacial Clinic Database shows Hispanics have a High Frequency of Additional Anomalies. 56th American Society for Human Genetics Annual Meeting, New Orleans, LO, Oct 2006.

37. Wu E, Vargervik K, **Slavotinek AM**. Subtypes of frontonasal dysplasia are useful in determining prognosis. Medical Student Research Poster Session, UCSF, San Francisco, CA, Jan 2007.

38. **Slavotinek AM**, Moshrefi A, Mendell A, Shaw GM, Pennacchio LA, Bates MD. Novel Sequence Variants in the HLX Gene in Patients with Congenital Diaphragmatic Hernia. 57th American Society for Human Genetics Annual Meeting, San Diego, CA Oct 2007.

39. Chao R Agarwal P, Chen J, Zayed H, Kwok P, **Slavotinek AM**. A novel 2.7 Mb deletion at Chromosome 18q22.1 in a male with R-sided diaphragmatic hernia and unilateral right anophthalmia. Institute of Human Genetics Retreat, UCSF, Nov 2007.

40. Shankar SP, Cotter P, **Slavotinek AM**. A novel microdeletion at 4q28.3 causing microtia and craniofacial anomalies. Institute of Human Genetics Retreat, UCSF, Nov 2007.

41. Hsieh EWY, **Slavotinek AM**. A Clinical and Molecular Study of Opitz G/BBB Syndrome Patients: Identification of a Novel Mutation and Review of the Phenotype-Genotype Data Shows a Correlation between Mutations affecting the PRY Domain and CNS Abnormalities. Institute of Human Genetics Retreat, UCSF, Nov 2007.

42. Shankar SP, Cotter P, **Slavotinek AM**. Partial chromosome 22q duplication resulting in congenital diaphragmatic hernia and multiple congenital anomalies. American College of Medical Genetics Annual Meeting, Phoenix, AZ, Mar 2008.

43. Jenkins L, Chen E, Tezcan K, **Slavotinek AM**. Molecular, clinical and cytogenetic characterization of a newly described microdeletion syndrome at 22q11.2 that involves the loss of the BCR gene. American Cytogenetics Conference, 2008.

44. Hogue J, Stephan M, Uribe P, Simper N, Arunda K, Stevens T, Puntel R, **Slavotinek AM**, Puntel R. CHARGE syndrome in a newborn infant presenting with complex congenital heart disease and severe hypocalcemia. 29th Annual David W. Smith workshop on Malformations and Morphogenesis, Lac Tremblant, Canada Aug 2008.

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47. **Slavotinek AM**, Crawford H, Perry H, Tao C, FitzGerald C, Oberoi S, Vargervik, Friez M. A Novel *FGFR2* Deletion in Beare-Stevenson Syndrome. 58th American Society of Human Genetics Annual Meeting, Philadelphia, PA, Nov 2008.

48. LopezJimenez N, Gerber S, **Slavotinek AM**, Trueb B. *Fgfrl1* null mice have Reduced Expression of *Tpm3* And other sarcomere genes in the diaphragm. 59th American Society of Human Genetics Annual Meeting, Honolulu, HI, Oct 2009.

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development of the ventral eye. 59th American Society of Human Genetics Annual Meeting, Honolulu, HI, Oct 2009.

51. Vats D, Alazami A, **Slavotinek AM**. A new family with camptodactyly, arthropathy, coxa vara, pericarditis (CACP) syndrome and review of the literature. American College of Medical Genetics Annual Meeting, Albuquerque, AZ, Mar 2010.

52. Hogue J, **Slavotinek AM**, Wat M, Danhaive O, Scott D, Rauen K. Chromosome 16p11.2 deletion: Expansion of the phenotype to include diaphragmatic hernia. American College of Medical Genetics Annual Meeting, Albuquerque, AZ, Mar 2010.

53. Bermudez Wagner K, Heon E, Duncan JL, **Slavotinek A**. Bardet-Biedl syndrome: A milder phenotype in a female with a proven BBS1 mutation. 60th American Society of Human Genetics Annual Meeting, Washington DC, Nov 2010.

54. Xu Z, Vats D, Blevins EM, Yang J, Sloper LJ, Willis MJ, **Slavotinek AM**, Black JH, McDonnell NB. Molecular and Clinical Findings in Type VI Ehlers Danlos with Lysyl Hydroxylase Deficiency. 60th Annual Meeting of the American Society of Human Genetics. Washington DC, Nov 2010.

55. Perry H, Klein O, **Slavotinek AM**. Blepharo-Cheilo-Dontic (BCD) Syndrome in a Mother and her Son. American College of Medical Genetics Annual Meeting, Vancouver, Canada, Mar 2011.

56. Sanford E, Bermudez-Wagner K, Rauen K, **Slavotinek AM**. Congenital Diaphragmatic Hernia in a Case of Smith-Magenis Syndrome. American College of Medical Genetics Annual Meeting, Vancouver, Canada Mar 2011.

57. Bermudez-Wagner K, Jeng L, Yu J, **Slavotinek AM**. A female with a marker chromosome characterized as an inverted duplication of proximal chromosome 15 causing tetrasomy and hexasomy for chromosome 15q11.2q13.2 - first description of hexasomy for this chromosome region. American College of Medical Genetics Annual Meeting, Vancouver, Canada Mar 2011.

58. Vats D, **Slavotinek AM**. Presentation of kyphoscoliotic form of Ehlers-Danlos syndrome with severe neonatal hypotonia, marfanoid habitus and joint hypermobility. UCSF Department of Pediatrics Research Day, UCSF, May 2011.

59. Hogue J, Wynshaw-Boris A, **Slavotinek A**. NDH syndrome due to a novel GLIS3 deletion with implications for gene function during development. 32nd Annual David W. Smith workshop on Malformations and Morphogenesis, Lake Arrowhead, CA, Sept 2011.

60. **Slavotinek A**, Chao R, Abouzeid H, Bardakjian T, Schneider A, Sherr EH, Youssef M, Lemke G, Schorderet DF. *VAX1* mutation associated with microphthalmia, corpus callosum agenesis and orofacial clefting – the first description of a *VAX1* phenotype in humans. 12th International Meeting on Human Genome Variation and Complex Genome Analysis, Berkeley, CA, Sept 2011.

61. Li B, Hogue J, **Slavotinek A**. A novel missense mutation in FLNB and tracheal hypoplasia in a patient with Atelosteogenesis type I. American College of Medical Genetics Annual Meeting, Charlotte, NC, Mar 2012.

62. Mehrotra P, Ben Li B, Oberoi S, Cordoro K, **Slavotinek A**. Two Siblings with Focal Facial Dermal Dysplasia Type IV and Intraoral Polyps. American College of Medical Genetics Annual Meeting, Charlotte, NC, Mar 2012.

63.Bermudez Wagner K, Zanko A, **Slavotinek AM**. A recurrent *COL1A2* mutation in a patient with a mild phenotype of osteogenesis imperfect type III. American College of Medical Genetics Annual Meeting, Charlotte, NC, Mar 2012.

64. Vats D, **Slavotinek AM**. Contiguous gene deletion syndrome at chromosome 2p11.2p13 and spastic paraplegia. American College of Medical Genetics Annual Meeting, Charlotte, NC, Mar 2012.

65. Pua HH, Krishnamurthi S, **Slavotinek AM**, Powers M, Jeng, LJB. Novel interstitial 2.6 Mb deletion on 9q21 associated with multiple congenital anomalies. American College of Medical Genetics Annual Meeting, Charlotte, NC, Mar 2012.

66. Van Ziffle JA, Hogue J, Lee C, Shieh JT, **Slavotinek A**, Jeng L. The clinical utility of very small copy number variations detected by microarray analysis that are below established laboratory criteria. American College of Medical Genetics Annual Meeting, Charlotte, NC, Mar 2012.

67. Swarr D, Nathanson J, Liu M, Khalek N, Zackai E, **Slavotinek A**. Novel *FREM1* Mutations Expand the Phenotypic Spectrum Associated with Manitoba-Oculo-Tricho-Anal (MOTA) and Bifid Nose Renal Agenesis (BNAR) Syndromes. 33rd Annual David W. Smith workshop on Malformations and Morphogenesis, Lake Lanier, GA, Aug 2012.

68. Esplin ED, Li B, Cox V, Clark R, Curry C, **Slavotinek A**, Hudgins L. Xp22.31 duplications: Indistinctly benign or inconspicuously pathogenic? 33rd Annual David W. Smith workshop on Malformations and Morphogenesis, Lake Lanier, GA, Aug 2012.

69. Yahyavi M, DePreux AS, Xiao T, Bardakjian T, Schneider A, Baier H, **Slavotinek A**. ALDH1A3 loss of function causes bilateral anophthalmia and hypoplasia of the optic nerve and optic chiasm. 62nd Annual Meeting of the American Society of Human Genetics, San Francisco, CA, Nov 2012.

70. Esplin ED, Li B, Cox V, Clark R, Curry C, **Slavotinek A**, Hudgins L. Xp22.31 duplications: Indistinctly benign or inconspicuously pathogenic? 62nd Annual Meeting of the American Society of Human Genetics, San Francisco, CA, Nov 2012.

71. **Slavotinek AM**, Mehrotra P, Li B, Nazarenko I, Tang PLT, Lao RZ, Chu C, Yahyavi M, Chou C, Marqueling AL, Cordoro K, Frieden I, Morren M-A, Devriendt K, Prescott T, Glaser T, Kwok P-Y, Petkovich M, Desnick RJ. Focal facial dysplasia, type IV, is associated with mutations in CYP26C1. 62nd Annual Meeting of the American Society of Human Genetics, San Francisco, CA, Nov 2012.

72. Singer A, **Slavotinek A**, Leibe H, Josefsberg C, Vinkler C. Variable expressivity of FREM1-related anomalies in a family with novel mutation. 62nd Annual Meeting of the American Society of Human Genetics, San Francisco, CA, Nov 2012.

73. Krishnamurthi S, **Slavotinek AM**. Phylloid Hypomelanosis: A rare Neurocutaneous Syndrome. A case report and a compendium of associated chromosomal abnormalities. American College of Medical Genetics Annual Meeting, Phoenix, AZ, Mar 2013.

74. Sparks TN, **Slavotinek AM**. A Case of Heterotaxy Syndrome in One Twin of a Monochorionic Monoamniotic Pair**.** Presented at Western Society for Pediatric Research, Carmel, CA, Jan 2014.

75. Alhariri A, **Slavotinek A**, Shieh J.T De Novo 1q41 duplication: Cataracts with Severe Ophthalmologic Complications, Pericardial and Diaphragmatic Defects and Gallbladder Agenesis. Presented at Western Society for Pediatric Research, Carmel, CA, Jan 2014.

76. Perry H, Klein O, **Slavotinek A**. A novel *SATB2* mutation linked to cleft palate, severe speech delay and hypotonia. American College of Medical Genetics Annual Meeting, Nashville, TN, Mar 2014.

77. Exome Sequencing in 20 Probands with Developmental Eye Defects Identifies Five Causative Mutations and Demonstrates Genetic Heterogeneity. Garcia S, Chandratillake G, Bardakjian T, Schneider A, Chen R, **Slavotinek AM**. American College of Medical Genetics and Genomics Annual Meeting, Nashville, TN, Mar 2014.

78. Mendelsohn B, Long R, **Slavotinek A**. Wiedemann-Steiner syndrome caused by a *de novo*, partial *MLL* deletion in a 4 year old female with short stature, dysmorphic features, hirsutism and an advanced bone age. American College of Medical Genetics and Genomics Annual Meeting, Nashville, TN, Mar 2014.

79. Choi AL, S. Mandal S, Talbot J, Wu D, Prochazkova M, Perry H, Gil-da-Silva-Lopes VL, Lao R, Wan E, Tang P, Kwok P-Y, Klein O, Zhuan B, **Slavotinek A**. Haploinsufficiency for DLX4 is Associated With Abnormal Craniofacial Development and Upregulated BMP4. American Society of Human Genetics 64th Annual Meeting, San Diego, CA, Oct 2014.

80. Ali MM, Smaoui N, **Slavotinek, AM**. Novel Mutation, p. (Lys1474*), in a Female adds Seizures and Ptosis to Clinical Findings in MED13L Haploinsufficiency Syndrome. American Society of Human Genetics 64th Annual Meeting, San Diego, CA, Oct 2014.

81. Ullah E, Saqib MA, Shah N, Sajid S, Lao R, Wan E, Tang PL, Kwok P-Y, Ansar M, **Slavotinek A**. Mutations in ALDH1A3, FOXE3 and VSX2 cause ocular abnormalities in consanguineous Pakistani families. American Society of Human Genetics 64th Annual Meeting, San Diego, CA, Oct 2014.

82. Qi Z, Jeng L, Slavotinek A, Yu J. Haploid-insufficiency and triploid-insensitivity of the same 6p25.1p24.3 region in a family. American Society of Human Genetics 64th Annual Meeting, San Diego, CA, Oct 2014.

83. Alhariri A, Pronold M, **Slavotinek A**, Shieh J. Constitutional chromothripsis: A novel phenomenon in congenital disorders. American Society of Human Genetics 64th Annual Meeting,

San Diego, CA, Oct 2014.

84. Wu D, Anderson A, Choi A, Schneider A, Shaw G, **Slavotinek AM**. *MAB21L1* is a Candidate Gene for Microphthalmia. American College of Medical Genetics and Genomics Annual meeting, Salt Lake City, UT, Mar 2015.

85. Sabbadini M, Shieh JT, Madou M, Alsadah A, Sherr EH, **Slavotinek AM**. Exome Sequencing and Counseling in a Personalized Genomics Clinic. American College of Medical Genetics and Genomics Annual meeting, Salt Lake City, UT, Mar 2015.

86. Sparks TN, **Slavotinek A**. A Mutation in the SH2B Adaptor Protein 1 Gene (SH2B1) is Associated with Infantile-Onset Type 1 Diabetes and Obesity. American College of Medical Genetics and Genomics Annual meeting, Salt Lake City, UT, Mar 2015.

87. Brin MF, Kirby R, **Slavotinek A**, Miller-Messana M, Parker L, Yushmanova I, Yang H. Pregnancy Outcomes Following Exposure to OnabotulinumtoxinA TOXINS 2015. Presented by Dr Brin.

88. Ullah E, R. Lao R, Tang P, Wan E, Bardakjian T, Kwok P-Y, Schneider A, Ansar M, **Slavotinek A**. Two missense mutations in *SALL4* in a patient with microphthalmia, coloboma and optic nerve hypoplasia. European Society for Human Genetics, Jun 2015.

89. De la Huerta I, Duncan JL, **Slavotinek A**, Moore AT, de Alba Campomanes AG. Phenotypic variation in affected members of a family harboring an NDP gene mutation. International Society Genetic Eye Disease, Halifax Canada, Aug 2015, Presented by Dr. de la Hueta.

90. Wu D, Anderson A, **Slavotinek A**. B-cell CLL/Lymphoma 9-like (Bcl9l) and eye development. American Society of Human Genetics 66th Annual Meeting, Baltimore, MD, Oct 2014.

91. Hunter JE, Biesecker LG, Buchanan AH, Irving SA, Lee K, Martin CL, Milko L, Niehaus A, Nussbaum R, O'Daniel J, Piper MA, Ramos EM, Schully S, Scott AF, **Slavotinek A**, Sobreira N, Strande NT, Weaver M, Webber EM, Williams MS, Berg4 JS, Evans JP, Goddard KAP. ClinGen Actionability Working Group: Clinical Actionability in the context of Secondary Findings in Adults and Application to the ACMG 56. American Society of Human Genetics 66th Annual Meeting, Baltimore, MD, Oct 2014. Presented by Dr, Hunter.

92. Alhariri A, Oza V, Hamilton, K. Cordoro K, Malloy M, **Slavotinek A**. Cerebrotendinous xanthomatosis in an adult with soft tissue masses and progressive neurological decline. American Society of Human Genetics 66th Annual Meeting, Baltimore, MD, Oct 2014. Presented by Dr, Alhairiri.

93. **Slavotinek A**, Gray K, Rodan L, Chaudhari BP, Rajkovic A, Steele D, Vanderwall R, Owens K, Hannibal M, Tan W-H. Congenital nephrosis, cerebral ventriculomegaly and heterotopias – expanding the phenotype associated with CRB2 mutations. American Society of Human Genetics 66th Annual Meeting, Baltimore, MD, Oct 2014.

94. Harel T, Gonzaga-Jauregui C, Gambin T, Kousi M, Griffin LB, Francescatto L, Ozes B, Karaca E, Jhangiani SN, Bainbridge MN, Lawson KS, Pehlivan D, Okamoto Y, Withers M, Mancias P, **Slavotinek A**, Reitnauer PJ, Goksungur MT, Shy M, Willer J, Flores BN, Wisznewski W, Parman Y, Antonellis A, Muzny DN, Katsanis N, Battaloglu E, Boerwinkle E, RGibbs RA, Lupski JR. Exome sequence analysis suggests genetic burden contributes to phenotypic variability and complex neuropathy. American Society of Human Genetics 66th Annual Meeting, Baltimore, MD, Oct 2014. Presented by Dr Harel.

95. Krall M, Mak ACY, Wu D, Criswell L, **Slavotinek A**. Genetic Burden Analysis in Developmental Eye Defects. 16th International Meeting of Human Genome Variation and Complex Genome Analysis, San Francisco, Nov 2015. Presented by Mr Krall.

96. Arunrut T, Sabbadini M Jain M, Scaglia F, **Slavotinek A**. Ehlers-Danlos Syndrome, Progeroid Type, Caused by a Novel Mutation, p.(Cys324Ser) in B4GALT7 in a Child with Joint Laxity, Growth Retardation, Dysmorphic Facial Features and Novel Eye Findings Including Bilateral Colobomas. American College of Medical Genetics and Genomics Annual meeting, Tampa, FL, Mar 2015. Presented by Dr Arunrut.

97. Tan WH, Bird LM, Sadhwani A, Barbieri-Welge RL, Skinner SA, Horowitz LT, Bacino CA, Noll LM, Fu C, Hundley RJ, Wink LK, Erickson CA, Barnes GN, **Slavotinek A**, Jeremy R, Rotenberg A, Kothare SV, Olson HE, Poduri A, Olson HE, Nespeca MP, Chu HC, Willen JM. A Trial of Levodopa in Angelman Syndrome. American College of Medical Genetics and Genomics Annual meeting, Tampa, FL, Mar 2015. Presented by Dr Tan.

98. Kuo DS, Sokol J, **Slavotinek AM**, Beyer EC, Gould DB. Novel GJA8 mutation in transmembrane domain IV associated with hereditary cataract. ARVO, April 2016. Presented by Dr Kuo.

99. Hunter JE, Biesecker LG, Bigler KD, Buchanan A, Irving SA, Jensen B, Lee K, Martin CL, Milko L, Niehaus AD, O'Daniel J, Piper MA, Ramos EM, Schully SD, **Slavotinek A**, Sobreira N, Strande N, Weaver M, Webber EM, Williams MS, Berg JS, Evans JP, Goddard KAB on behalf of the ClinGen Resource. Systematic assessment of clinical actionability of genetic disorders associated with genomic variation by the ClinGen Actionability Working Group: the ACMG 56 and beyond. ClinGen/DECIPHER meeting, 2016. Presented by Dr Hunter.

100. Sabbadini M, Shieh JT, **Slavotinek, AM**. Personalized Genomics Clinics: A model for delivery of genetics care. American Society of Human Genetics 65th Annual Meeting, Vancouver, Canada Presented by Dr Sabbadini.

101. Lee BH, Nazarenko I, Edelmann L, Morice-Picard F, **Slavotinek AM**, Desnick RJ. Molecular Genetics of Focal Facial Dermal Dysplasias Types 3 and 4. American Society of Human Genetics 65th Annual Meeting, Vancouver, Canada. Presented by Dr Lee.

102. Johnston JJ, Stewart FJ, Chapman HM, Chou CM, Sapp JC, Schäffer AA, Sen SK, **Slavotinek A**, Glaser TM, Black, GCM, Biesecker LG. Alterations in the *NAA10* Polyadenylation Site in Two

Families with X-Linked Anophthalmia. American Society of Human Genetics 65th Annual Meeting, Vancouver, Canada. Presented by Dr. Johnston.

103. Abu-ElHaija A, Marco E, **Slavotinek A**. A novel, de novo *FOXP1* mutation in male with developmental delays, macrocephaly. UC Davis Human Genomics Symposium 2016. Presented by Dr Abu-ElHaija.

104. Tan WH, Bird LM, Sadhwani A, Barbieri-Welge RL, Skinner SA, Horowitz LT, Bacino CA, Noll LM, Fu C, Hundley RJ, Wink LK, Erickson CA, Barnes GN, **Slavotinek A**, Jeremy R, Rotenberg A, Kothare SV, Olson HE, Poduri A, Nespeca MP, Chu HC, Willen JM. Levodopa in Angelman Syndrome – Results of a Multicenter Randomized Controlled Trial. Angelman syndrome foundation, 2017. Presented by Dr Tan.

105. Tan WH, Bird LM, Sadhwani A, Barbieri-Welge RL, Skinner SA, Horowitz LT, Bacino CA, Noll LM, Fu C, Hundley RJ, Wink LK, Erickson CA, Barnes GN, **Slavotinek A**, Jeremy R, Rotenberg A, Kothare SV, Olson HE, Poduri A, Nespeca MP, Chu HC, Willen JM, Haas KF, Weeber EJ, Rufo PA. Levodopa (L-dopa) in Angelman Syndrome – Results of a Multicenter Randomized Controlled Trial. Keystone Symposium on Rare and Undiagnosed Diseases: Discovery and Models of Precision Therapy March 2017. Presented by Dr Tan.

106. Abu-El-Haija A, Tenney J, Mendelsohn B, **Slavotinek A**. Neonatal Presentation of Copy Number Variants at 17q12. American College of Medical Genetics Annual Clinical Genetics Meeting, Phoenix, AZ. Presented by Dr Abu-El-Haijja.

107. Krall M, **Slavotinek A**. PTC124 (Ataluren) treatment of nonsense mutations in BMP4. 2017 European Society of Human Genetics Annual Meeting, Copenhagen, Denmark

108. Berger V, **Slavotinek A**. The misdiagnosis of achondroplasia in a neonate with skeletal anomalies, narrow chest, and respiratory distress. International Society for Prenatal Diagnosis, San Diego, July 2017. Presented by Dr Berger.

