Genetic Counselors in the Genomic Era—A Fellowship Program to Promote Public Health and Precision Medicine Roles

**This application is being submitted by the following individuals on behalf of the NSGC Public Health SIG

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Project Purpose

The purpose of this project is to provide an educational opportunity on genetics and genomics in public health and precision medicine to future genetic counseling leaders through a national, distance-learning based fellowship that includes opportunities to learn from and network with current leaders in public health genetics/genomics, parents and patients, and other fellows interested in public health participating in the fellowship. This competitive fellowship will be administered by the NSGC Public Health (PH) SIG and accept 50 individuals during the first year, and will include four live webinars, four LinkedIn discussions, an essay or PowerPoint presentation, and an in-person event for fellows, the project team, fellowship faculty, and genetic counseling experts in public health in conjunction with the NSGC Annual Conference. Upon the completion of the first year of the fellowship, the materials will be made broadly available to genetic counselors, healthcare providers, students and the public through the Audrey Heimler Special Projects Award (AHSPA) website.

Statement of Need and Relevance

Public Health Genetics and Genomics is a hybrid field that integrates both public health and genomic medicine with a focus on, "the effective and responsible translation of genomic research into population health benefits."¹ One of the first, and arguably the most successful, public health genetics programs is newborn screening, implemented in the 1960s.² The scope of public health genetics and genomics has evolved significantly from this inaugural program with a number of activities affecting various medical specialties being implemented including establishing the Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group, state cancer genomics programs, and recommendations and a research agenda for direct to consumer genetic tests.^{1,3,4} The recent launch of the NIH All of Us Research Program (formerly known as the Precision Medicine Initiative) in 2016 aims to involve a more diverse population in genomics research, which will likely bring genomics into the offices of primary care physicians and additional specialty physicians in the US.⁵ This growth in scope of public health genetics and genomics as well as genomic medicine is predicted to change the traditional paradigm of genetic counseling, with alternative providers and processes being used to deliver genetic services in some settings.⁶

Accountable care and population management will increasingly involve genetic/genomic services with systems thinking required for leadership roles. NSGC recognizes the importance of the continued evolution of the genetic counseling workforce and meeting the increasing consumer demand for genetic services, as outlined in their 2016-2018 strategic plan.⁷ Many of the recent NSGC Position Statements include aspects of public health genetics/genomics, underscoring the growing importance of public health in genetic counseling.⁸ Furthermore, many genetic counselors who do not indicate public health as their main practice area are engaged in activities related to public health as part of their positions, with most learning associated with performing those activities being "on the job".⁹ This makes it imperative that new genetic counselors receive training in public health genetics/genomics and precision medicine to effectively advocate for and educate patients and the public, stay at the forefront of delivering genetic and genomic information, educate providers and the public, and provide appropriate risk assessment, shared decision making and informed consent for patients through genetic counseling. The proposed Genetics and Genomics in Public Health (GPH) Fellowship provides a new opportunity for students to obtain instruction in public health genetics/genomics and precision medicine via an interactive distance-learning model, and faculty that includes patient advocates and the public, in addition to clinicians and public health experts.

Public health genetics and genomics is recognized as an important part of the education of genetic counseling students. The Accreditation Council for Genetic Counseling (ACGC) includes public health genetics and genomics specifically in Domain I:1: "Demonstrate knowledge of principles of human, medical, and public health genetics and genomics and their related sciences."¹⁰ A 2014 PH SIG survey of Genetic Counseling Program Leadership indicated that 15/16 respondents (93.8%) felt that public health skills concepts for genetic counseling students were either important or very important (unpublished data). While many Program Leaders

who responded to the survey indicated that they currently cover some public health genetics and genomics topics in their curriculum (16/17, 94.1%), 9/13 respondents (69.2%) indicated that time in the curriculum was a challenge to incorporating additional public health topics (Ns vary due to skipped questions). Program Leaders also indicated that they would use a variety of educational materials including public health curriculum with key learning points and learning activities specifically for genetic counselors (12/14), PowerPoint presentations (11/14), and webinars (10/14) if provided by the PH SIG. The expanding scope of public health genetics/ genomics underscores the importance of public health genetics/genomics training options for genetic counseling students. Given the challenges of fitting additional information into the Genetic Counseling Program curriculum, this fellowship fulfills a vital need in additional educational resources for genetic counseling students as well as genetic counselors and other healthcare providers/students.