ACADEMIC LEADERSHIP:

In August 2016, I was appointed as section head of the General Genetics and Genomics section in the Division of Genetics in Pediatrics at UCSF. I have lead the section and held monthly section meetings since this time, with the goals of improving clinical services provided by our division to patients and to the other divisions and departments in the medical center and creating a cohesive unit in which our health care providers can thrive.

SHANNON REGO

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WORK EXPERIENCE

Research Genetic Counselor II
Institute for Human Genetics, University of California San Francisco, San Francisco, CA
November 2017-Present

- Serve as genetic counselor for UCSF's CSER2 NIH grant to perform WES on children with undiagnosed suspected genetic conditions, including
  - Assist in identification of eligible patients
  - Consenting participants
  - Documenting detailed medical and developmental histories and pedigrees
  - Return results to families and facilitating follow-up care
  - Develop survey tools to address study research questions
  - Coordinate with other CSER2 sites to facilitate harmonization of study survey tools

Research Genetic Counselor
Stanford School of Medicine Department of Genetics, Snyder Lab, Stanford, CA
July 2014-November 2017

- Guided participants and families through the process of participating in research involving WGS/WES, including:
  - Consented research participants for WGS/WES
  - Documented detailed medical and developmental histories and pedigrees
  - Returned results to families and facilitated follow up care
- Created and managed lab IRB protocols and ensured compliance to protocols
- Hired and supervised clinical research coordinators
- Served as project manager for research projects in the lab including the NGLY1-Deficiency study
- Performed gene and variant curation from whole-exome and genome sequencing using ACMG guidelines in a range of cases of rare genetic disease ranging from cardiomyopathy to cancer, pediatric syndromes to infertility, as well as in healthy individuals
- Assessed exomes of research participants with elevated glucose for variants associated with or causative of diabetes
- Worked with a team to develop pipelines for gene and variant curation in the context of both disease discovery and "healthy" genome analysis
- Led medical genetic analysis for NASA Twin Study

Contract Genetic Counselor
PWN Health, New York, NY
September 2016-Present

- Provided genetic counseling via telephone and videoconference for patients with personal or family histories of cancer or other indications

EDUCATION

Stanford University—Stanford, CA
Master of Science, Human Genetics and Genetic Counseling, September 2012-May 2014

- Clinical rotations included pediatrics, cancer, prenatal, metabolics, and mixed-clinic

University of Auckland—Auckland, New Zealand
Biomedical Science coursework, July 2010-November 2011

University of Cincinnati—Cincinnati, OH
Master of Arts/Master of Business Administration, September 2006-June 2008

University of Wisconsin—La Crosse, La Crosse, Wisconsin, USA
Bachelor of Arts, English and Music, August 2002-June 2006

CERTIFICATION/LICENSURE

- Board certified by the American Board of Genetic Counseling (2014)
- Licensed genetic counselor in California

TEACHING/TRAINING PROGRAM INVOLVEMENT

- Designed and supervised variant curation rotations for genetic counseling students and post-doctoral students
- Served on the Admissions Committee for the Stanford Genetic Counseling Program
- Visiting Instructor for the Advanced Genetic Counseling Course in the Stanford Genetic Counseling Program
- Visiting Instructor for the Stanford medical students' human genetics course

PUBLICATIONS

- Currently Under Review: **Rego S**, Dagan-Rosenfeld O, Zhou W, Sailani MR, Limcaoco P, Colbert E, Avina M, Wheeler J, Craig C, Salins S, Rost HL, Dunn J, McLaughlin T, Steinmetz LM, Bernstein JA, Snyder MP; High Frequency Actionable Pathogenic Exome Mutations in an Average-Risk Cohort. Under review by Genome Medicine.
- Currently Under Review: **Rego S**, Snyder MP. "Sequencing to determine risk of disease." *Next Generation Sequencing in Medicine*, Cold Springs Harbor Laboratory Press.
- Currently Under Review: Zhou W, Sailani RM, Contrepois K, Zhou Y, Ahadi S, Leopold S, Zhang M, Rao V, Avina M, Mishra T, Lee B, Chen S, Johnson J, Tran DB, Nguyen H, Zhou X, Albright B, Hong BY, Peterson L, Bautista E, Hanson B, Spakowicz D, Chen L, Leopold B, Salins D, Ashland M, **Rego S**, Limcaoco P, Colber E, Allister C, Perelman D, Craig C, Rose S, Rost H, Tse D, McLaughlin T, Sodergren E, Weinstock G, Snyder MP. Complex Host-Microbial Dynamics in Prediabetes Revealed through Longitudinal Multi-Omics Profiling. Under review by Nature.
- Pre-print: Piening B, Zhou W, Contrepois K, Rost H, Gu G, Mishra T, Hanson B, Bautista E, Leopold S, Yeh C, Spakowicz D, Kukurba K, Perelman D, Craig C, Colbert E, Salins D, **Rego S**, Lee S, Zhang C, Wheeler J, Sailani R, Liang L, Abbot C, Gerstein M, Mardinoglu A, Smith U, Pitteri S, Sodergren E, McLaughlin T, Weinstock GM, Snyder MP; Integrative Personal Omics Profiles During Periods of Weight Gain and Loss. Cell Syst.
- Lal R, Bachrach L, Hoffman A, Inlora J, **Rego S**, Snyder MP, Lewis D; A Case Report of Hypoglycemia and Hypogammaglobulinemia: DAVID syndrome in a patient with a novel *NFKB2* mutation. J Clin Endocrinol Metab 2017 jc.2017-00341. doi: 10.1210/jc.2017-00341
- Reza Sailani M, Jahanbani F, Nasiri J, Behnam M, Salehi M, Sedghi M, Hoseinzadeh M, Takahashi S, Zia A, Gruber J, Lynch JL, Lam D, Winkelmann J, Amirkiai S, Pang B, **Rego S**, Mazroui S, Bernstein JA, Snyder MP. Association of AHSG with alopecia and mental retardation (APMR) syndrome. Hum Genet. 2017 Mar;136(3):287-296. doi: 10.1007/s00439-016-1756-5. Epub 2017 Jan 4. PubMed PMID: 28054173.

- **Rego S**, Snyder MP. Deep omics profiling for human health. Japanese Journal of Experimental Medicine (in Japanese). 2017 Jan.
- Li X, Dunn J, Salins D, Zhou G, Zhou W, Schüssler-Fiorenza Rose SM, Perelman D, Colbert E, Runge R, **Rego S**, Sonecha R, Datta S, McLaughlin T, Snyder MP. Digital Health: Tracking Physiomes and Activity Using Wearable Biosensors Reveals Useful Health-Related Information. PLoS Biol. 2017 Jan 12;15(1):e2001402. doi: 10.1371/journal.pbio.2001402. eCollection 2017 Jan. PubMed PMID: 28081144; PubMed Central PMCID: PMC5230763.
- **Rego S**. Newborn screening in the genomics era. J Law Biosci. 2014 Oct 16;1(3):369-377. eCollection 2014 Sep. PubMed PMID: 27774176; PubMed Central PMCID: PMC5033535.

TALKS/PANEL DISCUSSIONS

- Invited Speaker. Personalized Omics Profiling: Predicting Disease Risk in the Precision Medicine Era. Age Management Medicine Group Conference. Tucson, AZ. November 2017.
- Stanford Genetics Grand Rounds. Monogenic Diabetes: an underdiagnosed disease. April 2017
- Tie-Con Panel Discussion. Quantified Self and Personalized Medicine. May 2016.
- Stanford Human Genetics Journal Club. Exonic Transcription Factor Binding Directs Codon Choice and Affects Protein Evolution (Stergachis et al, 2013). February 2014.
- Stanford Genetics Grand Rounds. Genetic testing for autism: what can exomes and genomes add? November 2013.

OTHER PROFESSIONAL ACTIVITES

- Member of the ClinGen Actionability Working Group
- Member of the National Society of Genetic Counselors (NSGC), and the NSGC Personalized Medicine Special Interest Group

REFERENCES

- Available upon request

Kara L Weisiger
Clinical Instructor and Genetic Counselor III

Education

University of California, Berkeley Program in Genetic Counseling, School of Public Health. Master of Science Degree. 1995

University of California, Davis Bachelor of Science in Genetics. 1991

Certification American Board of Genetic Counseling. 1999

Work Experience

1996 to Present UC San Francisco (San Francisco, California) **Genetic Counselor**. Supervisor: Renata Gallagher, MD, PhD.

- Clinical Coordinator, Biochemical Genetics In-patient Service, Division of Medical Genetics
- Case Management and coordination of physicians, dietitians and other genetic counselors in the care of patients both in the inpatient and outpatient setting.
- Coordinator of the MS/MS Newborn screening positive referrals to UCSF.
- Department of Pediatrics Co-Investigator, Biochemical Genetic Research Protocols, Pediatric Clinical Research Center.
- Coordination of clinical trials.
- Advisor and instructor for genetic counseling interns and genetics fellows.
- UCSF Medical Genetics Curriculum Committee member.
- Small group discussion leader UCSF medical school.

1995 to 1996 UC Berkeley (Berkeley, California) **Genetic Counselor**. Supervisor: Brenda Eskenazi, PhD. Working on grant funded research project of Klinefelter syndrome. Contact, screen, interview and disclose result of study (sperm aneuploidy and parent of origin) to 20 or 40 families.

1991 to 1993 Kaiser Permanente (Oakland, California) Spina Bifida Clinic. Assistant to coordinator of clinic. Supervisor: Diane Rainosek, MSN, PNP. Assisted in administration of bimonthly clinic. Reviewed records, aided in preparation of clinic summaries and completed other miscellaneous duties.

1991 to 1992 Kaiser Permanente (Oakland, California) Supervisor: Sam Yang, MD. Assist with grant funded research project to determine whether Ehlers-Danlos IX and Menkes are allelic disorders. Interviewed, explained research being conducted and documented family histories.

Lectures and Teaching

Pediatrics Chief of Service Rounds: Guest speaker on Galactosemia and genetic counseling. 1996.
Guest speaker on Methylmalonic Aciduria. 2000.

Pediatrics 100: Medical Genetics (UC San Francisco): Discussion of Gaucher Disease and presentation of an affected family. 1997-2000

Health and Medical Sciences 298: Introduction to Inborn Errors (UC Berkeley): Course Coordinator and Lecturer, 1997-2001. Lectures on Phenylketonuria, Galactosemia, Maple Syrup Urine Disease, Ornithine Transcarbamylase Deficiency, Fatty Acid Oxidation Disorders, Mitochondrial Disease and Gaucher Disease.

Provide inservice to outside hospital staff regarding Gaucher disease. 1997-2001
Co-organizer and Moderator, Gaucher Patient Advocacy Meetings. 1996-2001

Life Cycle small group discussion leader UCSF medical school. Neurogenetics for 1st year students and Genetics of Common Disease, Ethics and Reproductive Genetics for 2nd year students. 2005-2016.

Bridges UCSF medical school, genetics small group discussion leader in Ground school (inheritance of Genetic Disorders), ABC (Genetics Common Disease), H and I (Genetics and Identity) and H and S (Genetic Testing , and Pharmacogenetics),. 2016-present.

Bridges UCSF medical school, H and S: Impact of Genetic Testing on Individuals, Families and Society. Invited small group session co-creator. 2016

Biology 5600 (CSU) and N294C (UCSF): Advanced Medical Genetics (Bay Area Genetic Counseling Program and UCSF Nurse Practitioner): Course Director and Lecturer, 2009.

Biology 5600 (CSU): Advanced Medical Genetics (Bay Area Genetic Counseling Program and UCSF Genetics Residents and Fellows): Course Director and Lecturer, 2009-current.

UCSF Medical Genetics curriculum planning committee member 2014-present.

Genomics and Precision Medicine elective IDS170.03 UCSF medical school: Co-Course director and lecturer. 2015-present.

Volunteer science and math parent teacher. Ross Valley School District and San Domenico School 2007-present.

Volunteer thesis committee member for genetic counseling students. 1999-present.

Publications

1. Eskenazi, B, Chuu, YJ, Kidd, S, Lowe, X, Aylstock, M, **Weisiger, K**, Moore, D, Wyrobek, AJ. Frequencies of aneuploid sperm (X-Y and 21-21) were elevated in fathers of boys with Klinefelter syndrome when the extra X was of paternal origin. Am J Hum Genet 61: A50, 1997.

2. Chuu, YJ, Lowe, X, Kidd, S, **Weisiger, K**, Moore, D, Eskenazi, B, Wyrobek, AJ. Sperm disomies involving chromosomes X, Y and 21 are highly elevated in a father of four consecutive aneuploid pregnancies. Am J Hum Genet 61: A121, 1997.

3. Eskenazi, B, Chuu YD, Kidd, S, Lowe, X, Aylstock, M, **Weisiger, K**, Moore D, Wyrobek, AJ. Elevated frequencies of aneuploidy sperm (X-Y and 21-21) in fathers of boys with klinefelter when the extra X-chromosome was of paternal origin. Am J Epid 147 (11) Supplement S P44, 1998.

4. Enns, GM, Bennett, MJ, Kerr, DS, **Weisiger, K**, Ohnstad, C, Golabi, M. Respiratory chain complex 1 deficiency presenting with clinical and biochemical features of long-chain 3-hydroxyacyl-CoA dehydrogenase (LCHAD) deficiency. Society for Inherited Metabolic Disorders Abstract Book: P16, 1998.

5. Enns, GM, Barkovich, AJ, Rosenblatt, DS, Frederick, DR, **Weisiger, K**, Ohnstad, C, Packman, S. Progressive neurologic deterioration and head MRI changes in a treated patient with *cblC* methylmalonic acidemia. Society for Inherited Metabolic Disorders Abstract Book: P17, 1998.

6. Lowe, XR, Eskenazi, B, Kidd, S, Alme, AKB, **Weisiger, K**, Aylstock, M, Melson, DO, Wyrobek, AJ. Sperm disomy 21 is associated with sex chromosomal aneuploidies but does not preferentially segregate with the Y chromosome: a study of 38 healthy fertile men. Am J Hum Genet 63: A143, 1998.

7. Enns, GM, Hoppel, CL, De Armond, SJ, Bass, NE, Zanko, A, **Weisiger, K**, Ohnstad, C, Golabi, M, Packman, S. Type I fiber predominance can be caused by isolated mitochondrial respiratory chain complex I deficiency. Am J Hum Genet 63: A266, 1998

8. Enns, GM, Seppala, R, Musci, TJ, **Weisiger, K**, Ferrell, LD, Wenger, DA, Gahl, WA, Packman, S. Clinical and Molecular Studies in Sialuria. The American Pediatric Society and The Society of Pediatric Research Abstract 814, 1999.

9. Kostiner, D, Peters, K, Das, S, Dudlicek, L, Ominsky, S, Barkovich, J, Chamlin, S, Williams, M, Sherr, E, Bass, N, **Weisiger, K**, Packman, S. Menkes Disease Phenotypes in Heterozygotes. Ped Res 45: 139A, 1999.

10. Kostiner, D, **Weisiger, K**, Moffatt, E, Linderman, N, Lamb, R, Lopez, G, Sharp, F, Goodman, S, Tuchman, M, Packman, S. Acute, fatal presentation of ornithine transcarbamylase deficiency in a 62-year-old man. Am J Hum Genet 61: A424, 1999.

11. Eskenazi, B, Lowe, X, Kidd, S, **Weisiger, K**, Moore II, D, Chuu, Y-J, Aylstock, M, Wyrobek, A. Higher frequencies of X-Y aneuploid sperm in fathers of boys with Klinefelter syndrome when the extra X-chromosome was of paternal origin. J Hum Genet 61: A72 , 1999.

12. Enns, GM, Barkovich, AJ, Rosenblatt, DS, Frederick, DR, **Weisiger, K**, Ohnstad, C, Packman, S. Progressive neurologic deterioration and MRI changes in *cblC* methylmalonic acidaemia treated with hydroxocobalamin. J Inher Metab Dis 22(5): 599-607, 1999.

13. Enns, GM, Bennett, MJ, Hoppel, CL, Goodman, SI, **Weisiger, K**, Ohnstad, C, Golabi,M, Packman, S. Mitochondrial respiratory chain complex I deficiency with clinical and biochemical features of long-chain 3-hydroxyacyl-coenzyme A dehydrogenase deficiency. J Peds 136(2): 251-4, 2000.

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Coordination of Clinical Trials

Genzyme, Cerezyme Bone Study: A Multicenter Study of the Efficacy of Cerezyme in Treating Skeletal Disease in Patients with Type I Gaucher Disease. 1997-2001

Mead Johnson: Clinical Experience with Phenyl free 1 in the Dietary Management of Hyperphenylalaninemias including PKU. 1998-2000

Genezyme, Gaucher Center Phase 4 studies. 1996-2001

Treatment of Hyperammonemic Coma in Patient with Urea Cycle Disorders with Intravenous Sodium Phenylacetate/Sodium Benzoate Protocol 2003-2005

Genzyme, Lysosomal disease registry. 1996-present

BioMarin, PKU registry. 2008-present

Actelion, Gaucher Center Miglustat Open Label study: 2008-2011

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EDUCATION

1978 - 1982	Tongji Medical University, China	B.S. (Medicine)	Biomedical Science and Medicine
1982 - 1984	Tongji Medical University, China	Resident	Medical Genetics
1984 - 1987	Tongji Medical University, China	M.Med. (Medicine)	Medical Genetics
1989 - 1992	Eleanor Roosevelt Institute	Postdoctoral Fellow	Molecular Genetics
1993 - 1997	University of Colorado Health Sciences Center	PhD	Biochemistry and Genetics
1997 - 1999	Yale University School of Medicine	Fellow	Clinical Cytogenetics

LICENSES, CERTIFICATION

1999	American Board of Medical Genetics and Genomics Certification (Certificate# 99174)
2006	State of California Clinical Cytogeneticist License (License# DRM45)

PRINCIPAL POSITIONS HELD

1987 - 1988	Tongji Medical University, China	Instructor/Attending	Medical Genetics
1992 - 1997	Eleanor Roosevelt Institute	Research Associate	Genetics
1999 - 2002	University of Colorado School of Medicine	Assistant Professor	Pathology

2002 - 2005	University of Wisconsin	Assistant Professor	Pathology & Laboratory Medicine
2005 - 2010	UCSF	Associate Professor of Clinical Laboratory Medicine	Laboratory Medicine
2010 - present	UCSF	Professor of Clinical Laboratory Medicine	Laboratory Medicine

OTHER POSITIONS HELD CONCURRENTLY

1999 - 2002	Univ. of Colorado Health Sciences Center	Assistant Director, Colorado Genetics Laboratory	Pathology
1999 - 2002	Eleanor Roosevelt Institute	Institute Scientist	Genetics
2000 - 2002	The Children's Hospital (Denver, CO)	Medical Staff	Pathology
2002 - 2005	Wisconsin State Laboratory of Hygiene	Staff Faculty	Disease Prevention
2002 - 2005	University of Wisconsin - Madison	Director, UW Cytogenetics Services	Pathology and Laboratory Medicine
2005 - present	UCSF Medical Center	Director, Cytogenetics Laboratory	Clinical Laboratories
2011 - present	Tongji Medical College, Huazhong University of Science and Technology, Wuhan, China	Guest Professor	Center for Reproductive Medicine

MEMBERSHIPS

1992 - present	Association of Chinese Geneticists in America
1996 - present	American Society of Human Genetics
1996 - present	Human Genome Organization
1999 - present	American College of Medical Genetics and Genomics
2002 - present	International Cytogenetics and Genome Society

PEER REVIEWED PUBLICATIONS

1. YU J, Xia WS, Huang W, Yu BC and Mei X. A study of soybean esterase Soybean Science, 1983;2:104-108.

2. Liu XX, Xu L, Mao T, Yu J and Zhang W. A cytogenetic study of a 45,X/46,XXr mosaicism with Turner's syndrome J. Wuhan Medical College , 1984;13:21-25.

3. Liu XX, Mao T, Zhang W, Yu J and Zhou ZR. The cytogenetic diagnosis and treatment rules for Hermaphroditism J. Wuhan Medicine , 1985;9:207-210.

4. Liu XX, Mao T, Zhang W, Yu J, Xu L, Chen D and Jin ZX. X chromosome abnormalities in primary amenorrhea: Cytogenetic study on 28 cases of primary amenorrhea J. Wuhan Medical College , 1985;14:33-37.

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13. Yu J, Hartz J, Xu Y, Gemmill RM, Korenberg JR, Patterson D and Kao FT. Isolation, characterization, and regional mapping of microclones from a human chromosome 21 microdissection library American Journal of Human Genetics , 1992;51:263-272.

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15. Yu J, Tong S, Qi J, Kao FT. Construction and characterization of region-specific microdissection libraries and single-copy microclones for short arm of human chromosome 2. Somat Cell Mol Genet, 1994;20(4):353-357.

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57. Qi Z, Jeng LJB, Slavotinek A and Yu J. Haploinsufficiency and triploinsensitivity of the same 6p25.1p24.3 region in a family. BMC Medical Genomics. 2015 July; 8:38

58. Yiu M, Qi Z, Ki A and Yu J. Trisomy Xp and partial tetrasomy Xq resulting from gain of a rearranged X chromosome in a female fetus: pathogenic or not? Molecular Cytogenetics. 2015 July; 8:53.

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60. Shu W, Zhou Q, Zhang H, Li M, Yu C, Yu J, Qi M, Bao L, Wu BL, Li P. Medical genetics specialty and allied professional systems in North America and Europe and its impacts on healthcare. Chinese Journal of Medical Genetics. 2016; 33(3):396-401.

61. Qin H, Hejna M, Liu Y, Percharde M, Wossidlo M, Blouin L, Durruthy-Durruthy J, Wong P, Qi Z, Yu J, Qi LS, Sebastiano V, Song JS and Ramalho-Santos M. YAP Induces Human Naive Pluripotency. Cell Reports. 2016; 14:2301-2312.

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63. Foley N, Van Ziffle J, Yu J, Qi Z, Grenert JP, Yeh I, Bastian BC, Kogan S and Mannis GN. Acute myeloid leukemia with t(14;21) involving RUNX1 and SYNE2: a novel favorable-risk translocation? Cancer Genet. 2017; 216-217:74-78.

REVIEW ARTICLES

1. Li, P; Zhang, HZ; Li, MM; Yu, C; Qi, M; Yu, J and Wu, BL. Progress and perspective of professional training in medical genetics and genomics: A report of the Association of Chinese Geneticists in America. North American Journal of Medicine and Science. 2013 October; 6(4):173-180.