The use of distance learning in student and health care provider continuing education has become more common during recent years. Currently, NSGC offers 13 online courses and 24 webinars through its online education center.¹¹ While few studies have been done on the use of distance learning in the field of genetic counseling, a 2014 systematic review of distance learning in undergraduate nursing education found that of 13 papers reviewed, 7 found increased knowledge of clinical skills among individuals who participated in online learning compared to in-person learning (53.8%) and 5 papers found no significant difference knowledge between these two groups (38.5%).¹² A mixed-method study of e-learning in graduate nursing students found that 86% of students in the study thought that e-learning was useful in their education regarding clinical skills and 60% felt it was useful in learning practical skills. Most participants (87%) indicated that it would be useful to combine e-learning with face-to-face learning for these skills.¹³ This previous research indicates that distance learning can be an effective method of teaching for students in healthcare professions.

The GPH Fellowship will be offered in a distance-learning format via live webinars and LinkedIn Discussions to first year genetic counseling students who are accepted into the Fellowship Program. From 2013-2017, this fellowship model, which was based off of the Advocate Leaders Program under ACMG¹⁴, was offered through the New York Mid-Atlantic Regional Genetics Network (NYMAC) to genetic counseling, public health genetics, and LEND students in training programs throughout the seven state (and District of Columbia) region. During this time, 54 trainees completed the fellowship (see Supplementary Document 1, ACMG poster of the project).¹⁵ Unfortunately, due to changing deliverables by their funding agency, NYMAC stopped offering the fellowship after 2017. A competitive application process will be implemented for the GPH Fellowship, and through this program expansion by the PH SIG, participation will be open to 50 first-year genetic counseling students in any ACGC-accredited genetic counseling program. The expansion of the GPH Fellowship will provide more students with access each year with plans to expand the fellowship to include other trainees in future years. By providing students who complete the GPH Fellowship with free membership to the NSGC PH SIG, this furthers their continuing education and networking opportunities in this growing area of genetic counseling. Through this program, the NSGC PH SIG will help the genetic counseling field fulfill one of the ten essential services of public health to "assure a competent public health and personal health care workforce."¹⁶

This is a unique opportunity for the future genetic professionals and the clinicians, public health experts, parents, families, and patients (Fellowship Faculty) involved in the presentations and discussions as it is an interactive model with focused discussion on current topics related to public health genetics/genomics. Fellowship faculty will benefit from leadership opportunities to share their experiences and provide valuable insights on specified topics to shape the understanding and value-added learning experiences for future genetic professionals. Parents/families/patients will specifically benefit from networking with other parents/families/patients and genetic professionals. They will also learn about the current trends in genetics and genomics from public health and precision medicine perspectives.

Program Plan

The specific aims of this project are aligned with the concept of SMART objectives, and we propose to conduct

the fellowship activities that are:

- Specific to provide unique educational opportunities to GC students
- Measurable with regard to fellows', program directors', project team's, GPH presenters', and discussion leaders' feedback on the utility and feasibility of this fellowship
- Realistic in offering accessible, interdisciplinary offerings to students to enhance learning experiences
- Aligned with current topics on public and precision health
- Sensitive to time commitment from students and faculty

Specific Aims:

1. Create, provide and evaluate interdisciplinary educational and leadership opportunities in public health genetics and genomics through a 1-year Fellowship Program via distance learning and social media by recruiting up to 50 future genetic counseling professionals during the 1 year project duration.