BOOKS AND CHAPTERS

1. Molofsky AB, Yu J, Siddiqi I. Chronic myelogenous leukemia. In: Krause J, Filicko-O'Hara J and Gulati G, eds. Case Studies in Hematology and Coagulation. ASCP Press: Chicago, IL. 2012.

ASSESSMENT OF INTERN PERFORMANCE
UCSF MASTERS PROGRAM
IN GENETIC COUNSELING

Intern:_____Site/Rotation:_____

Primary Supervisor(s):_____

Placement/Rotation Dates:_____

Check one: Mid-Evaluation_____ Final Evaluation_____

For students: Self-eval?_____

Please evaluate the student's overall performance:

	Below average	Average	Very good	Excellent	Comments
Overall genetics/genomics knowledge					
Overall clinical judgment and critical thinking					
Overall interactions with patients					
Overall interactions with health care team					
Overall quality of work					
Attitude, engagement and motivation to learn					
Dependability, timeliness, willingness to take initiative					

The skills below have been adapted from the ACGC's Practice Based Competencies (2013) which describe areas of proficiency expected for an entry level genetic counselor. Please use the 1-3 rating scale to evaluate each set of skills.

1 Student demonstrates basic knowledge and skills or takes on portions of task. May be inconsistent and/or require moderate supervision.
2 Student demonstrates ability to apply knowledge and analyze situation or addresses more complex aspects of area. Requires some supervision and may be inconsistent at higher skill levels.
3 Student has advanced skills in this area. Performs with autonomy consistently, requiring little or no supervision. Functioning at the level of an entry level genetic counselor.

I. Genetics Expertise and Analysis

- Demonstrate breadth and depth of knowledge of genetics and genomics core principles
- Case preparation: Critically assess literature and independently utilize resources
- Elicit/Review General (or Disease focused) Medical History
- Elicit/Review Pregnancy and Exposure History
- Elicit clinically targeted family history and construct pedigree using appropriate symbols and notation
- Understand clinical features, natural history, etiology, pathogenesis, inheritance, management and treatment of genetic conditions being evaluated
- Conduct risk assessment (and quantitative risk assessment or use of appropriate model when applicable)
- Interpret results of genetic testing
- Facilitate ordering genetic testing and identify and introduce research options when indicated
- Formulate and execute case management plan

Overall evaluation of Genetics Expertise and Analysis: (Please use the 1-3 rating scale above) _____

Comments on specific strengths and weaknesses in this domain:

II. Education

- Provide tailored inheritance information and risk assessment to clients
- Explain clinical features, natural history, etiology, pathogenesis, inheritance, management and treatment of genetic conditions being evaluated
- Explain testing options and potential outcomes
- Explain genetic testing results
- Present cases and communicate outcome of visit to health care team
- Write chart notes and perform clinical documentation

Overall evaluation of Education: (Please use the 1-3 rating scale above) _____

Comments on specific strengths and weaknesses in this domain:

Please use the 1-3 rating scale:

1 Student demonstrates basic knowledge and skills or takes on portions of task. May be inconsistent and/or require moderate supervision.

2 Student demonstrates ability to apply knowledge and analyze situation or addresses more complex aspects of area. Requires some supervision and may be inconsistent at higher skill levels.

3 Student has advanced skills in this area. Performs with autonomy consistently, requiring little or no supervision. Functioning at the level of an entry level genetic counselor.

III. Interpersonal, Psychosocial and Counseling Skills

- Contract, set tone, help patient/family feel at-ease, develop rapport
- Assess psychosocial needs of patient/family
- Use empathy responses and attending skills
- Use psychosocial interventions to facilitate decision making and/or adaptation
- Consider family issues, clients' culture, religion and other values
- Provide referrals (e.g. to support groups) as appropriate
- Adapt genetic counseling skills for phone or distance service delivery as appropriate

Overall evaluation of Interpersonal, Psychosocial and Counseling Skills (Please use the 1-3 rating scale above): _____

Comments on specific strengths and weaknesses in this domain:

IV. Professional Development and Practice

- Recognize own limitations in knowledge and capabilities
- Recognize own emotional responses to client interactions
- Provide valuable self-critique
- Establish and maintain clear and consistent limits and personal and professional boundaries with patients, colleagues and supervisors
- Process session and discuss with team members
- Seek feedback from team members
- Respond appropriately to constructive criticism
- Integrate critique into practice in future sessions
- Accept less than perfect performance in self and others
- Tolerate ambiguity
- Take risks and expose self to uncomfortable situations to provide optimum gc options to a client
- Handle stress
- Maintain client confidentiality
- Act in accordance with ethical principles of profession and institution

Overall evaluation of Professional Development and Practice (Please use the 1-3 rating scale above): _____

Comments on specific strengths and weaknesses in this domain:

If there was a presentation required as part of the rotation, please comment briefly upon the intern's performance:

Please suggest three goals that the student can focus on as they continue their clinical training:

Any additional comments about the intern's performance in this rotation. Please specifically address progress on goals set during the rotation and any categories where the intern did not perform at the level expected.

For Mid-rotation Assessment:

☐ I believe that the student / intern's current level of functioning demonstrates competence at or above the expected level of training at this point in the rotation.
☐ I believe that the student / intern's current level of functioning demonstrates minimum competence at the expected level of training at this point in the rotation.
☐ I do not believe the student / intern has demonstrated sufficient performance competency at the expected level of training at this point in the rotation.

For End of Rotation Assessment:

☐ I believe that the student / intern's current level of functioning demonstrates competence at or above the expected level of training, and that the internship experience has been successfully completed.
☐ I believe that the student / intern's current level of functioning demonstrates competence at the expected level of training, and that the internship experience has been successfully completed *with reservations.*
☐ I do not believe the student / intern has demonstrated sufficient performance competency at the expected level of training to successfully complete the internship experience.

This assessment was verbally reviewed with the intern, and a copy was provided, on _____ (date).

Student Signature: _____

Supervisor Signature: _____

The Genetic Counselor Workforce Working Group (WFWG) commissioned Dobson l DaVanzo & Associates, LLC to conduct a workforce supply and demand study of United States-based certified genetic counselors over the next decade (2017-2026). The WFWG includes the following organizations: Accreditation Council for Genetic Counseling (ACGC), American Board of Genetic Counselors (ABGC), American Society of Human Genetics (ASHG), Association of Genetic Counseling Program Directors (AGCPD), and National Society of Genetic Counselors (NSGC).

The genetic counselor workforce has grown by 88 percent from 2006-2016, and the study identifies additional growth of 72 percent over the next decade. The study focused on calculating the supply and demand for genetic counselors delivering care directly to patients in a variety of settings. The data indicate a shortage of genetic counselors engaged in direct patient care. Assuming demand of one genetic counselor per 100,000 people in the United States, supply is expected to reach equilibrium in2023 or 2024. If the demand assumption is based on one genetic counselor per 75,000 people, then equilibrium is not reached until 2029-2030.

The study provides data and context for the next steps of the WFWG's efforts. Some of the work may involve:

- Conducting additional research to assess whether one genetic counselor per 100,000 or 75,000 people is appropriate to meet demand in the clinical setting.
- Expanding existing training programs and developing new programs. The pipeline of applicants to training programs has remained strong and hundreds of qualified individuals are turned away each year. Activities around this initiative will be focused on accelerating growth, while being mindful of not overreaching and exceeding demand.
- Continuing efforts to draw highly-qualified individuals to the profession while making additional strides in attracting individuals from underrepresented groups.
- Ensuring a supply of genetic counselors involved in education as the base of trainees grows. The study indicates a shortage in this subset of genetic counselors.
- Examining factors that create a "substitution effect" (i.e., other healthcare providers providing genetic counseling to patients) and how that impacts quality of care, patient outcomes, and demand for genetic counselor services.
- Identifying and integrating tools that increase efficiency and productivity of genetic counselors in clinical practice.
- Identifying the demand for genetic counselors outside direct patient care settings.

Leaders within the organizations represented in the WFWG are engaged in developing collaborative strategies that will address the workforce challenges in the coming months and years. These strategies may involve collaboration with both public and private entities.

Projecting the Supply and Demand for Certified Genetic Counselors

A Workforce Study

Dobson | DaVanzo

Dobson DaVanzo & Associates, LLC Vienna, VA 703.260.1760 www.dobsondavanzo.com

Projecting the Supply and Demand for Certified Genetic Counselors

A Workforce Study

Submitted to:
American Board of Genetic Counselors (ABGC)
Accreditation Council for Genetic Counseling (ACGC)
Association of Genetic Counseling Program Directors (AGCPD)
American Society of Human Genetics (ASHG)
National Society of Genetic Counselors (NSGC)

Submitted by:

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Allen Dobson, Ph.D.
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Wednesday, September 07, 2016 — *Final Report*

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Executive Summary

Information about the certified genetic counselor workforce, while subject to uncertainty given rapid changes in technology, is critical to determining trends in employment, to addressing professional training needs, to quantifying barriers to quality service delivery, and to informing relevant policy and advocacy efforts. The Genetic Counselor Workforce Working Group (WFWG)[1] commissioned Dobson DaVanzo & Associates, LLC (Dobson | DaVanzo) , a Washington, D.C. metropolitan-area based health economics consulting firm, to conduct a workforce supply and demand projection study of U.S.-based certified genetic counselors over the next decade (2017-2026).

Workforce studies attempt to understand the various forces that create demand for and supply of workforce at various price levels. Workforce supply is driven by demand, as well as training, certification and licensure requirements, retirement trends, and other exits/transitions from the genetic counselor workforce. This study comes at a critical time for the genetic counselor profession to understand and anticipate how demand for, as well as training, licensure and certification of genetic counselors, could change the workforce supply in the future.

We collaborated with expert representatives from the WFWG to inform key model assumptions, conducted informational interviews with professional and industry stakeholders, and examined the available literature and available data sources. In considering two different demand scenarios, this study is designed to inform stakeholders and policy makers about the workforce implications of alternative futures and policies.

Key Findings

Future Supply of Certified Genetic Counselors: Projection Results

We calculated the number of certified genetic counselors as the active supply of genetic counselor graduates who became certified, along with the net flow of new entrants into the profession. We estimate the effective supply of all certified genetic counselors will increase from 3,814 to 6,562 between 2017 and 2026, or by approximately 72% over 10 years. The

[1] The Genetic Counselor Workforce Working Group (WFWG) includes the following organizations: Accreditation Council for Genetic Counseling (ACGC), American Board of Genetic Counselors (ABGC), American Society of Human Genetics (ASHG), Association of Genetic Counseling Program Directors (AGCPD), and National Society of Genetic Counselors (NSGC).

majority of certified genetic counselors will provide direct patient care, with industry making up the next largest group.

Future Demand for Certified Genetic Counselors: Reported Findings

While anecdotal evidence is supportive of an increased demand for certified genetic counselors, we were unable to precisely quantify a growing shortage (or excess) of U.S. certified genetic counselors using information found in either the peer-reviewed or grey literature. We limited our demand projection to only those certified genetic counselors in direct patient care, as this group comprises approximately 65% of the overall certified genetic counselor population.

Using two different rate scenarios – one FTE for a certified genetic counselor per 100,000 U.S. population ('Scenario 1') and one FTE for a certified genetic counselor per 75,000 U.S. population ('Scenario 2'), we calculated the number of direct patient care certified genetic counselors needed to meet the demand of an estimated U.S. population of 326,626,000 in 2017. Under Scenario 1, an adequate certified genetic counselor workforce would include 3,266 full-time providers in 2017, whereas under Scenario 2, 4,355 certified genetic counselors would be required.

When we compared the anticipated supply of direct patient care certified genetic counselors for each year between 2017 and 2026 to the number of genetic counselors demanded under Scenarios 1 and 2, we find, in 2017, a shortage of between 791 and 1,879 certified genetic counselors, respectively. Since our supply projection has the direct patient care certified genetic counselor population outpacing overall U.S. population growth (5.2 versus 0.8% per year over 10 years), overcoming provider shortages under either scenario is inevitable given a long enough projection window.

Conclusions

Our projections demonstrate that supply will meet demand within the 10-year period only under the assumption of one direct care certified genetic counselor per 100,000 persons; otherwise, a stricter model of one per 75,000 persons demonstrates that equilibrium will not be reached until 2029 or 2030.

In the short run, provider shortages appear to be inevitable; however, these shortages would be overcome over a long enough projection window under our "best" estimates of supply and demand growth. That said, neither of our demand models account for large-scale exogenous factors, such as the introduction of blockbuster tests and changes in commercial/public reimbursement. This uncertainty is what makes any workforce study somewhat tentative. Estimating demand for future certified genetic counseling services is particularly challenging in the current, rapidly changing healthcare environment. Thus, the demand for genetic counseling services will need to be carefully monitored over the next several years, in order to account for changing technology and payer preferences.

Purpose and Introduction

Purpose

In 2013, the Genetic Counselor Workforce Working Group (WFWG)[2] was tasked with assessing the growing demand for certified genetic counselors in the U.S. and coordinating strategies to expand the capacity of the certified genetic counselor workforce.

In 2015, the WFWG commissioned our firm, Dobson DaVanzo & Associates, LLC, a Washington, D.C. metropolitan-area based healthcare economics consulting firm with expertise in modeling healthcare professional workforces, to conduct a supply and demand workforce projection study of U.S.-based certified genetic counselors over the next decade (2017-2026). In developing this model, we collaborated with expert representatives from the WFWG to inform key model assumptions, conducted informational interviews with professional and industry stakeholders, and examined the available literature and available data sources.

Introduction

From a health economics standpoint, workforce demand represents the dynamic relationship between "price and quantity," provided all other things are equal. Workforce studies attempt to understand the various forces that create demand for and supply of workforce at various price levels. Workforce supply is driven by demand, as well as training, certification and licensure requirements, retirement trends, and other exits/transitions from the genetic counselor workforce. This study comes at a critical time to understand and anticipate how demand for, as well as training, licensure and

[2] The Genetic Counselor Workforce Working Group (WFWG) includes the following organizations: Accreditation Council for Genetic Counseling (ACGC), American Board of Genetic Counselors (ABGC), American Society of Human Genetics (ASHG), Association of Genetic Counseling Program Directors (AGCPD), and National Society of Genetic Counselors (NSGC).

certification of genetic counselors could change the workforce supply in the future within a transformed health care marketplace.

Genetic counseling has kept pace with technological advances and changes to health care delivery by evolving and expanding. Not only do certified genetic counselors have an increased presence in diverse settings (e.g., public health departments, academic medical centers, genetic test laboratories, education, etc.), but their roles and responsibilities have changed, as well.

Going forward, the increased use of value-based purchasing by health care payers as well as the growth of Accountable Care Organizations and population health management are likely to contribute to future changes in the roles and responsibilities of genetic counselors.

Several factors may affect demand for genetic counseling. The increasing emphasis in clinical settings on genetic predisposition to common complex diseases may result in a large increase in demand for patient-facing direct care genetic counselors. As the genetic origins of numerous diseases become more generally understood, risks and prognoses will be better assessed, and certified genetic counselors will be needed to communicate these risks and prognoses to both patients and other clinicians.

Genetic testing is becoming an increasingly common and important component of personalized disease management. Studies conducted over the past decade have identified genetic variants underlying many Mendelian diseases and genetic risk factors associated with common diseases, such as cancer, heart disease, and neurological disorders. These discoveries have led to greater insights in clinical evaluation, which offer the possibility of better targeting therapeutic strategies to prevent or mitigate diseases and, in certain instances, to potentially reduce overall healthcare costs (e.g., by better targeting expensive cancer drugs and medicines). Susceptibility to particular diseases can be detected before diseases manifest symptoms, which allows for earlier intervention.

Genetic counseling has become increasingly specialized in recent years. According to a National Society of Genetic Counselors (NSGC) Professional Status Survey (PSS) in 2014, 29% of genetic counselors practiced in the area of cancer – a 19 percentage point increase from 1994. Emerging specialties also include cardiovascular and neurological genetic disorders.[3] The expanded interest in genetic counseling may be associated with the increasingly complex nature of the testing, its rapid growth, and how it is seen as being a useful component of high-quality and efficient care. These factors may drive future demand as the health care marketplace moves to value-based purchasing, and

[3] National Society of Genetic Counselors. (2014). 2014 professional status survey: Executive Summary.

payers begin to understand the value of genetic counseling in ensuring that genetic testing is used most appropriately.

Since the early 1980s, the demand for genetic counselors has increased due to of a number of factors, including the explosion of new genetic tests coming to market, expansion of genetics into various specialty areas of medicine and the significant demographic trend of delayed child-bearing.

For example, between 2000 and 2014 the percent of first births among women 35 years and older increased by 23%, from 7.4% to 9.1%.[4] Delayed child-bearing is associated with an increased risk of infertility, pregnancy complications, and adverse pregnancy outcome. Many believe that a growing rate of delayed child-bearing profoundly influenced not only the genetic counselor job market but also the very practice of genetic counseling.[5] Delayed child-bearing rates may continue to increase as socioeconomic forces change and reproductive preferences fluctuate.

In addition to demographic trends, the increasing number of new genetic tests has influenced the demand for genetic counselors. There are approximately 60,482 genetic testing products on the market and an average of 8-10 new products enters the market every day.[6] Genetic testing panels account for a significant portion of the recent growth in tests. The increasing number of tests and complexity of panels has driven demand for genetic counselors who understand how to identify the correct tests and interpret those tests once results are available.

Although there is little available data on the genetic counseling profession, there are a considerable number of studies in the literature that discuss the value proposition of certified genetic counselors. Those studies suggest that the use of genetic counselors to better target genetic testing yields significant savings in healthcare spending for patients with cancer, neurologic, and cardiac disorders, or those concerned with inheriting genetic diseases.[7,8,9] Several payers and providers have calculated the savings realized within their programs once certified genetic counselors become involved in genetic testing for their members, and several health plans, such as Cigna,[10] have implemented policies

[4] Mathews TJ, Hamilton BE. Mean age of mothers is on the rise: United States, 2000–2014. NCHS data brief, no 232. Hyattsville, MD: National Center for Health Statistics. 2016.

[5] The Society of Obstetricians and Gynaecologists of Canada: Committee Opinion. Delayed Child-bearing. No. 271, January 2012.

[6] https://www.nextgxdx.com/insights; http://docs.nextgxdx.com/genetic-testing-infographic.jpg

[7] Mvundura M, Grosse SD, Hampel H, et al. The cost-effectiveness of genetic testing strategies for Lynch syndrome among newly diagnosed patients with colorectal cancer. *Genet Med* 2010; 12(93-104).

[8] Kotzer KE, Riley JD, Conta JH, et al. Genetic testing utilization and the role of the laboratory genetic counselor. *Clin Chim Acta* 2014; 427:193-5.

[9] Miller CE, Krautscheid P, Baldwin EE, et al. Genetic counselor review of genetic test orders in a reference laboratory reduces unnecessary testing. *Am J Med Genetic A* 2014; 164(5):1094-101.

[10] Cigna Genetic Testing and Counseling Program. Available online at: http://www.cigna.com/healthcare-professionals/resources-for-health-care-professionals/genetic-testing-and-counseling-program

mandating genetic counseling by certified genetic counselors or other trained genetics providers for precertification for certain genetic tests to be approved. This, and other similar requirements, may help drive additional demand for certified genetic counselors.

Certified genetic counselors in direct patient care are critical members of multidisciplinary teams, serving as integrators of information that helps patients understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease.[11] Based on a thorough assessment of a patient's family medical history and interpretation of genetic test results, certified genetic counselors provide critical information to patients regarding genetic testing and to physicians aiding decision-making concerning the optimal course of treatment. This information helps both patients and physicians understand the impact of genetics on the course of disease. Certified genetic counselors also provide information and support to individuals and families concerned with genetic disorders, birth defects, or those at risk for a variety of inherited conditions.

In this report, we triangulated the published literature, information provided by the WFWG, and anecdotal reports as the basis for quantifying provider shortages for a subset of certified genetic counselors providing direct patient care. Here, we modeled two workforce scenarios that show the growth in the supply of direct patient care certified genetic counselors will likely not meet population demand over the next seven to 10 years. The extent to which the results of these models track with actual future demand is largely unknown, and is likely highly sensitive to how the genetic counseling profession responds to pressures that could impact the provision of genetic services and the genomic medicine landscape at large.

The implications of these model results are important to the WFWG's goals of better integrating genetic counseling services in various clinical environments in order to improve individual and public health. The WFWG is aware of the impact that a potential shortage of certified genetic counselors would have on their mission to facilitate the delivery of high-quality, professional services over the long-term.

While the supply section of this report estimates the future supply of certified genetic counselors for each job category and overall, the report's demand section primarily focuses on certified genetic counselors with direct patient care responsibilities. This job category has, historically, represented the largest employer for certified genetic counselors, and would potentially be most responsive to changes in coverage and reimbursement. Outside direct patient care opportunities, however, the demand picture is less clear, as we were unable to identify a quantifiable demand trend in the literature that

[11] Genetic Counseling Definition Task Force. (2006). A new definition of genetic counseling: National Society of Genetic Counselors' Task Force Report. Journal of Genetic Counseling: 15(2): 77-83.

could be generalized to non-direct patient care certified genetic counselors. Interviews with industry representatives were also inconclusive on this point.

Supply Projection for the Certified Genetic Counselor Workforce

Introduction

The objective of this section is to present our estimates of the supply of certified genetic counselors over a 10-year period (2017-2026). These estimates can be used in conjunction with demand estimates in the next section to identify and address potential gaps in training. In this section, we discuss our methodology and estimates of the long-term supply of certified genetic counselors in the U.S. workforce.

Methodology

We estimated the aggregate supply of certified genetic counselors in terms of the following job classifications: direct patient care, genetic test and pharmacogenomics industries ('industry'), education, research and public health.

The certified genetic counselor workforce is defined as those providers who are board certified and working in the U.S. The supply model for certified genetic counselors is based on the number of active, board-certified genetic counselors in the U.S., the number of new entrants to the workforce, and the number of individuals exiting the profession (attrition). For new entrants, we considered the capacity of known extant training programs – now and in the future, and the limited number and capacity of clinical sites to provide clinical internships for trainees. We conducted a literature review to identify exogenous factors that might affect supply, such as counselor age distribution, program costs, tuition fees, scholarship availability, median salary, and state licensure. We also conducted 18 semi-structured interviews with certified genetic counselors and healthcare stakeholders who rely on or provide genetic counseling services.

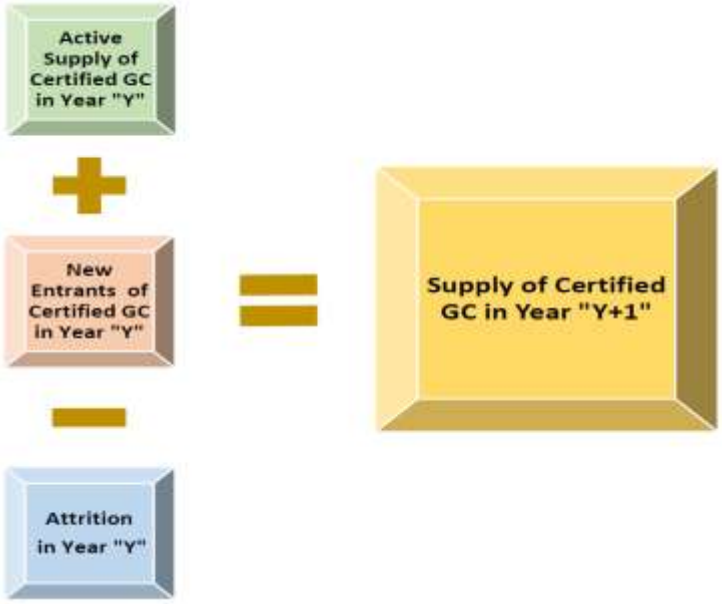
Supply Projection for Certified Genetic Counselors

To construct supply models of certified genetic counselors, we first calculated the total supply of certified genetic counselors in 2016 based on historical graduation and certification data provided by the American Board of Genetic Counselors (ABGC) and available in the 2016 NSGC PSS data.

Future Supply of Genetic Counselors: Model Framework

Given our baseline estimates, we projected the active supply of certified genetic counselors from 2017 to 2026. Supply projections of genetic counselor workforce are based on the model framework shown in Exhibit 1.

Exhibit 1: Supply Model Framework for Certified Genetic Counselors

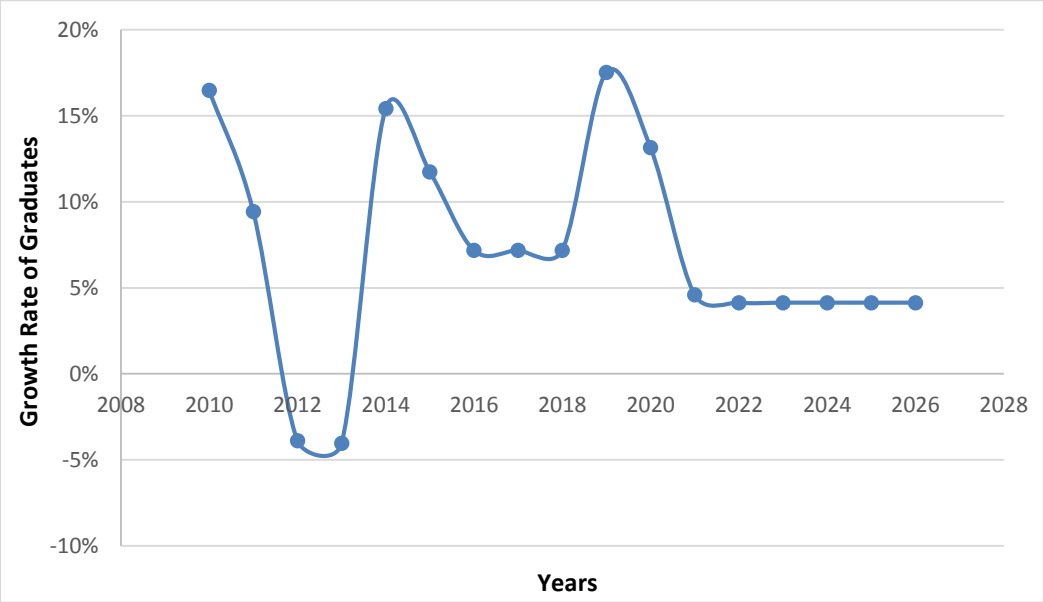


Our projection begins with the number of board-certified genetic counselor professionals estimated for our base-year 2016 and adds new entrants into the model each additional year. Attrition consists of genetic counselors who leave the workforce (e.g., retirement).

We calculated the number of certified genetic counselors as the active supply of genetic counselor graduates who become certified, along with the flow of new entrants into the profession. Historical trends and projected growth rates of graduation over time are shown in Exhibit 2. Projecting forward, all certified genetic counselors were estimated using the total number of certified genetic counselors.

Supply Projection for Certified Genetic Counselors

Exhibit 2: Historical Trend and Projected Growth Rates of Graduates



Future Supply of Certified Genetic Counselors: Baseline Estimation

We used ABGC historical data on numbers of graduates and certifications as a baseline for our estimates. Certification data are available from 1982 to 2015, and graduation data are available from 2009 to 2015.

After calculating the total number of certified genetic counselors in 2015, we restricted that total to include only those providers working within the U.S. Two NSGC sources estimated the percentage of certified genetic counselors working outside the U.S. to be 5.4% (2016 NSGC membership data) and 9.0% (2016 NSGC PSS). A lower-end estimate of 6% was used in the model.

Based on extant literature,[12] we calculated the attrition rate for certified genetic counselors at 2.3% (see below). In order to estimate the supply of certified genetic counselors in 2016 and forward, we used 2009 to 2015 ABGC graduation data to calculate a compound annual growth rate (CAGR) of graduation of 7.2%.

We next calculated the number of graduates in 2016 by assuming that 95% of graduates would eventually receive professional certification, and then extended supply growth into future years (2017-2026).

[12] A Model to Project the supply and demand of physical therapists 2010-2025. American Physical Therapy Association. Available online at: http://www.apta.org/WorkforceData/ModelDescriptionFigures/. Accessed on: April 1, 2016.

Supply Projection for Certified Genetic Counselors

Future Supply of Certified Genetic Counselors: Calculation of Our Projection

The following assumptions were made in order to calculate new entrants into the genetic counselor profession and the subsequent attrition rate:

> **ASSUMPTION-I**: There will be approximately 7 new accredited training programs in the next two years. Four new programs will begin in 2017 and three new programs will begin in 2018 according to the Accreditation Council for Genetic Counseling (ACGC).
>
> **ASSUMPTION-II:** Average class size of these new programs will be 8 over the forecast time period.
>
> **ASSUMPTION-III:** From 2021 to 2026, the graduation growth rates for existing programs and new programs will be constrained so that the 10-year CAGR will be 7.2%, thus the overall supply will roughly double from 2017 to 2026.
>
> **ASSUMPTION-IV**: To take into account the availability of clinical sites, the growth rate of graduation for 2021-2026 is limited to 90% of the anticipated growth rate according to Association of Genetic Counseling Program Directors (AGCPD) and ACGC.
>
> **ASSUMPTION-V:** 95% of all graduates of accredited programs eventually receive professional certification according to ABGC.

We assumed that 85% of certified genetic counselor professionals aged 55 years and older will retire over the next 10 years, and 14.3% of the professionals under 55 will retire over the same period.

Using age distribution information from the NSGC 2016 PSS survey, we first determined the number of certified genetic counselors who are over and under 55 years old. We then applied the aforementioned attrition rates for these age groups to calculate the weighted average growth rate of attrition for both age groups over the 10-year period. We calculated the CAGR for attrition as -2.3%.

We assumed that the distribution of positions will change over time to reflect changes in job postings. Table 1 shows our assumptions regarding the change in distribution of job categories between 2016 and 2026.

Supply Projection for Certified Genetic Counselors

Table 1: Changes in the distribution of job categories over time

Job Categories	Distribution in 2016	Distribution in 2026
Direct Patient Care	65%	60%
Industry	32%	35%
Education	1%	3%
Research & Public Health	2%	2%
Total	**100%**	**100%**

Future Supply of Certified Genetic Counselors: Projection Results

We estimate the effective supply of all certified genetic counselors will increase from 3,814 to 6,562 between 2017 and 2026, or by approximately 72% over 10 years. The majority of certified genetic counselors will provide direct patient care, with industry making up the next largest group.

This distribution—with a large majority of certified genetic counselors in direct patient care—strongly influenced our decision to focus our demand model (in the next chapter) on the demand for direct patient care. It is worth noting that the projected number of certified genetic counselors employed in direct patient care is modeled to grow at a slightly slower rate than total certified genetic counselors to account for possible saturation in clinical sites and the expectation that future certified counselors will devote a portion of their work time to educating other healthcare providers. See Table 2.

Table 2: Projected Supply of Certified Genetic Counselors

Providers	2017	2018	2019	2020	2021	2022	2023	2024	2025	2026
Total Certified Genetic Counselors	3,814	4,021	4,276	4,570	4,875	5,190	5,516	5,853	6,202	6,562
Direct Patient Care	2,476	2,588	2,729	2,891	3,058	3,228	3,400	3,576	3,755	3,937
Industry	1,217	1,297	1,394	1,505	1,623	1,745	1,874	2,008	2,149	2,297
Education	46	56	69	82	98	114	132	152	174	197
Research & Public Health	75	80	85	91	97	103	110	117	124	131

Through our review of the literature, we believe it is likely that genetic counselors may play a larger role in the education of primary care providers in the near future; these providers may then incorporate more extensive genetic care into their daily practice. Certified genetic counselors in industry will grow at a faster rate than any of the other provider types due to the rapid growth in commercial genetic testing, the availability of competitive salaries, and changing dynamics within healthcare infrastructure and policy.

Supply Projection for Certified Genetic Counselors

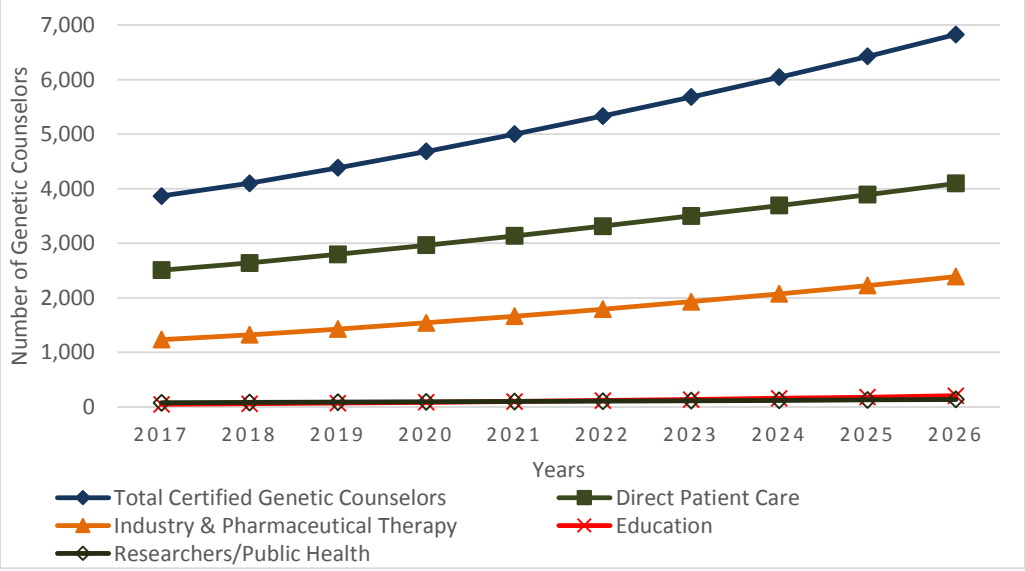
Overall, we project that the total number of **active certified genetic counselors** will grow at a CAGR of 6.2%, from 3,814 to 6,562 between 2017 and 2026, or 72% overall, a rate more than two-and-a-half times the Bureau of Labor Statistics' 2014 to 2024 employment growth projection of 29%.[13] We predict that there will be substitution among different job sectors, and the growth rates for the four job categories reflect that trend. Supply of certified genetic counselors in the direct patient care category will grow at a CAGR of 5.3% from 2017 to 2026, while the supply of certified genetic counselors in industry will grow at CAGR of 7.3% within the same study time period. See Table 3.

Table 3: Compound Annual Growth Rate by Job Classification

Job Classification	CAGR
Total Certified Genetic Counselors	6.2%
Direct Patient Care	5.3%
Industry	7.3%
Education	17.6%
Research & Public Health	6.4%

Among these four categories, genetic counselors who are serving within the education sector will grow at the fastest rate over the same study period; the CAGR for this group is 17.6%. The number working within research and public health will grow at 6.4% annually from 2017 to 2026. Exhibit 2 demonstrates the projected supply of genetic counselors over the 10-year period.

Exhibit 2: Projected Supply of Genetic Counselors



Supply Projection for Certified Genetic Counselors

Conclusions

Our interview results indicated that there are exogenous factors (such as age distribution, program costs, tuition fees, scholarship availability, median salary and state licensure) that could affect the supply of certified genetic counselors. Underlying all CAGR projections were assumptions for historical certification trends, and those CAGR projections were directly informed by our projected changes in graduation, such as anticipated expansion of existing programs and launching of new programs, as well as qualitative assessments provided through interviews with stakeholders and the profession. Should the profession undertake new initiatives to rapidly increase the number of new programs beyond the anticipated 7 programs planned through 2018, our supply estimates would likely underestimate actual growth.

Demand Model for Direct Patient Care Certified Genetic Counselors

Overview of Demand Model

To determine whether our overall projected supply of certified genetic counselors, which is expected to grow from 3,814 to 6,562 between 2017 and 2026 (or 6.2% per year) is sufficient to meet future demand, we conducted 18 interviews with stakeholders actively practicing in the major employment settings of most certified genetic counselors. These included: direct patient care, industry, education, and research-based settings.

The subset of certified genetic counselors primarily employed in healthcare settings with direct patient care responsibilities comprised 65% of all CGCs in 2014.

The purpose of these interviews was to identify and understand the factors expected to impact demand for certified genetic counselor services in different segments of the profession. We also examined the peer-reviewed and grey literature with a similar intent, and we more broadly considered how large-scale market dynamics could disrupt genetic service marketplaces, including the genetic test pipeline and pharmacogenomics, changes in regulatory approval pathways for genetic tests, changes in commercial and public coverage and reimbursement for genetic services, and growing public awareness of personalized genomic medicine.

Future Demand for Certified Genetic Counselors: Reported Findings

There is a general expectation within the profession and the larger genetics community that the demand for certified genetic counselor services will increase moderately, if not markedly, over the next 10 years across all major employment settings. This expectation is

grounded in multiple factors, which include growing public awareness of genomic medicine and recent adoption of precertification requirements for genetic testing by some health plans (e.g., Cigna and UnitedHealth) that mandate genetic counseling in order to approve coverage for certain genetic tests.

Additionally, the explosion of new genetic tests in recent years,[14,15] coupled with genetic counseling services becoming an increasingly common and important component of personalized disease management, a near-zero unemployment rate for certified genetic counselors,[16] and near 20% annual growth in job postings for certified genetic counselors between 2013 and 2016,[17] appear to all support a 'bull-market' demand outlook for the profession, with increases across all fields of direct patient care, education, and industry.

Despite our 10-year projected supply of genetic counselors growing by 72%, the profession's current education, certification and program accreditation processes are unlikely to generate enough trained providers to satisfy the expected growth in demand according to the profession.[18] Thus, the profession expects the current shortage of genetic counselors to increase in the future.[19] Proactive initiatives that anticipate potential shortages through targeted education, outreach, advocacy, and certification may facilitate closing the gap in the later years modeled in this report with respect to growth in the profession.

Future Demand for Certified Genetic Counselors: Stakeholder Interview Findings

In reviewing the transcripts from the 18 stakeholder interviews conducted in March 2016, we find conflicting understandings of the concept of 'demand' for certified genetic counselors, which may provide some insight into the current shortage and expected future shortage of certified genetic counselors. Nearly all direct patient care certified genetic counselors we interviewed reported increases in patient volume in recent years, which, for some, translated into longer patient wait times for appointments. From the perspective of these providers and their patients, this increased demand for services feels like a growing shortage of genetic counselors.

[14] NextGxDx, Inc. The current landscape of genetic testing: Market size, market growth, and the practical challenges of the clinical workflow. March 1, 2016. Available online at: https://www.nextgxdx.com/insights.

[15] McKinsey & Company. The outlook for personalized medicine – the path forward. 2013. Available online at: http://www.mckinsey.com/~/media/mckinsey/dotcom/client_service/pharma%20and%20medical%20products/pmp%20new/pdfs/mckinsey%20on%20personalized%20medicine%20march%202013.ashx.

[16] National Society of Genetic Counselors. 2016 Professional Status Survey: Work environment.

[17] National Society of Genetic Counselors analysis of *Job Connection* job postings between June 2013 and June 2016.

[18] National Society of Genetic Counselors. Workforce Working Group Memo – Genetic counselor Workforce demand projection. June 20, 2016.

[19] Ibid.

On the other hand, these and other interviewees also observed more certified genetic counselors leaving patient care for what, today, are sometimes higher-paying industry positions, a phenomenon also observed in data reported in the last three NSGC Professional Status Surveys. The number of vacant direct patient care positions has also increased according to Job Connection data provided by NSGC. Reportedly, the increase in the number of open positions in direct patient care, combined with a flow of certified genetic counselors into industry positions is resulting in difficulty filling direct patient care positions with the existing supply of certified genetic counselors. According to survey reports, the percentage of certified genetic counselors who identified their primary employment setting as 'clinical' (versus 'non-clinical') decreased from 84% to 65% between 2012 and 2016.[20]

Thus, while genetic counselors who are currently active in a direct patient care role may perceive a growth in demand for genetic counselor services, we hypothesize that many of the healthcare systems and clinical practices that employ these providers may not view it the same way. If, for example, a hospital is unwilling to compete with industry salaries at this time, or if genetic counseling services generate inadequate revenue, then the hospital may not hire more genetic counselors and the perceived shortage will not translate into actual demand. It is important to note, however, that this dynamic and our interpretation of it does not obviate the possibility of a serious shortage of patient-facing certified genetic counselors; indeed, from the perspective of a patient trying to access a certified genetic counselor, there is a potentially significant growing shortage of providers.

Additionally, some organizations' inability to retain genetic counselors and to fill vacancies in a timely manner is likely a consequence of current reimbursement structures. However, there are emerging trends in coverage and reimbursement that are favorable to direct patient care demands. For example, the Affordable Care Act requires Marketplace Health Plans to provide genetic counseling as a preventive service when testing for the BRCA gene. That said, there is salary competition from industry in the short-run, and many industry positions are not in direct patient care. Although certified genetic counselors can bill certain counseling services under Medicare incident to a supervising provider with independent billing status, several interviewees noted that many genetic counselors' salaries are heavily subsidized by the employing institution – usually an academic medical center – as the revenue generated from genetic counseling services often falls short of costs. State licensure of certified genetic counselors allows independent practice and this may further improve the reimbursement landscape.

[20] Liberman, S. et al. To Be a Clinical or Non-Clinical Genetic Counselor, That is the Question. Abstract submitted to the 2016 NSCG Annual Education Conference. Seattle, Washington. September, 2016

This relative balance may be changing as health plans continue to evaluate their payments and policies for genetic counseling services, as demonstrated in updated HRSA guidelines, released by HHS in 2011, which better facilitate access to breast cancer screenings. Furthermore, some health plans have enacted policies requiring genetic counseling prior to authorizing coverage of genetic tests. For example, Cigna required counseling for BRCA, colorectal cancer syndromes, and Long QT syndrome; beginning July 15th, 2016, they will also require counseling for all cancer and cardiac testing as well as whole exome sequencing, hereditary cardiomyopathies, and microarray analysis for pediatric cases.[21]

Increasing the productivity of certified genetic counselors could alleviate some unmet patient demand and hospital costs. According to the 2016 NSGC PSS,[22] the mean caseload of a patient-facing certified genetic counselor was approximately 36 patient visits per month. Several interviewees noted that improving genetic counselor productivity was needed and possible, yet cautioned that significant productivity gains were unlikely due to the inherently time-intensive nature of providing genetic counseling services.

To enhance the overall productivity of certified genetic counselors, some interviewees were open – others were not – to having other providers manage and/or triage less complicated patients, thereby allowing genetic counselors to focus on more complicated cases- referred to as the "substitution effect." This arrangement, which currently is taking place (although not in a consistent and purposeful way), could conceivably alleviate some genetic counseling patient access issues in some communities by increasing the size of the effective workforce. Similarly, interviewees noted that educating physician specialties about genetic tests and when to refer patients to certified genetic counselors could present an opportunity to improve patient access. These efforts also appear to be reflected in the recent NSGC PSS survey data, which show a large majority of respondents dedicating time to teaching and educational activities designed to inform other healthcare professionals of various available genetic services.[23]

[21] Cigna Genetic Testing and Counseling Program. Available online at: http://www.cigna.com/healthcare-professionals/resources-for-health-care-professionals/genetic-testing-and-counseling-program.

[22] National Society of Genetic Counselors. 2016 Professional Status Survey: Work environment.

[23] National Society of Genetic Counselors. 2016 Professional Status Survey: Work environment.

Demand Model for Direct Patient Care Certified Genetic Counselors

Demand Projection Models: Quantifying Adequacy of Supply of Direct Patient Care Certified Genetic Counselors

While anecdotal evidence is supportive of an increased demand for certified genetic counselors, we were unable to precisely quantify a growing shortage (or excess) of U.S. certified genetic counselors using information found in either the peer-reviewed or grey literature. The literature, to our knowledge, simply does not offer a firm numerical relationship between provider supply and the demand for genetic counseling services.

Because of the uncertainty in demand factors cited above, we were unable to find information that would enable us to quantify the number of U.S. certified genetic counselors needed to meet population demand. We did find, however, that the United Kingdom's Association of Genetic Nurse and Counsellors recommends one full-time equivalent (FTE) certified genetic counselor per 100,000 population.[24] A similar rate of one FTE certified genetic counselor per 75,000 covered lives has, anecdotally, been attributed to a large U.S. health system. Both rates describe services provided by direct patient care certified genetic counselors.

Using these two rate scenarios – one FTE per 100,000 ('Scenario 1') and one FTE per 75,000 ('Scenario 2'), we calculated the number of direct patient care certified genetic counselors needed to meet the demand of an estimated U.S. population of 326,626,000 in 2017. Under Scenario 1, an adequate certified genetic counselor workforce would include 3,266 full-time providers in 2017, whereas under Scenario 2, 4,355 certified genetic counselors would be required.

Assuming these rates remain constant over the next 10 years, the number of certified genetic counselors needed would increase proportionately with U.S. population growth, which is expected to increase at an average annual rate of 0.8% between 2017 and 2026.[25]

Table 4 shows the number of full-time direct patient care certified genetic counselors needed between 2017 and 2026 under Scenarios 1 and 2 for a U.S. population growing at 0.8% each year.