First year GC students will be recruited through an online application form, which will be distributed through the genetic counseling program directors via the AGCPD list serve. The study team will develop review criteria, review the application forms and select a maximum of 50 students to participate in this online fellowship program. If fewer than 50 first-year genetic counseling students apply for the fellowship, it will be opened up to NSGC members and other students at the discretion of the project directors to ensure a full cohort.

The project team will plan the topics and content of the educational activities (webinars, LinkedIn discussions, and Twitter content) during the preliminary period between the award announcement and funding availability (please see project timeline). Four webinars and corresponding LinkedIn discussions will be planned on current topics in public health genetics/genomics and precision medicine and will be led by topic experts. The learning objectives and discussion questions with relevant reading materials for each educational activity will be shared at least 2 weeks in advance with the fellows. Genetic counselors, clinicians, public health professionals, parents of children with genetic conditions, and patients will be invited to serve as faculty for educational activities and offered an honorarium for their participation.

Fellows will be provided with leadership and networking opportunities such as connecting with students from other institutions, the diverse pool of GPH presenters and discussion leaders, and the project team. They will also read and respond to Twitter questions/posts posted by the by the PH SIG (@NSGC_PubHlthSIG). Leadership opportunities will include but are not limited to completing an essay or PowerPoint presentation on a public health genetics/genomics topic of their choice that could be presented in a class or at a local/regional meeting. These projects will be reviewed by a panel including the project directors, and the students with the top submissions will be asked to present at an in-person event for GPH Fellows to be held in conjunction with the 2019 NSGC Annual Conference. These submissions will also be included with the project documents provided on the AHSPA website. Students successfully completing the GPH Fellowship would also have the opportunity to mentor the next year's participants and/or become faculty for a future GPH Fellowship year. Leadership development throughout the GPH Fellowship will be based on the conceptual framework outlined for the Maternal and Child Health Leadership Competencies, commonly used as part of the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, and will focus on developing leadership skills in the spheres of self and others so that fellows are better prepared to make an impact on the wider community after completion.¹⁷

2. Increase the network of practicing genetic counselors engaged in public health genetics and genomics activities.

We aim to increase the network of practicing genetic counselors engaged in public health via encouraging participation in existing public health genetics/genomics groups. First, fellows completing the GPH Fellowship will be provided with reimbursement for one year of membership in the PH SIG, which will further involve them in the field and encourage them to continue to explore public health applications in genetics and genomics as they

begin their careers as genetic counselors. Through this project, we hope to increase the membership in the PH SIG by 35 members in the year after the completion of the first GPH Fellowship.

Individuals participating in the GPH Fellowship will be introduced and encouraged to participate in other public health genetics/genomics organizations including the APHA Genetics Forum, Academy Health, the Regional Genetics Network, the National Coordinating Center, etc. Furthermore, research in public health genetics/genomics by the fellows will be encouraged via the availability of a competitive research scholarship available exclusively to GPH Fellows.

An assessment will be completed at the end of the GPH Fellowship to determine the number of students who successfully met criteria for completing the fellowship. The number of students who complete the GPH Fellowship during the first year and subsequently join the PH SIG will be assessed. Involvement in other public health genetics/genomics organizations will be assess through the final evaluation, which will include a question asking which public health genetics/genomics groups that the individual has or plans on joining. Finally, engaging genetic counselors in continuing education in public health genetics/genomics through access to the GPH Fellowship educational materials after the completion of the GPH fellowship will enhance the knowledge of current public health genetics and genomics topics and further encourage ongoing work in this area. Ongoing determination of the number of certified genetic counselors accessing the webinars for CEUs will be made over the two year period for which the CEUs would be approved.

3. Evaluate the implementation of the GPH Fellowship and the use of social media and distance-learning to provide educational opportunities to future genetics/genomics leaders by eliciting the knowledge, satisfaction, and feedback of GPH Fellows continuously throughout project planning and implementation.

Each educational activity will be evaluated through online surveys developed in Qualtrics that elicit participant knowledge, satisfaction, and feedback. These will be adapted from evaluations previously used for the NYMAC fellowship (Supplementary Document 2). Surveys will be made available at the completion of each webinar, and a final survey at the end will evaluate the LinkedIn discussions, Twitter content, fellow projects, and overall feedback on the Fellowship. Fellow participation will be tracked throughout the program. Eligibility for receiving a certificate of completion for the fellowship includes: attend at least 3 webinars, participate in at least 3 LinkedIn discussions (at least two substantial comments), submit an essay, PowerPoint presentation, or research proposal, and complete all evaluation surveys including the final evaluation. Participation and evaluation data will be used to improve project implementation in real time and apply for continued funding to make the GPH Fellowship available for future cohorts.

Based on preliminary data, LinkedIn continues to be a preferred social media tool to provide unique educational and leadership opportunities to students, practicing genetic counselors, and parents/advocates.¹⁵ The study team will assess the use of LinkedIn features and address the limitations of the LinkedIn features with additional strategies including targeted use of Twitter for quick announcements and resource sharing (as observed by the increase of genetic counselors on Twitter). The study team will draw inferences from the survey results and discuss the trends, limitations, and strategic options for sustainably offering of this program to future genetics/genomics leaders. Evaluation of the GPH Fellowship and faculty members will be accomplished through an online survey using Qualtrics. The study team will develop these evaluation questions in the project planning phase i.e., the initial two months of the grant period.

4. Make the webinars, discussion questions, and student essays/presentations available to an expanded audience through the AHSPA website, and offer CEUs to genetic counselors who view the archived versions of the GPH Fellowship webinars by the end of the project year.

Given that a small number of genetic counselors report public health as their area of practice (0.5%), but that far more genetic counselors either incorporate or have the opportunity to incorporate some aspect of public health and precision health into their indicated specialty areas, it is important that the webinars be open to practicing genetic

counselors and other stakeholders after the GPH Fellowship is completed.^{9,18} At the completion of the fellowship, educational materials including the recorded webinars, discussion questions, and top student essays/presentations will be posted to the AHSPA website for stakeholders including genetic counselors, public health professionals, medical students and residents, allied health professionals, and/or parents/advocates as part of a support, disease, or advocacy group. These stakeholders will be made aware of the webinars through email communication with and through existing relationship with regional and national agencies such as NSGC, the Regional Genetics Networks and National Coordinating Center for the Regional Genetics Networks, Parent to Parent USA, etc. The PH SIG will apply for CEUs for the archived webinars for genetic counselors.

Project Timeline

Preliminary work on the project will begin prior to fund availability if the project is selected for the AHSPA, indicated on the timeline as P1-P4, corresponding to August-November 2018 (preliminary work may start later depending on award announcement timeline). The funds will not be utilized until December (month 1) with the commencement of the first webinar, when honorariums will begin to be paid. If flexibility in fund availability is not available, the first webinar can either be delayed by 1 month or the honorarium can be paid in January.

Tasks/Months	P1	P2	P3	P4	1	2	3	4	5	6	7	8	9	10	11	12	13
Project team virtual meetings – planning & evaluation	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х
Recruitment through application form and contact		Х	Х														
with program directors (PDs)																	
Student application review (with any required			Х	Х													
discussion with PDs)																	
Selection of GPH Fellowship Class				Х													
Introduction email with instructions				Х													
Webinar & LinkedIn faculty recruitment			Х	Х													
Webinars (1-4: one each month)					1	2		3	4								
Webinar Evaluations (1-4: available for 2 months)					1	2		3	4								
LinkedIn Discussion – 1					Х	Х	Х	Х	Х	Х	Х	Х					
LinkedIn Discussion – 2						Х	Х	Х	Х	Х	Х	Х					
LinkedIn Discussion – 3								Х	Х	Х	Х	Х					
LinkedIn Discussion – 4									Х	Х	Х	Х					
Essay, PPT presentation, or research proposal due												Х					
Review & selection of student projects by Project												Х	Х				
Team & Faculty																	
Review by Project Team to determine individuals who													Х	Х			
meet criteria for GHP Fellowship completion																	
Apply for CEUs for archived webinars														Х			
Plan in-person event in conjunction with NSGC 2019														Х	Х		
Student presentations, certificate awards, networking																Х	
event Nov'2019 NSGC conference (Optional to attend)																	
Final Evaluation & Program Director Survey																Х	
Materials available on AHSPA website																	Х