[24] National Centre for Medical Genetics. Inadequate staffing levels. Available online at: http://www.genetics.ie/clinical/inadequate-staffing-levels/.

[25] U.S. Census Bureau. 2014 National Population Projections. U.S. Census Bureau: Washington, DC. Available online at: http://www.census.gov/population/projections/data/national/2014.html.

Demand Model for Direct Patient Care Certified Genetic Counselors

Table 4: Number of Direct Patient Care Certified Genetic Counselors Needed between 2017 and 2026: Scenarios 1 and 2

	2017	*2018*	*2019*	*2020*	*2021*	*2022*	*2023*	*2024*	*2025*	*2026*
Per 1,000 U.S. Pop	326,626	329,256	331,884	334,503	337,109	339,698	342,267	344,814	347,335	349,826
Scenario 1: 1 FTE GC per 100k pop	3,266	3,293	3,319	3,345	3,371	3,397	3,423	3,448	3,473	3,498
Scenario 2: 1 FTE GC per 75k pop	4,355	4,390	4,425	4,460	4,495	4,529	4,564	4,598	4,631	4,664

Demand Projection Models: Estimating Future Direct Patient Care Certified Genetic Counselor Shortages

Our projected supply of certified genetic counselors with direct patient care, which currently represents approximately 65% of all certified genetic counselors, is expected to increase, on average, by 5.3% per year over the next 10 years.

In our supply model, the rate of increase for direct patient care genetic counselors is slower than the overall increase in the certified genetic counselor supply growth rate of 6.2%. This reflects historical trends that show fewer new graduates pursing direct patient care positions. By 2026, we estimated the supply of direct patient care certified genetic counselors will increase to 3,937, or 60% of all employed certified genetic counselors expected by that year. This assumes no dramatic/extraordinary intervention on behalf of genetic counseling organizations with regard to education and advocacy; however, in discussion with the WFWG, initiatives to increase the number of graduates are likely.

When we compared the anticipated supply of direct patient care certified genetic counselors for each year between 2017 and 2026 to the number of genetic counselors demanded under Scenarios 1 and 2, we find, in 2017, a shortage of between 791 and 1,879 certified genetic counselors, respectively. Since our supply projection has the direct patient care certified genetic counselor population outpacing overall U.S. population growth (5.2 versus 0.8% per year over 10 years), overcoming provider shortages under either scenario is inevitable given a long enough projection window.

In Table 5, Scenario 1 shows that between 2023 and 2024 the number of direct patient care certified genetic counselors would satisfy a one FTE per 100,000 population demand. Scenario 2 shows a consistent provider shortage through 2026, with 727 certified genetic counselors still needed that year. Indeed, under Scenario 2, shortages would persist at the one per 75,000 ratio until between 2029 and 2030. These models

suggest that the projected direct patient care certified genetic counselor supply would not catch-up with demand until 2024, under Scenario 1, or 2030, under Scenario 2.

Table 5: Expected Shortage of Direct Patient Care Certified Genetic Counselors under Scenarios 1 and 2.

	2017	*2018*	*2019*	*2020*	*2021*	*2022*	*2023*	*2024*	*2025*	*2026*
Shortage at 1 genetic counselor per 100k pop (Scenario 1)	(791)	(704)	(590)	(454)	(313)	(169)	(23)	128	281	439
Shortage at 1 genetic counselor per 75k pop (Scenario 2)	(1,879)	(1,802)	(1,696)	(1,569)	(1,437)	(1,302)	(1,163)	(1,022)	(876)	(727)

Conclusions and Recommendations

Our projections demonstrate that supply will meet demand within the 10-year period only under the assumption of one direct care certified genetic counselor per 100,000 persons; otherwise, a stricter model of one per 75,000 persons demonstrates that equilibrium will not be reached until 2029 or 2030.

In the short run, provider shortages appear to be inevitable; however, these shortages would be overcome over a long enough projection window under our "best" estimates of supply and demand growth. That said, neither of our demand models account for large-scale exogenous factors, such as the introduction of blockbuster tests and changes in commercial/public reimbursement. This uncertainty is what makes any workforce study somewhat tentative.

Estimating demand for future certified genetic counseling services is particularly challenging in the current, rapidly changing healthcare environment. For example, if barriers to certified genetic counselor coverage and reimbursement fall or the uptake of genomics in medicine rises quickly over the next decade, we would expect both estimates modeled under Scenarios 1 and 2 to underrepresent the effective demand that could arise from any single factor.

On the other hand, new policies that restrict reimbursement to direct patient care certified genetic counselors who are not affiliated with a commercial laboratory would likely reduce the effective demand for care, while at the same time reducing the ability of providers to meet patient need.

Given the extant uncertainty, demand growth – and the factors contributing to said growth – should be closely monitored so as to provide for supply growth commensurate with increased demand pressures. This is especially important for training programs and

the advocacy and policy activities of certified genetic counselor organizations and certification bodies.

At the opposite extreme, the profession should closely monitor factors that may undercut the demand for certified genetic counselors, such as the substitution effect (i.e., use of non-certified genetics professionals to meet patient need). Restrictions on payer coverage and application of value-based purchasing policies to genetic and genomic services, wherein every dollar spent is examined for comparative clinical and economic value should also be monitored.

Under such arrangements, the rate of growth of healthcare expenditures could be curtailed by eliminating services and procedures that have not been proven to be clinically efficacious. Efforts to improve coverage and payment must be continued if patient need is to be met. Likewise, value-based purchasing could increase the demand for patient-facing care if managers in organizations involved in value-based payment schemes believe that certified genetic counselors can reduce population health expenditures. Thus, while the future of technology is uncertain, many factors that influence the demand for certified genetic counselors might be influenced such that need is more adequately served in coming years.

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January 31, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute for Human Genetics
513 Parnassus Ave, S965, Box 0794
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Dear Cynthia:

I am pleased to extend my enthusiastic support for the development of a self-supporting master's degree graduate program in Genetic Counseling at UCSF. As you know, we (the Dean's office) have been providing you this year with financial support through the Institute for Human Genetics to launch this program.

I believe the timing of the development of this program could not be better. Over the past several years, UCSF has expanded our clinical offerings in genetics and genomics, specifically through the Genomic Medicine Initiative (GMI), which has also been supported by the SOM Dean's Office and by the UCSF Chancellor and Provost. Recently the GMI achieved two milestones – the launch of the UCSF 500 for tumor sequencing, and germline exome sequencing for pediatric and prenatal patients. Both are now under CLIA certification. In addition, UCSF has been the recipient of two major NHGRI-funded grants related to the clinical use of exome sequencing – one investigating its utility for newborn screening as an adjunct or replacement for traditional mass spectrometry methods, and the other investigating the clinical utility of exome sequencing for prenatal and pediatric patients, with an emphasis on under-represented minority populations and also the medically underserved.

UCSF is world renowned in the areas of human genetics and molecular biology more generally, as evidenced by our position in the top 5 of all universities globally for the past three years in those disciplines, as reported by US News and World Report. The UCSF Institute for Human Genetics has grown since its inception 12 years ago into a major contributor to the field of human genetics, and over the past several years focused on enhancing clinical genetics at UCSF through some of the initiatives mentioned above.

These efforts are also a reflection of the fact that advances in genomic technology have created an unprecedented time of growth for clinical

genetics. At the same time, the complexity of this information as well as its abundance has created significant challenges for us as a health provider to deliver for our patients the best possible experience when it comes to genetics.

This is where the role of genetic counselors comes in. They traditionally work closely with the entire health care team, and especially the clinical geneticists, to ensure accurate and timely information is provided to patients. Beyond that, they are also critical to families receiving genetic information to make informed and autonomous decisions about their own care, reproductive decisions, and often informing relatives. They also play a critical role in the relationship to payors to ensure proper reimbursement for ordered genetic tests.

It is now well documented that there is a dire shortage of well-trained genetic counselors to take up the work load before us. This is why I see the new UCSF program to train master's degree genetic counselors as a critical step to help fill that need. The program you have designed is cutting edge, and will guarantee that our graduates are both board certified and have multiple professional options upon graduation.

I also believe that, because of our depth and breadth in human and clinical genetics, UCSF offers unique resources for students seeking the most current and broad applications of clinical genetics. What we have been missing is a training program for genetic counselors, and I also see that this new program will enhance our already outstanding educational environment here, bringing new exceptional students to our campus.

With all best wishes for success on your proposal.

Sincerely,

Talmadge E. King, Jr., MD
Dean, School of Medicine

UCIRVINE | UNIVERSITY of CALIFORNIA

January 29, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

I am pleased to support the establishment of a genetic counseling training program at UCSF. We have discussed your plans by phone, and I strongly support the development of more genetic counselors. A program at UCSF would be a welcome addition to the field.

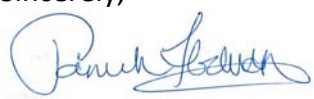
There is a critical need for the development of high caliber genetic counseling training programs to meet the demand for genetic counselors in academic medicine, public health, higher education, and industry. This need will continue to increase as genetics becomes integrated into all aspects of healthcare.

As Director of the Graduate Program in Genetic Counseling at UC Irvine, I am very familiar with the essential ingredients for a successful graduate program. UCSF has the faculty, clinical and research resources (including a strong genetic counseling community) to produce well-trained genetic counselors with the skill and competency to become excellent practitioners.

Identifying appropriate clinical training sites can be an issue for genetic counseling training programs. However, given the distance between our programs, I do not anticipate competition for sites during the school year. We have discussed possible opportunities for students within the UC system to participate in summer clinical training rotations at our mutual campuses, and are looking forward to working together to increase the opportunities for students in both of our programs. This supports our goal of providing a rich training environment for our students across multiple diverse settings.

I look forward to further developing our relationship as the UCSF program becomes established and wish you much success with your program.

Sincerely,



Pamela Flodman, MSc, MS, LCGC
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February 5, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

We are pleased to support the establishment of a genetic counseling training program at UCSF. There is an increasing need for genetic counselors and a program at UCSF would be a welcome addition to the field.

We have first-hand knowledge that UCSF possess all the necessary resources to train genetic counselors. For the past ten years, our CSU-Stanislaus Genetic Counseling Program has been strongly affiliated with the various genetics departments and care providers at UCSF. This pertains to both academic and clinical training as many UCSF employees have served as faculty instructors, clinical supervisors and as thesis research mentors. Additionally, many CSU Stanislaus graduates are now practicing clinicians at UCSF. As we previously agreed with Cindy, Neil and Ophir, we plan to graduate the last cohort of students at UCSF in the spring of 2020. We are grateful for the valuable partnership that the Stanislaus State Genetic Counseling program has had with UCSF.

We are therefore in full support of the development of a program at UCSF. To exemplify our support, we have already served as consultants to Cindy Morgan as she has been working toward starting the program at UCSF and will continue to offer our support and assistance as we go forward. As you may know, there is a current shortage of genetic counselors nationally and a projected need to train an increasing number of genetics professionals in the future. We are delighted that a world-renowned institution such as UCSF will continue to educate the next generation of genetic counselors.

Sincerely,
Laurie Nemzer

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STANFORD
UNIVERSITY

KELLY ORMOND
Professor

January 14, 2018

Cynthia Morgan, MS
Director, Master's Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

I am pleased to write this letter to support the establishment of a genetic counseling training program at UCSF. We have discussed your plans by phone, and the development of a program at UCSF, ultimately replacing the California State University, Stanislaus genetic counseling training program, will augment the training of excellent genetic counselors in the Bay Area and supporting the provision of genetic services for all of Northern California and beyond.

As you know, there is a tremendous need for the development of high caliber genetic counseling training programs across the country, and right now there are nearly 2-3 jobs per graduate. As Director of the Genetic Counseling Master's Program at Stanford University (and previously at Northwestern University), I am very familiar with the essential ingredients for a successful graduate program. UCSF has the requisite faculty, genetics and genomics clinical and research resources, and genetic counseling community to produce exceptionally well-trained genetic counselors who will be well-positioned to become leaders in the field.

The Bay Area has a long history of cooperation in genetics education and in the delivery of medical genetics services. This includes the genetic counseling training programs, with both CSU and Stanford students sharing many clinical rotation sites since 2008. Our programs and the students training are both strengthened by this approach. I look forward to continuing and developing this relationship as the CSU genetic counseling program transitions to UCSF. Obviously the availability of clinical training sites is always a challenge when more than one clinical training program exists in the same region. However, since the UCSF training program will essentially replace the student load of the CSU program, and with the expectation of ongoing cooperation around clinical training sites that we have discussed, I would not expect any significant impact on either program regarding our ability to meet our clinical training needs. I also expect our programs will be able to continue working together on professional education

opportunities for practicing genetic counselors who function as our educators and clinical supervisors.

Maryann, Andrea and I look forward to working with you as a colleague program director and wish you luck in establishment process. If you have any questions, please do not hesitate to contact me directly at 650-736-9847 or kormond@stanford.edu

Sincerely,

Kelly E. Ormond, MS, CGC
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Co-Director, MS in Human Genetics and Genetic Counseling

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January 17, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

We are writing this letter to strongly express our support of your proposed program in Genetic Counseling at University of California, San Francisco (UCSF).

Our program at UCSF Fresno was established as a branch campus of UCSF over 40 years ago to address the shortage of healthcare professionals in the San Joaquin Valley (SJV) of California. The SJV consists of 8 counties spanning 27,000 square miles, covering the southern part of California's Central Valley. Approximately one-quarter of the food consumed in the U.S. comes from the Central Valley, and Fresno County is the number-one agricultural producing county in the nation.

Several aspects of this region present valuable learning opportunities and expose genetic counseling students to a different population mix as part of their training experience:

1) As an agricultural center of California, Fresno is a destination for many immigrant laborers. These migrants predominantly come from Mexico. Many of these families relocate permanently to Fresno County so that a majority of the permanent and transient population in the SJV is of Hispanic origin. Additionally, Fresno has the second largest Hmong population in the United States. In addition to large communities of indigenous individuals from Mexico and Southeast Asia, there are significant population groups from other countries in Asia and the Middle East. The result is a diverse and distinct ethnic population in the SJV, different from that in other large metropolitan areas.

2) Despite its agricultural wealth, 23.4% of Fresno's population lives below the poverty level, compared to 14.3% in the United States. Over 20% of families in the SJV live in high-poverty neighborhoods, defined as areas with poverty rates of 40% or more, with 53% of Fresno households (compared to 41% of California households) having an income below $50,000/year. There are 32 HRSA-defined Medically Underserved Areas in the SJV region centered around Fresno, its largest metropolitan area.

3) Health literacy is lower overall in the SJV. There is limited English proficiency because of the over 100 languages spoken in the area, with 43% of Fresno's population age 5 or older speaking a language other than English at home. About 73% of Fresno's population (compared to 81% of California's population) age 25 and older has completed high school. Immigrants attending school in a foreign country prior to migrating may go through an educational system with different standards and curriculum material than that presented in the United States. Different cultural norms and beliefs in traditional medicine present additive barriers to the accurate transmission of clinical genetic information.

We are extremely excited to be an integral part of the proposed UCSF Genetic Counseling Master's program. Over the years, we have hosted many students from various genetic counseling programs throughout the United States and Canada, including California State University, Stanislaus; University of Colorado; Ohio State; and University of British Columbia. With UCSF's proposed program, we envision greater involvement in the training of prospective genetic counselors by giving lectures and conducting workshops as part of the didactic sessions, in addition to being a featured site for clinical rotations. UCSF Fresno, along with the Community Medical Centers, the largest regional healthcare network in the Central Valley, is a multi-disciplinary practice, with genetic services provided in pediatrics, adult medicine, prenatal, cardiovascular, neurogenetics, cancer, and inborn errors of metabolism. Genetic counseling students rotating through this region learn and observe across all these disciplines, gaining broad training and clinical experiences with a population of rich ethnic and linguistic diversity who face significant socioeconomic challenges and barriers in accessing care.

We wish you the best in this important endeavor, and wholeheartedly and enthusiastically support your proposed program in Genetic Counseling at UCSF.

Sincerely,

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January 11, 2018

Cynthia Morgan, MS
Director, Master's Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, Box 0794
San Francisco, CA 94117

Dear Ms. Morgan:

I writing this letter to express my enthusiastic support for the development of a genetic counseling program at UCSF. As director of the Genomics Minor in the School of Nursing, I have an active role in educating the nursing workforce about the implications of genomics for clinical care. Given the major advances in genomic technologies over the past decade, there is an urgent need for a larger number of genetic counselors and other health care providers with expertise in genomics. UCSF is an ideal academic institution to house an educational program for genetic counselors. This program will be able to leverage the vast existing resources, including the Institute for Human Genomics, the Preventive Genomics Clinic, and the numerous disciplines with specialized emphasis on genomics in clinical care.

It has been our great fortune to access your expertise in genetic counseling, including obtaining family histories and generating pedigrees, in our elective genomics courses over the past several years. I see a lot of potential for collaboration between our nursing students who pursue a minor in genomics and the genetic counseling program. I know we both value interdisciplinary learning opportunities and see the potential multiplicative strengths that may come from collaboration between our educational programs. I very much look forward to continuing to work with you as your program develops.

Please let me know if I may be of any further support at this time.

Sincerely,

Elena Flowers, PhD, RN
Assistant Professor
Department of Physiological Nursing &
Institute for Human Genetics
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Department of Biochemistry & Biophysics

Katherine M. Hyland, Ph.D.,
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RE: Support for Masters in Genetic Counseling program

January 22, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

I am writing to offer my enthusiastic support for the development of a Masters program in Genetic Counseling at UCSF. As the Director of the UCSF School of Medicine's genetics/genomics curriculum and Chair the Medical Genetics Curriculum Committee, I oversee the genetics/genomics content that is integrated throughout the medical school curriculum. I work closely with several genetic counselors who help me develop teaching cases and facilitate small group discussions with the medical students. Their training in clinical genetics, ethical issues and in conveying challenging information to patients and their families make them outstanding teachers and an indispensable part of my educational effort.

Recent advances in decoding the human genome and genetic/genomic diagnostics have changed the practice of medicine. With the new genomic tests recently launched at UCSF, including the UCSF 500 Tumor Panel and the Whole Exome Sequencing test, genetic counselors are in even higher demand to help interpret these test results and convey their clinical utility to physicians and patients. It is of paramount importance that healthcare providers entering the workforce have basic competence and literacy in genomics. Genetic counselors have played a prominent role in the genetics/genomics education for the UCSF medical students for many years. As I mentioned, they have been involved in curriculum development and have served as small group facilitators. Our medical students have benefited immensely from the genetic counselors' ability to illustrate the clinical application of core genetic concepts. I also developed and co-directed a Genomic and Precision Medicine elective with a genetic counselor that was created for medical, pharmacy, nursing, dental, as well as genetic counseling students. The genetic counseling students brought a great deal of clinical genetics/genomics expertise, which greatly benefited the other students in the class. Additionally, these efforts in interdisciplinary education create strong healthcare teams once students enter the workforce.

There are numerous opportunities for collaborative training between our programs. Such partnerships would provide a richer experience for students than one program alone could provide. Additionally, I look forward to creating teaching resources for both programs and exploring the most effective methods to provide genetics/genomics education to the newest generation of clinicians.

I am very pleased to offer my enthusiastic support for your new Genetic Counseling Masters program, and look forward to collaborating with you on genomics education efforts.

Sincerely,

Katherine M. Hyland, PhD
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Jan 26, 2018

Cynthia Morgan, MS
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San Francisco, CA 94117

Dear Cindy,

It is my pleasure to support the efforts to establish a genetic counseling program at UCSF. I work closely with genetic counselors in my medical practice as a clinical geneticist, and genetic counselors play a key role in delivering care. As director of the Medical Genetics and Genomics Residency program at UCSF, I am committed to furthering genomics education for all trainees.

There is a tremendous need for genetics providers. The addition of this genetic counseling program will help serve the needs locally, nationally and in our own institution. Advances in genetics have led to unique opportunities to leverage genomic information in healthcare and in disease prevention. As genetic technology continues to evolve and the complexity of genomic information increases, the number of qualified genetics professionals must increase.

I look forward to partnering with you in training genetic counselors and clinical geneticists. There are many opportunities for inter-professional collaboration in training the next generation of genetics healthcare providers—in teaching sessions, clinical training, and research. Additionally, this new genetics program will complement the efforts of the Institute of Human Genetics and of Medical Genetics to expand genetics education in other disciplines.

I enthusiastically support the new genetic counseling program efforts. I look forward to our future collaborations.

Sincerely,

Joseph T.C. Shieh

Joseph Shieh, MD, PhD
Co-Director, Personalized Genomics Clinic
Program Director, Medical Genetics and Genomics Residency
Institute for Human Genetics and Department of Pediatrics, UCSF
joseph.shieh2@ucsf.edu

University of California
San Francisco

UCSF

School of Medicine
Department of Pediatrics
Division of Medical Genetics

Department of Pediatrics,
Division of Genetics,
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Tel: (415) 514 1783
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January 12th, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
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Clinic Location
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6th Floor, Pediatric Specialties

Physicians
Renata Gallagher, MD, Ph,D
Bryce Mendelsohn, MD, Ph.D
Joseph Shieh, MD, PhD
Anne Slavotinek, MBBS, PhD
Jessica Tenney, MD

Genetic Counselors
Vicki Cox, MS LCGC
Patricia Miranda, MS, LCGC

Dear Cindy

I am delighted to offer my very strong support of the effort by the Institute of Human Genetics and the Department of Pediatrics to establish a graduate program in Genetic Counseling at the University of California San Francisco (UCSF).

Genetics is one of the most rapidly growing fields of medicine and the advances that have occurred as a result of next-generation sequencing have altered the paradigm of medical care. In order to bring precision medicine to the clinic, expert genetic counseling is required. There is an ever-increasing demand for genetic counselors that can only be relieved by increasing the number of training opportunities. At UCSF, we are ideally placed to launch a new graduate program in genetic counseling due to our expanding Division of Pediatric Genetics and our outstanding Genomics Medicine Institute, both of which provide a stimulating educational environment and expert Geneticists and health professionals.

Genetic counselors play a critical role in supporting patients with genetic diagnoses. They help providers to navigate the rapidly evolving world of genetic testing. Counselors are also valuable educators for numerous students, residents, Fellows and physicians who are all involved in providing Genetics care. Their involvement is paramount for the successful delivery of genetic medicine at UCSF.

I state that can commit to supporting the new Genetic Counseling program in whatever capacity I can, including lecturing, mentoring students in their research projects and providing all aspects of a thorough clinical education.

I wish you the best in your endeavor.