Sequence of events in implementing GPH Fellowship

Planning Recruitment Activities Evaluation Next Steps

Logic Model

Inputs	Activities	Outputs	Short Term	Long Term
			Outcomes	Outcomes
 Professional GPH Fellowship Project Directors & Advisors PH SIG Members GCs with PH Genetics Expertise Public Health Genetics Professionals Patients/Families First-year genetic counseling students Partners GC Training Program Directors NSGC PH SIG The Jackson Laboratory Parent to Parent Groups Funding AHSPA Funding In-Kind Funding PH SIG Funds Delivery Platforms GoTo Webinar LinkedIn Twitter Qualtrics Accumptione: Students are interested on the second seco	 Develop the curriculum for the 2018-2019 GPH Fellowship Recruit presenters for 4 webinars Recruit leaders for 4 LinkedIn discussions Finalize the schedule Develop presentations for webinars per timeline Develop LinkedIn discussion questions per timeline Develop Twitter updates/schedule Establish application and review process Distribute announcement of the GPH Fellowship to GC Program Leadership Select first GPH Fellowship class Establish final project guidelines & review criteria Plan in-person networking event (NSGC) Develop evaluation surveys 	2018-2019 GPH Fellowship curriculum Finalized 2018- 2019 GPH Fellowship class 4 webinars on public health genetics and genomics topics Discussion questions for 4 online discussion sessions via LinkedIn Evaluation survey instrument	Provide interdisciplinary education and leadership opportunities via distance learning in public health genetics and genomics to up to 50 selected first- year genetic counseling students (or other participants) by the end of the project year. Achieve an 85% completion rate amongst students selected for the GPH Fellowship. Evaluate student participation and satisfaction in the GPH Fellowship and gather feedback from students after completion of the Fellowship. Make the GPH Fellowship webinars and discussion questions available to genetic counselors and others through inclusion on the AHSPA website (CEUs provided).	 Facilitate the expansion of the network of practicing genetic counselors engaged in public health genetics and genomics activities. Increase the NSGC PH SIG Membership by 35 individuals by 2020 Encourage participation by GPH Fellowship participants in the APHA Genomics Forum, Regional Genetics Networks, NCC, etc. Develop a manuscript describing the project and evaluation outcomes for publication, to be submitted 6-8 months after project completion.
Assumptions: Students are int	erested in participating in a di-	stance-learning fellowsh	up on public nealth genetics	genomics; Program

Assumptions: Students are interested in participating in a distance-learning fellowship on public health genetics/genomics; Program Directors are willing to disperse information about the fellowship to students; Experts in public health genetics and patients/families are willing to lead the webinars and discussion forums.

Final Product

The final product of this project will include the implementation of the GPH Fellowship, with plans to continue offering this opportunity annually. The four recorded webinars on current topics regarding Public Health Genetics and Genomics and a companion document containing the discussion questions for the four LinkedIn interactive discussion sections will be made available through the AHSPA website after the completion of the GPH Fellowship. The private LinkedIn group will remain available for use by the GPH Fellowship class to further facilitate networking among the participants. The Project Directors and Project Advisors will compose a manuscript describing the GPH Fellowship and the outcomes of the project evaluation for submission to a peer-reviewed journal for publication. A link to this publication will be listed on the AHSPA website.

Future Plans

Data gathered from this project will be leveraged to secure funding for additional years of the fellowship and to augment efforts to disseminate educational opportunities for genetics/genomics public health training.

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