Sincerely

Anne Slavotinek, MBBS, PhD
Professor

University of California
San Francisco

Department of Obstetrics, Gynecology and Reproductive Sciences

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Mary E. Norton, MD
Professor and Interim Chair

January 16, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

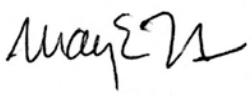
I am delighted to offer my wholehearted support of the effort by the Institute of Human Genetics and the Department of Pediatrics to establish a graduate program in Genetic Counseling. As a board certified Clinical Geneticist, with an active practice in Prenatal Genetics for many years, I have had the opportunity to work alongside, and employ, many genetic counselors. I have a very strong appreciation for the invaluable skill set that they bring to the medical encounter. As the number and complexity of genetic testing options continues to grow, the need for genetic counselors will only increase. As you know, there is currently an acute shortage of genetic counselors, and this important program will serve to meet that need.

It is my belief that the UCSF program will make a significant contribution to the field of clinical genetics while providing the graduates with a strong foundation for employment in clinical settings, industry, or research. I also believe that this new program will enhance the visibility of clinical genetics endeavors already occurring on the UCSF campus and serve as a model for incorporating medical genetics curriculum into other clinical training programs at this institution.

I commit to supporting the new Genetic Counseling program in whatever capacity I can, including lecturing, mentoring students in their research projects, and providing a clinical rotation site.

I wish you the best in your endeavor. Please let me know if I can be of any further help.

Sincerely,



Mary E. Norton, MD
Professor and Interim Chair
Department of Obstetrics, Gynecology and Reproductive Sciences
David E. Thorburn, MD and Kate McKee Thorburn Endowed Chair in Perinatal Medicine and Genetics
University of California, San Francisco

University of California
San Francisco

Laura Esserman, M.D., M.B.A.
Director, Carol Franc Buck Breast Care Center
Professor of Surgery and Radiology
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San Francisco, CA 94115
(415) 885-7691

January 25, 2017

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cynthia:

I am writing to offer my full support of UCSF's proposed new degree, Master of Genetic Counseling. As the director of the Breast Care Center, I have worked alongside genetic counselors for many years and have found them to be valuable members of the healthcare team.

Genetic testing is now standard of care in many types of cancer management and the field of oncology has become a model of how genomics should be incorporated into medical care. Genomic information is currently guiding diagnostics, prevention strategies, treatment decisions and therapeutic management. Genetic counselors are on the front line of this form of personalized medicine and are empowering patients that often feel helpless to their disease. As the availability and complexity of genomic information escalates, the need for professionals trained in the combination of molecular genetics and the psychosocial aspects of shared familial conditions will only continue to increase.

The UCSF Cancer Risk Program is the largest genetic testing center for cancer susceptibility in Northern California. Genetic counselors are the core of this service. I see a UCSF Genetic Counseling program as instrumental to staying current in the field of cancer genomics and feel that it will only enhance UCSF's efforts to provide precision medicine.

I hope that your proposal will be favorably considered as I can think of no better time to train professionals in the complex field of genomics. Again, I am pleased to offer my enthusiastic support for this initiative and I wish you much success with your program.

Sincerely,

Laura Esserman, MD, MBA
Director, Carol Franc Buck Breast Care Center
Professor of Surgery and Radiology, UCSF
Alfred A. de Lorimier Endowed Chair in General Surgery

UCSF Benioff Children's Hospital San Francisco

Department of Pediatrics, Division of Medical Genetics
550 16th St., Mail Stop 0706
San Francisco, CA 94143
PH: (415) 476-2757 / FAX: (415) 476-9305

1/16/2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

It is my honor to enthusiastically support UCSF's Institute of Human Genetics and Department of Pediatrics in their efforts to establish a program in Genetic Counseling.

Genetics has already infiltrated every field of medicine, and will continue to extend its reach for the foreseeable future. As a clinical geneticist, I will be the first to admit that our ability to perform genetic testing on individuals has greatly outpaced our ability to offer skilled interpretation and support for these tests, and we are only getting farther behind. Just as so many fields of medicine are finally embracing patient-centered, non-paternalistic care, how ironic it is that the growth in genetics is occurring through means devoid of human contact, such as online retailers!

Genetic counseling is an important solution to the challenge of delivering personalized, human medicine to every patient with a genome—everyone.

This program will also be a boon for UCSF. Genetic counselors hold positions in private practice, academics, industry, and beyond, filling positions deep within the leading institutions and corporations in the field, even beyond that of physician geneticists. To place UCSF alumni in these roles can only serve to further the University's mission and ambitions.

Whatever I can do to further this program, I offer without hesitation.

Sincerely,

Bryce Mendelsohn MD PhD FACMG
Assistant Clinical Professor
UCSF Department of Pediatrics, Division of Medical Genetics

University of California
San Francisco

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JEFFREY OLGIN, MD
GALLO-CHATTERJEE DISTINGUISHED PROFESSOR OF MEDICINE
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January 16, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cynthia,

I am pleased to offer my support to your efforts to develop a genetic counseling program at UCSF. As a cardiologist working closely with genetic counselors and I strongly believe they play an important role in ensuring comprehensive care to patients with inherited cardiovascular disease.

Genetic testing is a valuable tool for managing individuals and families with inherited cardiovascular disease. It can assist in accurate diagnosis, provide etiology, provide prognostic insights and refine family management. Yet despite all these advantages, genetic testing results in cardiovascular disease are exceedingly complex and these complexities differentiate it from traditional laboratory diagnostics. Advanced concepts such as genetic susceptibility, variable expressivity, incomplete penetrance, reduced detection rates and locus heterogeneity make the application of genomics much more nuanced in cardiovascular conditions as compared to other healthcare specialties. Therefore, importance of healthcare providers, such as genetic counselors, with genetic competency is of the utmost importance.

Additionally, genetic counselors possess a unique skill set for dealing with the strong emotions frequently experienced by cardiovascular patients. Many of these individuals are dealing with chronic life-altering disease or a family history of sudden death and need the psychosocial support provided by genetic counselors. This integrated multidisciplinary approach results in better outcomes for cardiovascular patients and I support the training of more genetic counselors.

I wish you much success in this endeavor.

Sincerely,

Jeffrey Olgin, MD
Gallo-Chatterjee Distinguished Professor of Medicine
Chief, Division of Cardiology
Co-Director, Heart and Vascular Center

UCSF

University of California
San Francisco

Department of Laboratory Medicine

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January 19, 2018

Cynthia Morgan, MS
Director, Master Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

I am writing to offer my wholehearted support for the development of a graduate program in Genetic Counseling at UCSF. Genomic medicine is transforming contemporary healthcare and cytogenetics is at the core of genomic medicine. Chromosomes are the physical carrier of the genome, and their behaviors during the cell cycle determine the patterns of inheritance of the genomic information, including Mendelian inheritance. Cytogenetics studies chromosomal structure and behavior and therefore is the foundation of the genomics and genetics. In addition, cytogenetic aberrations, including chromosome numerical, structural and behavioral changes, are the major cause of known constitutional genomic/genetic disorders and cancer. Training the next generation of healthcare providers to be competent in the field of cytogenetics remains of critical importance.

Genetic counselors are more critical than ever in the era of genomic and precision medicine. They are on the frontline working with patients to navigate the increasing complex array of testing options, conveying results, supporting affected individuals and advocating payers and policy makers for the inclusion and advancement of genetic technologies. Additionally, genetic counselors are employed in laboratory settings, including UCSF, and serve as a conduit between healthcare providers and the diagnostic laboratory.

UCSF is well positioned for a genetic counseling program. The faculty, clinical and laboratory resources, researchers and strong base of genetic counselors make this a solid investment for the university in the delivery and advancement of precision medicine. Again, I am pleased to offer my enthusiastic support for this endeavor. As an ABMGG board-certified cytogeneticist with many years of experience of teaching cytogenetics in multiple genetic counselor training programs, I am willing to aid in the training of your students with my expertise and experience in whatever way I can.

Sincerely,

Jingwei Yu, MD, PhD
Professor and Director
Cytogenetics Laboratory
Tel: 415-353-4809
Jingwei.Yu@ucsf.edu

University of California
San Francisco

UCSF

School of Medicine
Department of Psychiatry

January 9, 2018

Lauren A. Weiss, PhD
Staglin Family/IMHRO Associate Professor

Langley Porter Psychiatric Institute
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Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

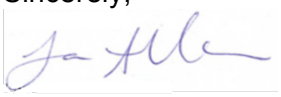
Dear Cindy,

I am writing to offer my enthusiastic support for the efforts by the Institute of Human Genetics and the Department of Pediatrics to establish a graduate program in Genetic Counseling. I strongly believe this program will be a fantastic contribution to the academic environment at UCSF. I have lectured both to genetic counseling students alone and as part of a cross-disciplinary genomic medicine course. My more extensive classroom teaching experiences with the same subject matter, complex human genetics, are with PhD students in biomedical sciences, medical students, and medical residents/fellows. However, bar none, the genetic counseling students are my favorite group to teach – they are genuinely interested and engaged with the subject matter, ask insightful questions, and think actively about applying concepts to realistic situations.

The field of genetics is experiencing an unprecedented time of growth and this has provided opportunities to understand how genetic variations may cause rare disorders and influence more common complex disease. Genetic counselors are more critical than ever as they are not only working with patients to translate this information to medical care, they are a critical component of the research team as well. I have supervised a research project for a genetic counseling student, and she was engaged in the research process at all levels, from designing a questionnaire, distributing it to families, and analyzing the resulting data. This student is a co-author on a current publication *In Revision* at the American Journal of Medical Genetics from my laboratory. Further, I have actively sought and hired on recent graduates from genetic counseling programs as study coordinators. There is no one better qualified or trained to explain a genetic study and possible results to families who may want to participate, and earn their wholehearted trust. Having a program housed right at UCSF, I can only envision more interaction and collaboration with genetic counselors and trainees, and I think the program would not only be well-supported by the medical, academic, and research environment at UCSF, but simultaneously enrich the community around it.

I can think of no better time to establish a new genetic counselor training program in order to facilitate responsible integration of genomic medicine into the healthcare system and the biomedical research that supports health advances. Again, I am pleased to offer my enthusiastic support for this endeavor and am more than willing to offer my support in whatever way I can.

Sincerely,



Lauren A. Weiss, PhD

UCSF Benioff Children's Hospital
San Francisco

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University of Callfornla San Francisco
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NF/Ras Pathway Genetics
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Fax:(415) 476-9305

Neurometabollc Genetics
Tel: (415) 476-9997
Fax: (415) 476-9976

www.ucsfbenioffchildrens.org

Ophir D.Klein,MD, PhD
Professor, Departments of Orofacial Sciences and Pediatrics; Chief, Division of Medical Genetics

Renata Gallagher, MD, PhD
Professor of Clinical Pediatric
Director, Biochemical Genetics and Neurometabolic Program & Clinics

Bryce Mendelsohn, MD,PhD
Assistant Professor of Pediatrics

Anne Slavotlnek, MD, PhD
Professor of Clinical Pediatrics
Director, Personalized Genomics Clinic

Joseph T. Shieh,MD, PhD
Associate Professor of Pediatrics
Director, NF/Ras Genetics
Co-Director, Personalized Genomics Clinic

Jessica Tenney, MD
Assistant Professor of Pediatrics

Jacqueline Chui, MS, LCGC
Genetic Counselor
Medical Genetics

Kelsey McClelland, MS,LCGC
Genetic Counselor
Biochemical Genetics

Marta Sabbadlnl,PhD, MS, LCGC
Genetic Counselor
Biochemical Genetics

Summer Segal, MS, LCGC
Genetic Counselor
Biochemical Genetics
Integrated Pediatric Pain & Palliative Care (IP3)

Kara Weisiger, MS,LCGC
Genetic Counselor
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Jennifer Janov, MPH, RD, CSP
Clinical Dietitian

Allie LaTray, MS,RD, CSP
Clinical Nutritionist

Lisa Ta, DTR
Registered Dietary Technician

Carol Zlatunlch, RD,CSP
Clinical Nutritionist

Janelle Arqulza
Genetic Counselor Assistant

Bren Spates
Practice Manager

Miranda Chiu
Division Administrator

Eve Wiston-Charbonneau
Administrative Coordinator

Cynthia Morgan, MS

January 20, 2018

Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cynthia

I am writing to whole-heartedly support the development of a graduate program in Genetic Counseling at UCSF. I have had the good fortune to be involved with Genetic Counseling programs at four institutions (the Sarah Lawrence program while at University of Connecticut, the University of Arizona program, the Case Western Reserve University program which I helped establish, and the University of California, Irvine program). There is no question in my mind that having those programs added greatly to the university and department, to the clinical genetics programs at the relevant institution, and to the regional communities.

While genetic counselors have been a beneficial component of genetics services for many years, recent unprecedented advances in genomics have led to countless opportunities to use genomic information in health care and disease prevention. As the complexity of genomic information increases, the need for care providers with genetic literacy is outpacing this growth. Genetic counselors are critical members of the healthcare team and work directly with patients and clinicians to ensure accurate interpretation of genomic information, help patients apply the information to their families, support autonomous healthcare decision making based on genetic results, and advocate for patients to payors and policy makers. There is high demand for genetic counselors and this training program will help fill an unmet need.

UCSF offers unprecedented resources for students seeking the most current applications of genomics and precision medicine. These range from the clinical genetics services, to the Genomics Medicine Institute, the Institute of Human Genetics and clinical exome laboratory. All of these will provide graduates with a strong foundation of knowledge and experience.

The genetic counseling program will be a valuable addition to the university and the community. I am extremely supportive of your program and offer my support and assistance.

Sincerely,

Suzanne B Cassidy, MD, FABMG, FAAP
Clinical Professor of Pediatrics
Division of Medical Genetics

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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SANTA BARBARA · SANTA CRUZ

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DEPARTMENT OF NEUROLOGY
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
675 Nelson Rising Lane, Room 214B
SAN FRANCISCO, CALIFORNIA 94158

January 16, 2018

Cynthia Morgan, MS
Director, Master's Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

I am delighted to offer my support for the development of a graduate program in Genetic Counseling at UCSF. UCSF offers unprecedented resources for students seeking the most current applications of genomics and precision medicine, and this program will be a welcome addition to the university.

I have had the opportunity to work with genetic counselors and genetic counseling students in both my clinical and research endeavors. This has included working alongside genetic counselors in clinic (as you know I co-directed the neurometabolic clinic here at UCSF for 10+ years), hiring genetic counselors as research study coordinators, lecturing to students and supervising research projects for genetic counselors in training. In my experience, genetic counselors fill a critical need that is not met by other clinicians or researchers. No one is better to explain complex genetic testing results and assist family members in understanding implications for other family members. With the expansion of whole exome and whole genome testing and the high degree of clinical utility for these tools, the need for genetic counselors will only continue to grow. Additionally, their counseling training enables them to support and advocate for patients and research subjects in ways not equaled by other care providers.

There are currently not enough genetic counselors and as the use of genomic information continues to increase, this deficit will only become more pronounced. More genetic counselors are needed and I can state, without reservation, that this training program is also needed. I am highly supportive of your program and look forward to working with the outstanding graduates from your program.

Sincerely,

Elliott H. Sherr M.D. Ph.D.
Professor in Neurology and Pediatrics

Fax: 415-502-2249

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

SCHOOL OF MEDICINE
DEPARTMENT OF PEDIATRICS

DIVISION OF MEDICAL GENETICS
February 4, 2018

Cynthia Morgan, MS
Director, Masters Degree Program in Genetic Counseling, UCSF Institute of Human Genetics
San Francisco, CA 94117

Dear Cynthia:

I am delighted to offer my strong support for the development of a Graduate Program in Genetic Counseling at UCSF.

Clinical genetics is experiencing unprecedented growth, with advances in genomics leading to opportunities to use genomic information in disease prevention and treatment. In this setting, Genetic Counselors are critical clinician members of the genetic medicine healthcare team. They work with both patients and physicians to ensure accurate interpretation of genomic information, and to assists patients in applying genetic information to patients' individual families. Counselors support autonomous healthcare decision making based on genetic results, and advocate for patients to payers and policy makers. The need for additional and exceptional genetic counselors has never been greater than at the present time.

For well over three decades, UCSF has been at the forefront of graduate education in Genetic Counseling, playing major collaborative roles in the UC Berkeley-UCSF and California State University – UCSF programs. During this time, I have been both an educator and a program director of such graduate training programs, and can attest that UCSF is exactly that kind of academic institution that can provide graduate students in Genetic Counseling with a strong background and knowledge, supporting all phases of clinical applications of genomics and precision medicine.

UCSF resources for the proposed graduate program include diverse and robust clinical genetics services; a Genomics Medicine Institute; an Institute of Human Genetics; and a clinical exome laboratory. These resources are nationally and internationally recognized academic endeavors of excellence, and will provide graduates with a strong foundation for employment as superior clinicians in all current and future settings in genetic medicine.

In sum, the Genetic Counseling Program is necessary, and will be an excellent and timely contributor to the educational mission of UCSF. I am highly supportive of the program, and wish you success as you move forward with your endeavor.

Sincerely,

Seymour Packman, MD
Professor Emeritus, Pediatrics
Director Emeritus, Biochemical Genetics Service,
Neurometabolic Program and Clinics, and Lysosomal Disease Center

University of California
San Francisco

School of Medicine
Department of Pathology

Jessica Van Ziffle, PhD, FACMG
Assistant Clinical Professor,
Department of Pathology
Associate Director, Clinical Cancer Genomics Lab
Director, Genomic Medicine Lab

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23 January 2018

Cynthia Morgan, MS
Director, Master's Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cynthia

I am writing to express my enthusiastic support for the development of a Master's program in Genetic Counseling at UCSF. As a laboratory director in molecular genetics, I see a great need for Genetic counselors who can interface effectively with testing laboratories, clinic teams, and directly with patients.

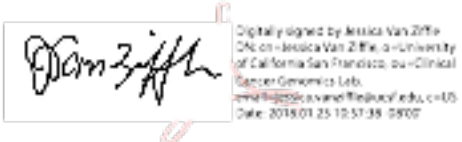
The use of genomic information in the diagnosis, treatment and prevention of disease has dramatically changed the delivery of modern medicine. Determining the root cause of many heath conditions has positively impacted countless patients and allowed for the diagnosis of many conditions previously considered undiagnosable. These advances will only continue as longer and deeper tracks of the genome are interrogated and integrated with other additional approaches to precision medicine.

Genetic counselors play a critical role in the delivery of precision medicine as they are frequently working directly with the patients undergoing testing, explaining results to patients and supporting them after diagnosis. In order to better serve our patients at UCSF, and to reach the full potential of precision medicine, more practicing genetic counsellors are needed.

I am highly supportive of your program and am willing to work with you to develop the Variant Interpretation and Advanced Technologies course, assist in mentoring students and offer the Genomic Medicine Lab as a clinical rotation site.

I look forward to hearing more about the program, and wish you success in its development.

Sincerely,



Jessica Van Ziffle, PhD, FACMG, CGMB
Associate Director, UCSF Clinical Cancer Genomics Lab
Director, UCSF Genomic Medicine Lab

February 11, 2018

Cynthia Morgan, MS
Director, Master's Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965
Box 0794
San Francisco, CA 94117

Dear Cindy,

As a recent Medical Director of the Master's Program in Genetic Counseling at the University of Colorado I am thrilled to know that my current institution, UCSF, is supportive of a program here. The enthusiasm of both the Institute of Human Genetics and the Department of Pediatrics for this program is a testament to the growth of Genetics and genetic testing, and to the recognition among clinical-translational scientists and clinicians of the need for trained practitioners in Genetics. Translation of the rapidly expanding new knowledge in Genetics by those who understand the uses, benefits and limitations of genetic testing is critical. UCSF is at the forefront of genetic testing and its clinical translation, and the preeminence of UCSF in this arena will be furthered by the establishment of a graduate program in Genetic Counseling at UCSF.

Genetic counselors are trained in medical genetics including prenatal genetics, cancer genetics, metabolic genetics, and neurogenetics; and in psychosocial aspects of genetic counseling; and in the techniques and uses of genetic testing. They are invaluable to clinicians and patients who may not fully understand the full limitations and benefits and results of a genetic test. They educate patients and are patient advocates, and can be a resource regarding genetic testing for clinicians.

A graduate program in Genetic Counseling will enhance the visibility of Clinical Genetics at UCSF, and serve as a model for the incorporation of a Medical Genetics curriculum into other degree and training programs at UCSF.

As you know, I am committed to supporting the new Genetic Counseling program in any capacity needed, including as Medical Director, lecturer, and research and clinical mentor.

Sincerely,

Renata Gallagher, MD, PhD
Professor of Clinical Pediatrics
Director, Biochemical Genetic Medicine

January 8, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy:

I am writing to express my enthusiastic support for the establishment of a Masters Program in Genetic Counseling at UCSF. I am thrilled to learn that UCSF is launching a training program. I have much personal experience in Genetic Counseling training as Medical Director of the Joint Hopkins/NIH training program for many years when I was in the NHGRI as well as teaching in the Cal State Program for students rotating through UCSF, and I greatly value the contributions genetic counselors can make to the health care system.

The country desperately needs more genetic counselors and this need will become even more acute as the use of genomic testing grows and expands into areas of medicine for which genetics is not traditionally practiced. Genetic counselors serve a critical role in all aspects of genetic medicine,

- Directly counseling patients before and after genetic testing, including obtaining informed consent
- Providing psychological support for patients and outreach to family members impacted by a genetic diagnosis.
- Consulting with non-genetics providers on how to choose appropriate testing and interpret test results
- Educating patients and providers

At Invitae, in particular, we also employ genetic counselors in important roles such as

- Working in laboratories to design clinically relevant test panels and participating as part of the team interpreting variants found in the course oftesting
- Developing test reports

Students in this program will benefit from the education, training and experiential learning that an institution like UCSF can provide. The long history of training clinical genetics professionals in the Division of Medical Genetics and the Institute of Human Genetics makes it an ideal place for a genetic counseling program.

The Bay Area is rich with opportunities for academic and industry collaborations. Invitae employs a large number of genetic counselors and as a company, we have been involved in training numerous

genetic counseling students. We look forward to supporting your program and continuing as a training site for students.

I wish you much success with your program.

Sincerely,

Robert L. Nussbaum, MD, FACMG, FACP, Diplomate ABMGG
Chief Medical Officer, Invitae
Volunteer Clinical Faculty, Department of Medicine, UCSF

Counsyl

Date: January 22, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cynthia,

I am writing to express my enthusiastic support for the establishment of a Masters Program in Genetic Counseling at UCSF. I have worked with genetic counselors my whole career. Initially as Director of the Reproductive Genetics Unit at UCSF and now as Chief Medical Officer at Counsyl where we employ over 50 genetic counselors.

Genetic testing and genomic information is transforming the practice of medicine. We are in the age of personalized medicine where information from genetic testing is being used to offer accurate diagnoses, guide treatment choices at multiple stages in life and offer strategies for maintaining health. Counsyl has been on the forefront of this change and the company relies on genetic counselors to support both patients and other healthcare providers through complex results as well as the implications and limitations of those results. In addition to providing this support, genetic counselors at Counsyl serve in a variety of scientific and leadership roles.

Counsyl has also been involved in the clinical training of many genetic counseling students. We look forward to supporting your new program and continuing as a training site for students. I wish you all the best in this very important endeavor.

Sincerely,

James D. Goldberg, M.D.
Chief Medical Officer

pwnhealth
123 West 18th Street, 8th Floor
New York, NY 10011
tel 888 362 4321
info@pwnhealth.com

January 15, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy:

I am writing to express my support for the establishment of a Masters Program in Genetic Counseling at UCSF. This is exciting news, and I strongly support the training of more genetic counselors.

As you may know, I have held both clinical and commercial roles in the genetics field at organizations like Kaiser Permanente, Cord Blood Registry, and Veracyte; I also served as the President of the National Society of Genetic Counselors in 2010. I continue my passion for building leaders among genetic counselors by teaching leadership workshops for genetic counseling students across the nation and co-facilitating the NSGC's leadership development program. I am currently the VP of Genetic Services for PWNHealth, where I oversee innovation and implementation of emerging service delivery models to increase access to the expertise of genetic counselors.

The diversity of positions I have held in my career not only demonstrates the broadening application of genetic counseling skills but also gives me a panoramic view of the growing importance of genetic counselors. Expansion of the genetic counselor workforce is essential to capturing the promise of genomic medicine. The gap between the potential and the actual application of genetic technology is widening. Fortunately, genetic counselors are explicitly trained to translate complex genomic science to real-world patient care. As an example, it is this core skill set that has enabled me to lead the growth of clinical practices, provide guidance to the California state newborn screening program, contribute to shaping national policy on genetic counseling reimbursement and oversight of lab-developed tests, and create a new delivery model as a company executive. Many other genetic counselors have followed more and more diverse paths and provide instrumental leadership in their communities and organizations.

The serious shortage of genetic counselors threatens to undermine the promise of precision medicine. New training programs are critical to addressing this documented shortage. The San Francisco Bay Area is an epicenter of genomic technology and therefore an opportune location for training genetic counselors. Establishing a training program would be a visionary investment by UCSF in a growing area of medicine.

Sincerely,

Elizabeth Kearney
VP, Genetics Services, PWNHealth, Inc.
2010 President, National Society of Genetic Counselors

Cbr® From AMAG Pharmaceuticals

January 26, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

I am writing to express my enthusiastic support for the proposed program in Genetic Counseling at UCSF.

As a graduate of a Bay Area genetic counseling training program myself (U.C. Berkeley, 1993), I see this program filling a need not only to provide educational opportunities for California residents, but to help reduce the extreme shortage of genetic counselors the field is facing today. The Bay Area location provides not only expert level experience in medical genetics education, but a wealth of training venues in both traditional and non-traditional roles.

In my current position as Vice President of Scientific & Medical Affairs at Cord Blood Registry, I lead a team of genetic counselors who are responsible for research programs, healthcare education, clinical trial management, and medical needs-based programs. We have hosted a number of genetic counseling graduate students in industry-based rotations in the past and we would welcome the opportunity host UCSF students in the future in order for them to gain exposure to a unique role for genetic counselors working in industry at an umbilical cord blood bank.

I wish you the best in your endeavor, and look forward to collaborating with you in the future to ensure the success of this program.

Sincerely,

Heather Brown, MS, LCGC
Vice President, Scientific & Medical Affairs

illumina®

Tuesday, January 16, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,
I am writing this letter to express my support of the proposed program in Genetic Counseling at UCSF.

Following the sequencing of the human genome, genetics has become a driving force in medical research and is relevant to all aspects of medicine. Illumina has been at the forefront of this transformation and we strive to advance the awareness of the importance of genetics and health. The ability to inquire larger and more complex tracts of DNA requires professionals trained in interpretation of results, and individuals trained in the ability to communicate the complexities to patients and other healthcare providers. Genetic counselors have a unique skill set that allows them to accomplish both of these tasks. Illumina is a strong supporter of medical genetics education and training more genetic counselors is in line with our core values.

Illumina employs many genetic counselors and has served as a clinical training site for numerous genetic counseling students. We would be thrilled to establish the same relationship with the genetic counseling students at UCSF.

I wish you the best in your endeavor.

Sincerely,

Nina Gonzaludo, PhD
Senior Health Analytics Manager
Clinical Genomics Research

Color Genomics, Inc.
1801 Murchison Dr.
Burlingame, CA 94010
(650) 239 9438

January 16, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

We are writing together to express enthusiastic support for the establishment of a Masters Program in Genetic Counseling at UCSF. We strongly support the development of more opportunities for increasing the number of genetic counselors and are thrilled to learn that UCSF is launching a training program. Currently, there is a tremendous need for genetic counselors, and as the use of genomic testing grows this demand will only continue to increase.

Students in this program will benefit from the education, training, and experiential learning that an institution like UCSF can provide. The Division of Medical Genetics long history in the practice and training of clinical genetics professionals makes it an ideal place for a genetic counseling program.

The Bay Area is rich with opportunities for academic and industry collaborations. Color employs a large number of genetic counselors and as a company, and we have been involved in training numerous genetic counseling students as well as educating through lectures and events. We look forward to supporting your program and continuing as a training site for students.

We wish you much success with your program.

Sincerely,

Jill Hagenkord, MD
Chief Medical Officer, Color

Lauren Ryan, MS, LCGC
Head of Clinical Genetics, Color

Helix

1 Circle Star Way, Floor 2
San Carlos, CA 94070
helix.com

Feb 6, 2018

Cynthia Morgan, MS
Director, Masters Program in Genetic Counseling
UCSF Institute of Human Genetics
513 Parnassus Ave, 965 Box 0794
San Francisco, CA 94117

Dear Cindy,

I writing this letter to express my support of the proposed program in Genetic Counseling at UCSF. This is an exciting time to be in field of genetics and the need for more genetic counselors is unquestionable. As a genetic counselor who has worked in clinical practice, academic institutions and private industry I've witnessed the impact genetic information can have on the individual.

At Helix I lead our Policy and Clinical Affairs teams. Working for the first consumer marketplace for genetic/genomic-powered insights is creating even more job opportunities for genetic counselors, whether working to establish policy and ethics standards, working with our partners to develop responsible, patient-centric testing and results experiences, working with genetic counseling services to provide pre- and post-test counseling to consumers, as well as working with product and marketing teams to ensure our tools and communications reflect accurate and effective representation of the impact of genomic data. Throughout my career in industry I have pushed to hire genetic counselors into multidisciplinary roles, where their core skills are applied every day, translating complex concepts and requirements to a broad set of stakeholders. Again and again, genetic counselors have proven that our training sets them up for success and high impact in these settings.

Improved technology and plummeting prices have fueled the use of personal genomic information in healthcare. Genetic testing is no longer limited to those at risk of rare, heritable conditions. The public has become more proactive in managing their own personal health which has led to the expansion of direct-to-consumer testing. This evolution has resulted in a critical need for provider education, public genetic literacy and policy development for the responsible use of genetic information. Genetic counselors nurture skills that are integral to all of these needs. The training genetic counselors receive enables them to take the complex genomic information and apply it not only to the individual, but society at large by helping shape the public perception of genetic testing and development of policy to maintain the value of genetic tests in this new world of genomics

I wish you the best in this endeavor and look forward to the launch of your program.

Sincerely,

Elissa Levin, MS, CGC
Director, Policy & Clinical Affairs
Helix
1 Circle Star Way, Floor 2
San Carlos, CA 94070

PROFESSIONAL STATUS SURVEY 2018: EXECUTIVE SUMMARY

National Society of Genetic Counselors

Facts about the Genetic Counseling Profession

Did you know…?

- ✓ Genetic Counselor was named one of the "25 Amazing Healthcare Support Jobs" for 2016 in an article published by U.S. News and World Report[1].
- ✓ The U.S. Bureau of Labor Statistics[2] projects a growth rate of 29% for genetic counseling positions over the years 2016 to 2026. This far exceeds the average growth rate of 7% for all occupations.
- ✓ Genetic counselors work in a variety of settings, including university medical centers, private and public hospitals/medical facilities, diagnostic laboratories, health maintenance organizations, not-for-profit organizations, and government organizations and agencies.
- ✓ Genetic counselors can work in multiple areas of practice, including prenatal, cardiovascular disease, cancer, metabolic disease, neurology, pediatrics, infertility, pharmacogenetics, genomic medicine, and others.
- ✓ Increasing demands for genetic expertise in varied fields provides genetic counselors new ways of using their training in genetic counseling. These include working in administration, research, public and professional education, web content development, public health, laboratory support, public policy, and consulting.
- ✓ The average salary for a full-time genetic counselor is $88,498[3] but can reach up to $246,000 depending on specialty area and experience.
- ✓ Most genetic counselors have a Master's degree in human genetics or genetic counseling.
- ✓ Nine of ten genetic counselors (91%) report they are satisfied with their current job.
- ✓ The National Society of Genetic Counselors (NSGC), founded in 1979, promotes the professional interests of genetic counselors and provides a network for professional communications. As of 2018, NSGC has over 3,600 members.
- ✓ The American Board of Genetic Counseling (ABGC) is a not-for-profit organization incorporated in 1993 for the purpose of certifying and recertifying genetic counselors. As of the date of this survey, ABGC has over 4,600 certified genetic counselors, an increase of 95% over the number of certified genetic counselors in 2008.
- ✓ The Accreditation Council for Genetic Counseling (ACGC) accredits genetic counseling training programs. As of May 2018, there are 43 accredited training programs in the U.S. and Canada.
- ✓ The Canadian Association of Genetic Counsellors (CAGC) was formed in 1987 with the goal of promoting high standards of practice, facilitating and supporting professional growth and increasing public awareness of the genetic counselling profession in Canada. CAGC has a membership of over 340 genetic counselors.

[1]http://money.usnews.com/money/careers/slideshows/25-amazing-health-care-support-jobs-for-2016
[2]http://www.bls.gov/ooh/healthcare/genetic-counselors.htm
[3]Data from the PSS 2018.

About the Survey

The National Society of Genetic Counselors (NSGC) administers a biennial Professional Status Survey (PSS) to its members. Since the survey was first administered in 1980, results from the NSGC PSS have served many purposes, including establishing benchmarks for salaries and benefits for genetic counselors, identifying workforce issues, and gauging job and professional satisfaction in the genetic counseling community. Data from the PSS originates from genetic counselors who provide direct patient care as well as those who do not provide direct care and work in commercial diagnostic laboratories, research, and public health.

The published reports from the PSS provide a detailed profile of the current genetic counseling community and identify new and emerging trends in this growing profession. The analysis also provides information useful to individual genetic counselors and those who interact with them, including prospective employers, human resource departments, medical associations, as well as individuals who are considering entering the profession or obtaining genetic counseling services.

The 2018 PSS

The Professional Status Survey (PSS) was administered from January 8th, 2018 through February 28th, 2018 to genetic counselors who are either full or new members of the National Society of Genetic Counselors (NSGC), the Canadian Association of Genetic Counselors (CAGC), or diplomates of the American Board of Genetic Counseling (ABGC).

A total of 2,543 completed surveys were received from the 4,780 solicited from the three organizations, resulting in a 53% percent response rate. This is an equivalent response rate to NSGC Professional Status Surveys administered in previous years, and demonstrates the widespread interest in sharing professional information. The response rate also reflects the commitment genetic counselors have to their profession and to the NSGC.

Scope of the PSS

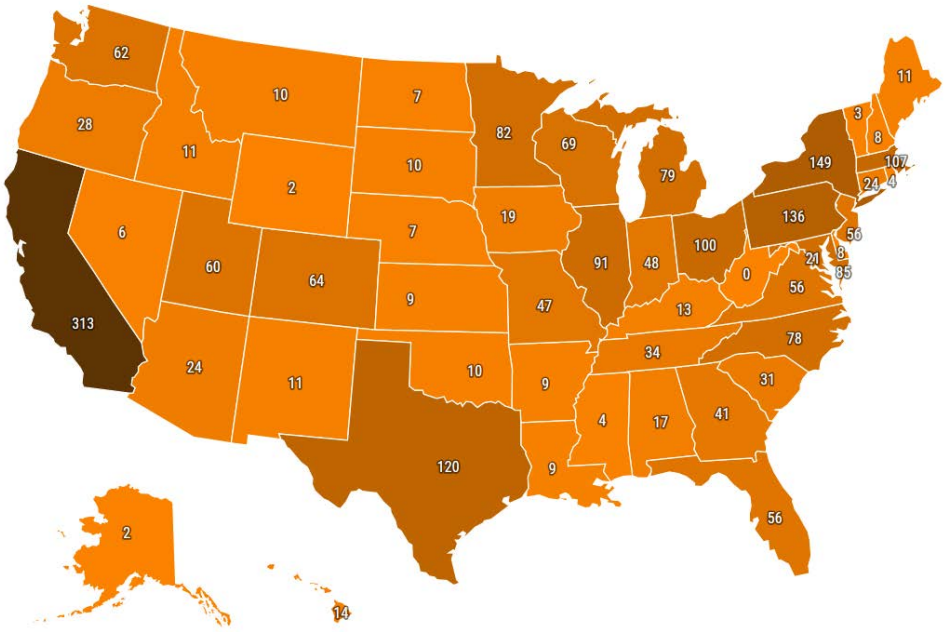
The Professional Status Survey addresses more than 200 questions in the following areas:

- Genetic Counselor Preparation and Education
- Salary and Benefits
- Job Satisfaction
- Job Descriptions
- Work Environment
- Board Certification/Licensure/Credentialing
- Faculty Appointments
- Professional Activities

Geographical Representation

The 2018 PSS generated responses from every U.S. state except West Virginia. Over half of survey respondents (52%) work in ten U.S. states (in descending order; generated from work zip codes): California, New York, Pennsylvania, Texas, Massachusetts, Ohio, Illinois, Maryland, Minnesota, and Michigan.

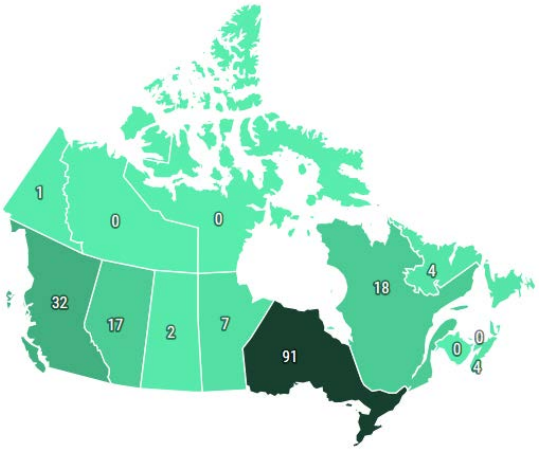
Figure 1. PSS Respondents: United States



Canadian genetic counselors represent a growing share of respondents to the PSS: 5% in 2016, and 7% in 2018. The increase in percentage and overall number of Canadian respondents is due, in large part, to the new 2018 PSS partnership with CAGC. The majority of Canadian respondents work in Ontario (51%), followed by British Columbia (18%).

Please note that the PSS analysis does not show any survey responses by geographical regions where there are fewer than five respondents.

Figure 2. PSS Respondents: Canada



Data Analysis & Methodology

The online administration of the PSS was completed in February 2018. The survey data were independently analyzed by Boston Information Solutions using SPSS[4] version 25. The data were further validated to eliminate inconsistencies, duplicates, outliers, input errors and other data anomalies.

Frequencies and means reported are based on the number of respondents who answered the specific question. Statistical comparisons of group differences, such as T-tests and Chi-Square procedures, are calculated at $p<.05$. More information can be found in the *Demographics & Methodology Report.*

Geographic Data

The 2018 PSS asked genetic counselors to furnish their home zip codes, their work zip codes, and their employer's zip code if they work remotely. Descriptive and comparative geographical data seen throughout the series of PSS reports (U.S. states, major metro areas, NSGC regions, and Canadian provinces) are derived from the work zip codes reported by genetic counselors.

Remote Workers

Approximately one third (32%) of genetic counselors who responded to the PSS work remotely, either some or all of the time. About half of the remote workers are required by their employer to do so as part of their position, and the other half have a flexible role and can decide to work a given number of hours or days remotely.

Among genetic counselors who work remotely 100% of the time (434 genetic counselors, 54% of remote workers), nine of ten (90%) work in a different state than their employer. Our analysis found that the salaries of the remote workers were statistically aligned with the state where they physically work compared to the state of their employing company. In other words, a remote worker who is employed by a California company and works in Colorado is more likely to have a salary on par with Colorado workers than California workers. Therefore, genetic counselors who work remotely 100% of the time are included among other workers in the U.S. state or Canadian province where they work.

Salary Data

Information about the salaries of genetic counselors is one of the most useful aspects of the PSS. The accuracy and specificity of the compensation analyses depends on the willingness of genetic counselors to divulge this sensitive information and trust that it will be held in the strictest confidence.

Over the past two decades, the NSGC has adhered to a strict policy whereby no aggregate salary information will be shared when N<5, or in cases where any individual or group of genetic counselors might be personally identified. Additionally, PSS data are analyzed by professionals with no affiliation to the NSGC and who are not in the genetic counseling community.

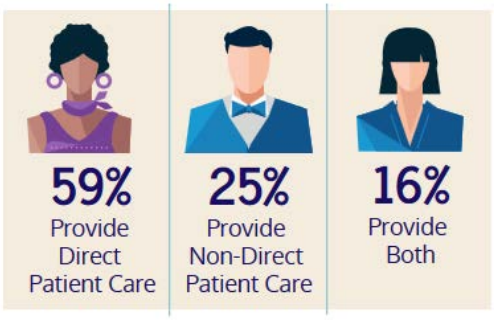
Of the 2,543 total respondents to the 2018 PSS, a record 2,122 (83%) shared salary information. Canadian dollars were converted to U.S. dollars for comparability, as were the handful of salaries reported by genetic counselors who lived or worked outside the U.S and Canada. Statistical outliers (extreme high and low salaries) were removed before analyses were performed using an

[4] SPSS (Statistical Package for the Social Sciences) is a widely used program for statistical analysis in social science.

Interquartile Range Rule of 3. Unless otherwise noted, salary comparisons are for full-time genetic counselors (part-time salaries were not converted into full-time equivalents). Salary information for part-time workers is reported separately. More detailed information about compensation levels for genetic counselors can be found in the *Salary & Benefits Report*.

Genetic Counselor Positions

The majority of PSS respondents reported working full-time (defined as 37.5 or more hours per week). Most respondents to the PSS provide **direct patient care** as a regular part of their jobs (59%), while 25% do not provide **direct patient care**, and 16% provide both[5]. Also, over the past two decades the percentage of genetic counselors who do not provide **direct patient care** has grown as the profession has expanded to include new roles[6].



Three-quarters of genetic counselors work in one of just four settings: university medical center (30%), diagnostic laboratory (commercial, non-academic) (18%), or a public or private hospital or medical facility (31%). As would be expected, those who provide **direct patient care** were more likely to be employed in a hospital or other medical setting than those in **non-direct patient care** or **mixed** positions. Conversely, those who had no direct patient contact were more likely to be employed in a commercial, non-academic diagnostic laboratory.

Cancer and Prenatal were the most frequently cited specific practice areas by a substantial margin – together, they were chosen by 78% of the respondents. This is similar to the total found in the 2016 survey. As in 2016, the next two most common areas reported were Pediatrics and General Genetics.

Table 1. Top 5 Areas of Practice	Direct patient care		Non-direct patient care		Mixed position		Total	
	N	Percent	N	Percent	N	Percent	N	Percent
Cancer	773	52%	214	35%	155	39%	1,142	46%
Prenatal	609	41%	102	17%	91	23%	802	32%
Pediatrics	431	29%	56	9%	94	24%	581	23%
General Genetics	404	27%	91	15%	76	19%	571	23%
Preconception	302	20%	64	10%	69	18%	435	18%

[5] One quarter of the respondents report no **direct patient care** activities. Among those who hold a **mixed** position, only 19% report providing **direct patient care** more than half the time. Because of the importance of this factor, the analyses shown in the PSS reports are presented in tables that separate out the position types as well as totals across the different position types. Statements about differences across groups are made when the difference is statistically significant.

[6] The 2018 PSS is the first to ask about **direct patient care** versus non-direct care, so direct comparisons with the 2016 PSS results are not available. The 2016 PSS asked respondents to self-classify their work as "Clinical," "Non-Clinical," or "Mixed." Of those who answered this question 58% percent said they were in a clinical position, 22% said "non-clinical," and 17% described their position as "**mixed**."

Within their primary **area of practice**, the top roles reported by genetic counselors were clinical care (71%), student supervision (31%), and clinical coordination (28%). Responses varied greatly across those in **direct patient care** positions, **non-direct patient care** positions, and **mixed** positions, as would be expected. For more information please see the *Work Environment Report.*

Salary & Benefits

The average yearly gross salary reported by full-time genetic counselors was $88,498. This is significantly higher[7] than 2016's average of $81,377. The median salary for a full-time genetic counselor was $82,000, compared to $75,000 in 2016.

Salaries differed by the type of position a genetic counselor holds. In general, full-time genetic counselors in non-direct care positions earned the most, followed by genetic counselors in **mixed** positions, and then those in **direct patient care** positions.

Table 2. Full-Time Genetic Counselors	N	Mean	Median	Min	Max
Direct patient care	1,105	$79,364	$76,000	$29,626	$175,000
Non-direct patient care	536	$105,356	$99,558	$46,769	$226,700
Mixed position	332	$91,708	$86,247	$35,100	$246,306

The top ten benefits offered to full- and part-time genetic counselors are shown below. For more information about genetic counselor salaries, benefits, and other forms of compensation, please see the *Salary & Benefits Report.*

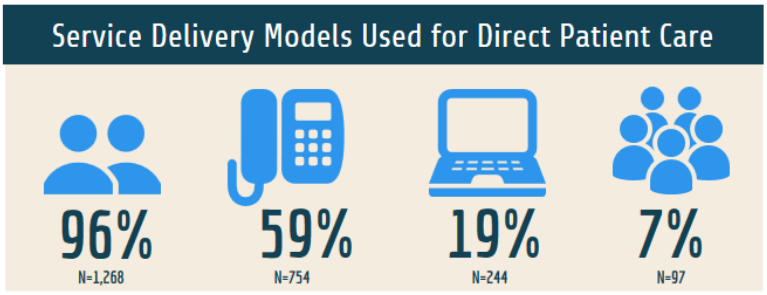
Table 3. Benefits	Full-Time		Part-Time		Total	
Health insurance	2,074	95%	200	67%	2,274	92%
Dental insurance	2,005	92%	180	60%	2,185	88%
Life insurance	1,884	87%	174	58%	2,058	83%
Continuing Education/Conference funding	1,829	84%	192	64%	2,021	82%
Vision plan	1,860	86%	160	54%	2,020	82%
Disability (short or long term) insurance	1,849	85%	170	57%	2,019	82%
Retirement savings (with employer match)	1,671	77%	168	56%	1,839	74%
Pre-tax expense accounts (childcare, medical)	1,408	65%	143	48%	1,551	63%
Accidental death and dismemberment insurance	1,372	63%	132	44%	1,504	61%

Respondents could select more than one item, so the total will not add up to 100%. Percentages reflect the total number of respondents indicating each item divided by the total number who responded to the question.

[7] $p<.01$.

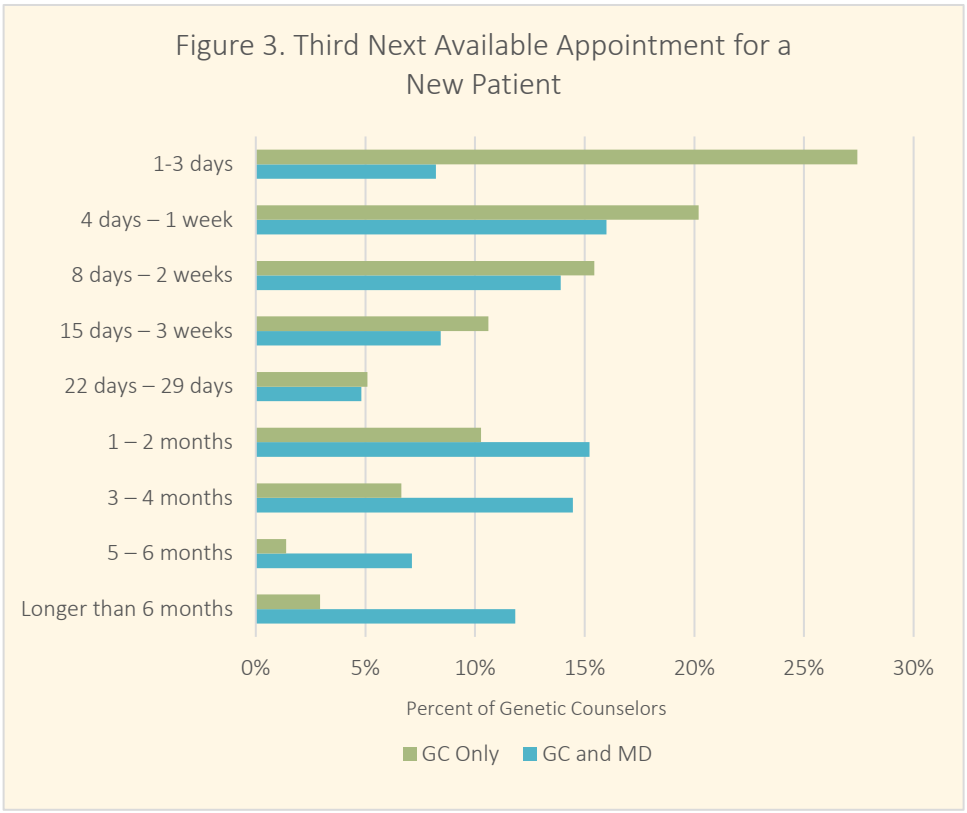
Service Delivery and Access to Care

The most common delivery method reported among genetic counselors is still in-person (96%), followed by phone (59%), web-based or video (19%), and group counseling (7%). Please note that survey respondents could indicate more than one service delivery model as genetic counselors may employ more than one model in providing **direct patient care**. Therefore, the percentages below will add up to more than 100%.



Percentages include **direct patient care** providers and **mixed** care providers who provide direct care to patients more than 50% of the time.

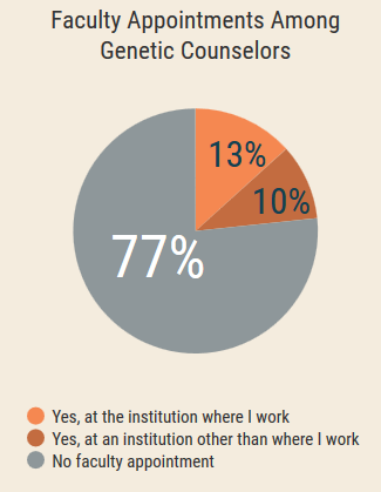
The graph below shows that, for new patients, the wait time (**third next available appointment**) to see a genetic counselor is significantly less than to see a genetic counselor accompanied by a physician. More information by **area of practice** can be found in the *Service Delivery & Access to Care Report.*

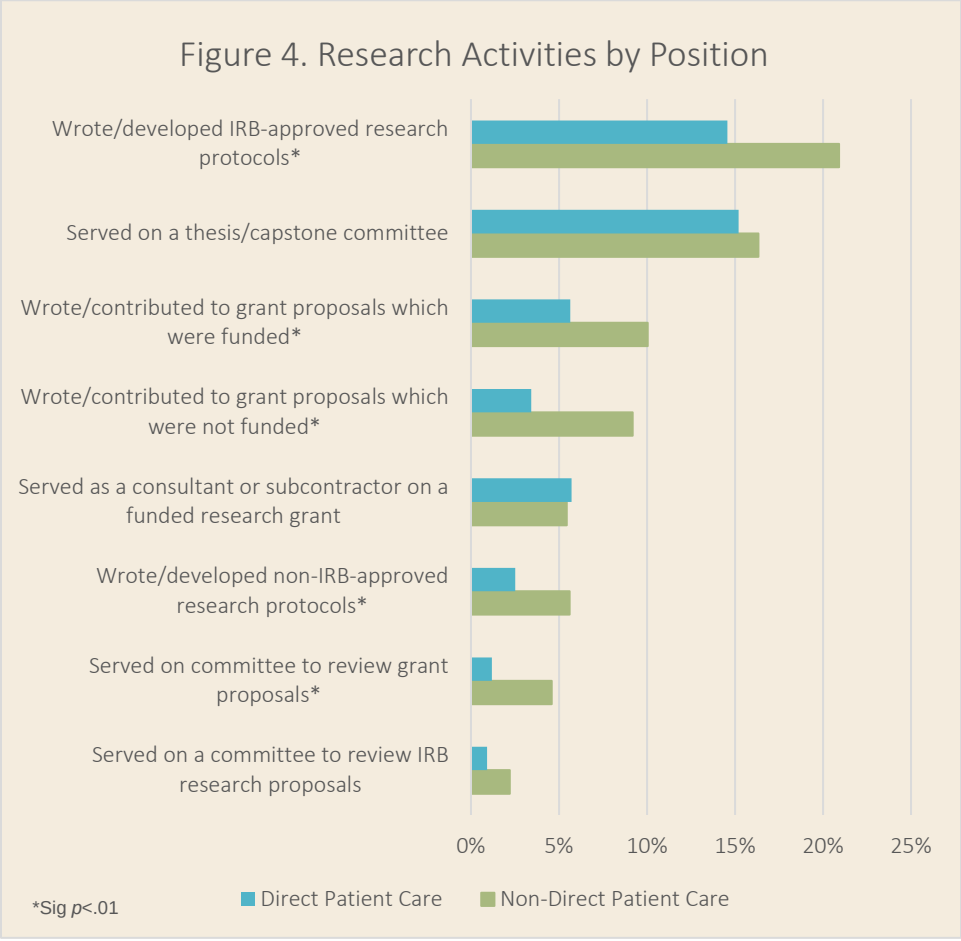


Professional Contributions

Approximately 23% of genetic counselors who responded to the 2018 PSS had faculty appointments. The most common appointment was as an adjunct instructor (16%), followed by assistant professor (14%), and instructor (12%).

One in five genetic counselors reported being involved in research activities (21%). Genetic counselors who do not provide **direct patient care** were significantly more likely to be engaged in research activities than genetic counselors who provide **direct patient care**[8].





[8] $p<.01$

A large proportion of genetic counselors who responded to the PSS were involved in teaching. The most commonly taught audiences were genetic counselors and/or genetic counseling students (69%), followed by medical students (51%), and physicians (47%).

Well over half of genetic counselors who responded to the 2018 PSS (64%) reported that they authored or co-authored publications in 2016-2017. The most common publications were abstracts and/or posters (46%), followed by peer-reviewed original research (24%), and website content and/or web education modules (13%).

In addition, many genetic counselors who responded to the PSS (44%) contributed posters and/or presentations at professional meetings in 2016 and 2017. For more information about the professional activities undertaken by genetic counselors, please see the *Professional Overview & Satisfaction Report.*

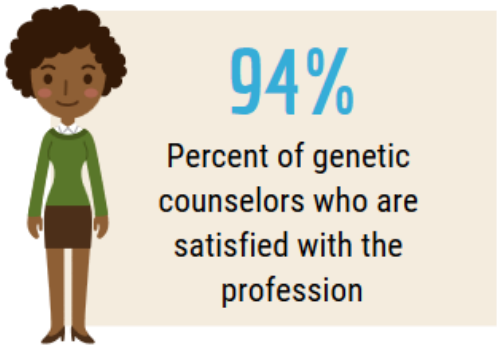
Table 4. Posters/Presentations at Professional Meeting 2016-2017	N	Percent
No posters/presentations	1,398	56%
Yes, poster presentation(s) at a genetics-focused meeting	803	32%
Yes, platform presentation(s)/workshop(s) at a genetics-focused meeting	284	11%
Yes, poster presentation(s) at a non-genetics-focused meeting	178	7%
Yes, platform presentation(s)/workshop(s) at a non-genetics-focused meeting	162	7%

Respondents could select more than one item, so the total will not add up to 100%. Percentages reflect the total number of respondents indicating each item divided by the total number who responded to the question.

Satisfaction with the Genetic Counseling Profession

Almost all genetic counselors who responded to the 2018 PSS (94%) reported they are "satisfied" or "highly satisfied" with the genetic counseling profession. This high level of satisfaction exists regardless of position type (direct patient care, non-direct patient care, or mixed).

For more information please see the *Professional Overview & Satisfaction Report.*



Find Out More

Six reports were authored to document results from the 2018 PSS. Please contact the NSGC if you would like copies of the reports.

1. The Demographics & Methodology Report shows who responded to the 2018 PSS by gender, race/ethnicity, geographic representation, education, years of experience, and many other variables of interest.
2. The Salary & Benefits Report provides detailed analyses of salaries in the genetic counseling profession. The report also provides information about per diem and hourly rates, bonuses and commissions, average raises and extra income, benefits, vacation time, conference funding and employer-funded extras for genetic counselors.
3. The Work Environment Report provides information from genetic counselors about the nature of their work, areas of practice, and involvement in professional activities.
4. The Service Delivery & Access to Care Report details how genetic counselors deliver their services to clients, weekly caseloads, and patient access to genetic counselors.
5. The Professional Overview & Satisfaction Report examines the various facets of satisfaction with the genetic counseling profession.
6. The Executive Summary provides a high-level overview of the survey responses of most interest to members of the NSGC and others who may be interested in the results of the 2018 PSS.

The National Society of Genetic Counselors (NSGC), incorporated in 1979, is the leading voice, authority and advocate for the genetic counseling profession, representing more than 3,600 health professionals. NSGC advances the various roles of genetic counselors in health care by fostering education, research, and public policy to ensure the availability of quality genetic services and is committed to ensuring that the public has access to genetic counseling and genetic testing.

For additional information about NSGC, visit www.nsgc.org.

For additional information about genetic counselors, please visit www.aboutgeneticcounselors.com

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330 N. Wabash Avenue, Suite 2000
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(312) 321-6834

UCSF Academic Senate

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500 Parnassus Ave, MUE 230
San Francisco, CA 94143-0764
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July 25, 2018

Cynthia Morgan, MS, LCGC
Proposed Director, MS in in Biomedical Imaging

Re: Academic Review of the Masters of Science in Genetic Counseling Proposal

Dear Ms. Morgan,

Thank you very much for your detailed response to our review of The Masters in Genetic Counseling Proposal. Again, we remain very enthusiastic about this program and think it will make a wonderful addition to the intellectual, clinical and pedagogical community at UCSF.

We did have some lively discussions among the council members about the few remaining recommendations and so I am reporting back on these. These are sent with the intent of both helping the proposal through the next stage of review and also for ensuring the longevity and success of the program here at UCSF. If you wish to revise your response again, please let us know and the revised response/revised proposal will be forwarded directly without the need for further consideration by Graduate Council. If you do not wish to revise your response/proposal, you should let us know and we will send it on as is.

Here are the final recommendations:

1. Director Position: While the split leadership role makes sense, we highly recommend that you briefly add language indicating that the 50% position for the Director would be for a full time employee at UCSF, or that the program would work to make that possible for whoever takes that role (again, even if the position as Director is only at 50%).

2. Teaching Funds: We remain somewhat worried that although you are following per-hour compensation rules for UC, the proposal seems to underestimate the amount of funding needed for courses in comparison

to other courses at UCSF. Additionally, regarding the voluntary teaching Dr. Bachman, we highly recommend that you add language indicating how you will cover the cost for teaching a required course without an uncompensated volunteer. We highly recommend that you budget for it.

3. GRE: Although we note that you do not require the GRE, the language in the proposal still makes it a strong element of application. In keeping with the trend of the majority of grad programs at UCSF, we still recommend that you drop it as a requirement and component of the application altogether.

4. Electives: Although it is clear there is opportunity for specialization in clinical areas, we still highly recommend adding wording that enables students who may want an intellectual pathway for training that exceeds the program's offerings may be able to pursue that through other electives – that is, enabling students to more fully take advantage of the broad intellectual community that is UCSF.

Once again, these are our recommendations, but we will not require you to make these changes before it goes to CCGA. Our hope, in line with yours, is that this exciting program makes it through the review swiftly and that the program is a huge success here at UCSF.

Vincanne Adams, PhD
Chair, Graduate Council

Cc:
Elizabeth Watkins, PhD, Dean, Graduate Division
Elizabeth Silva, PhD, Associate Dean, Graduate Division
Lilly Fine, Analyst, Academic Senate
Barbara Koenig, Professor of Medical Anthropology & Bioethics Dept. of Social & Behavioral Sciences, Institute for Health & Aging

UCSF Academic Senate

http://senate.ucsf.edu

October 5, 2018

David Teitel, MD
Chair
UCSF Academic Senate
UCSF Box 0764

RE: CEP Review of New Degree Program Proposal Review - Masters in Genetic Counseling

Dear Chair Teitel,

We have reviewed and discussed the Masters in Genetic Counseling new degree program proposal.

Cindy Morgan and Neil Risch met with the committee to answer any questions.

The committee noted that faculty and staff affiliated with the proposal have experience in teaching, but asked whether program personnel have background in education. We were encouraged to learn that the program director has engaged with the renowned UCSF Academic of Medical Educators.

We asked about competitor programs. The field of genetic counseling is growing. Within California there are programs at the Claremont Colleges, CSU Stanislaus, Stanford, and UC Irvine.

We support the proposed Masters in Genetic Counseling program.

Sincerely,

Jennifer Perkins, DDS, MD
Chair, Educational Policy
UCSF Academic Senate
2018-2019

UCSF Academic Senate

http://senate.ucsf.edu

October 12, 2018

David Teitel, MD
Chair
UCSF Academic Senate
UCSF Box 0764

RE: APB Review of New Degree Program Proposal Review - Masters in Genetic Counseling

Dear Chair Teitel,

Academic Planning and Budget has reviewed and discussed the Masters in Genetic Counseling new degree program proposal and we would like to express our support for the program's budget and financial model.

We acknowledge and appreciate the thorough review conducted by the Office of Budget Resource Management and the subsequent revisions that were incorporated as a result. We agree that the proposal meets the criteria of the Policy on Self-supporting Graduate Professional Degree Programs and presents a viable and sustainable program budget.

We approve the proposed Masters in Genetic Counseling program.

Sincerely,

S. Majumdar

Sharmila Majumdar
Chair, Academic Planning & Budget
UCSF Academic Senate
2018-2019

University of California
San Francisco

Michael Clune
Associate Vice Chancellor
Budget & Resource Management
UCSF Finance

654 Minnesota Street, 2nd Floor
San Francisco, CA 94143-0285
tel: 415.476.0944

September 13, 2018

Elizabeth Watkins, PhD
Dean of the Graduate Division
Vice Chancellor Student Academic Affairs

Re: Genetic Counseling Budget Review and Approval

Budget & Resource Management (BRM) has completed a review of the proposal to create a new Master of Science in Genetic Counselling degree program and believe the program's budget to be viable and sustainable. The program meets the criteria of the Policy on Self-supporting Graduate Professional Degree Programs with direct and indirect costs covered by the proposed fee by the third year of inception.

Please find attached a revised budget for insertion into the proposal as it moves forward in the process. BRM staff coordinated with Cindy Morgan on the revision, which more accurately reflects student services costs projections. Due to the higher costs, the initial student fee estimate was raised from $42,000 per year to $44,000 per year.

Please contact me at (415) 476-0944 if you have any questions pertaining to this review.

Sincerely,

DocuSigned by:
Michael S Clune
AA74599114AC46C...

Michael S. Clune
Associate Vice Chancellor
Budget and Resource Management

Cc: Vice Chancellor and Chief Financial Officer Costantinidis
Associate Dean for Graduate Programs Silva
Executive Director Fry
Interim Program Director Morgan

UCSF Cost of Education Model
Self-Supporting Graudate Professional Degree Program

Program: Masters in Genetic Counseling
Chartstring: DeptID-3080-ProjectID

	2020-21 Year 1	2021-22 Year 2	2022-23 Year 3	2023-24 Year 4	2024-25 Year 5
Projected Enrollment First Year Students	11	11	11	11	11
Projected Enrollment Second Year Students	-	11	11	11	11
Total Students Per Year	11	22	22	22	22
Annual Fee Level First Year (Requested Annual Fee Level)	$ 44,000	$ 45,320	$ 46,680	$ 48,080	$ 49,522
Annual Fee Level Second Year (Requested Annual Fee Level)	$ -	$ 44,000	$ 45,320	$ 46,680	$ 48,080
Projected Revenue					
Fee Revenue	$ 484,000	$ 982,520	$ 1,011,996	$ 1,042,355	$ 1,073,626
Gift (e.g. Fee Scholarship) - Student Svcs Fees					
Other- Transfers Other Support					
Total Annual Revenue:	$ 484,000	$ 982,520	$ 1,011,996	$ 1,042,355	$ 1,073,626

Projected Expenses (Level C Accounts)	FTE		Support Model Components $ Per Student	FTE		Support Model Components $ Per Student	FTE	Support Model Components	Support Model Components $ Per Student	FTE	Support Model Components	Support Model Components $ Per Student	FTE	Support Model Components	Support Model Components $ Per Student
Faculty Salaries (As reported on Regents Table 4)	0.12	$ 35,290		0.12	$ 36,348		###	$ 37,439		0.12	$ 38,562		0.12	$ 39,719	
Non-Faculty Academic Salaries		239,480			265,467			273,431			281,634			290,083	
Staff Salaries		100,458			103,472			106,576			109,773			113,066	
Benefits (faculty, staff and IAP)		145,368			156,605			161,303			166,142			171,126	
Occupancy Expense															
Supplies and Materials (general supplies & marketing materials)		15,000			16,500			16,995			17,505			18,030	
Services (GAEL, Campus Recharges, Honoraria, rotation site support)		9,800			22,300			22,969			23,658			24,368	
Travel, Meetings & Entertainment student travel, receptions)		16,000			19,500			20,085			20,688			21,308	
Scholarship/Fellowship (Financial Aid)															
Professional memberships & expenses (eporting fees, memberships)		6,500			6,500			6,695			6,896			7,103	
Subtotal Department Support:		$ 567,895	$ 51,627		$ 626,691	$ 28,486		$ 645,492	$ 29,341		$ 664,857	$ 30,221		$ 684,803	$ 31,127
Student Services Costs (Estimates - subject to change)															
Student Academic Affairs services (excl SHCS)		$ 35,838	$ 3,258		$ 73,826	$ 3,356		$ 76,041	$ 3,456		$ 78,322	$ 3,560		$ 80,672	$ 3,667
Library		18,326	1,666		37,752	1,716		38,884	1,767		40,051	1,820		41,252	1,875
Graduate Division		7,337	667		15,114	687		15,568	708		16,035	729		16,516	751
Campus Community Center Facilities Fee		1,804	164		3,608	164		3,784	172		3,784	172		3,982	181
Graduate & Professional Student Association		297	27		594	27		594	27		594	27		594	27
Associated Students of the Graduate Division		396	36		792	36		792	36		792	36		792	36
Student Health & Counseling Services Fee		12,382	1,126		25,506	1,159		26,272	1,194		27,060	1,230		27,871	1,267
Student Health & Counseling Services Supplemental Fee		1,749	159		3,696	168		3,894	177		4,158	189		4,158	189
Student Health Insurance Premium		59,048	5,368		121,639	5,529		125,288	5,695		129,047	5,866		132,918	6,042
Subtotal Student Services Costs:		$ 137,177	$ 12,471		$ 282,527	$ 12,842		$ 291,116	$ 13,233		$ 299,842	$ 13,629		$ 308,755	$ 14,034
Total Direct Costs:		$ 705,071			$ 909,219			$ 936,609			$ 964,699			$ 993,558	
Net Revenue less Expense (Loss):		$ (221,071)			$ 73,301			$ 75,387			$ 77,657			$ 80,068	
Net Total (Loss)		$ (221,071)			$ 73,301			$ 75,387			$ 77,657			$ 80,068	
Prior Year Carry forward		$ -			$ (221,071)			$ (147,770)			$ (72,383)			$ 5,273	
Net position at 6/30/xx (Reserve)		$ (221,071)			$ (147,770)			$ (72,383)			$ 5,273			$ 85,341	