

Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Training Program

Welcome to the Spring 2016 edition of the Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program Newsletter. This newsletter is intended to highlight exciting achievements and events in the Hopkins/NHGRI community.

PROGRAM UPDATES

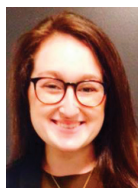
Welcome to the Class of 2019!

We are elated to introduce our incoming class of students. Although I am sure that they are looking forward to enjoying the summer, we are anxiously awaiting their arrival in the fall!



Katherine Anderson

Katherine Anderson graduated from the Honors Program at Miami University in 2014 with a B.A. in Zoology, Speech Communication and Environmental Science. She is currently an educator at the Cosley Zoo in Wheaton, IL and previously worked at Disney World as an Animal Behavior intern. Katherine has volunteered as a group facilitator for Growth from Grief, a program for children mourning the loss of a loved one. As an undergraduate research assistant, Katherine worked on research using voles as a model for evolutionary biology and behavioral neuroscience.



Alexa Geltzeiler

Alexa Geltzeiler will graduate in May from NYU with a bachelor's degree in psychology. She is currently working on her senior thesis on the effects of self-esteem upon the interpretation of supportive messages in romantic relationships. Alexa worked as a helpline operator at the National Eating Disorders Association from 2014 to 2015. She is also assisting NYU Professor Eric Brenner on a paper on a laboratory exercise examining polymorphisms at the phenylthiocarbamide (PTC) locus. Alexa studied abroad in London in 2014.



Chenery Lowe

Chenery Lowe graduated from Kenyon College in 2014 with a B.A. in French Area Studies. She also minored in Chemistry and Humanities. Last year, Chenery worked as a primary and middle school teaching assistant in Dax, France. She is currently volunteering as an intern at the Genetics Department of the UCSF Hereditary GI Clinic Cancer Risk Program. While at Kenyon, Chenery was a competing member and officer of the equestrian team. She now puts those skills to

use as a dismantled education coordinator at Redwood Hills Pony Club.



Ahna Neustadt

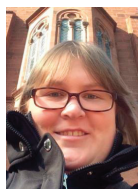
Ahna Neustadt grew up in Newbury Park, California. She graduated in 2014 from the University of California, San Diego with a B.S. in Biochemistry and Cell Biology. As an undergraduate and Amgen Scholar at UCSD, Ahna worked on a cancer immunotherapy nanoparticle vaccine research project at Genelux and the Moores Cancer Center. She also co-founded the first UCSD undergraduate interdisciplinary research journal, called *Equilibrium*, which emphasizes the importance of ethics in research. Following graduation, Ahna began shadowing genetic counselors and working as an academic specialist and after-school program coordinator at Maple Elementary School. She is also currently serving as an intern with the BreakThrough Student Assistance Program, which assists middle school and high school students and their families with navigating the local school system. Ahna is excited to pursue her interests of cancer genetics, teaching, patient care, and public health policy during her training in the field of genetic counseling. She is thrilled to be joining the JHU/NHGRI Genetic Counseling Program and is excited to live on the East Coast. Ahna enjoys singing, cooking, and swimming.

Reaccreditation

We are pleased to report that the Johns Hopkins/NHGRI Genetic Counseling Training Program was recently reaccredited by the ACGC for 8 years. In preparation for submitting our accreditation application at the end of last year, we carried out a self-study that included reflection on our strengths in genomics, therapeutic counseling, and social science research; on the accomplishments of our current students and alumni; and on possible opportunities for change in response to the ever-evolving genetic counseling landscape. We wish to thank the many alumni, faculty, supervisors, and students who dedicated their time to the self-study process, as well as the more than forty individuals who offered their time to be interviewed by the site visitors.

Welcome to our New Program Coordination Team

This year, we welcomed new staff at both the NIH and Johns Hopkins campuses. Although it was difficult to say goodbye to Chris Anderson and Mary Ann Dunevant when they retired last year, we were fortunate to have **Alexis Heidlebaugh** join us as our NIH program coordinator and **Jami-Lin Williams** join us as our Hopkins program coordinator. If you have business with the program, you'll likely be hearing from one or both, but feel free to say hello anytime!



Alexis Heidlebaugh

Alexis is originally from York, PA; a small suburban city in South-Central PA. She graduated from Philadelphia University in 2013 with a BS in Pre-Medical Studies and a Minor Concentration in Genetics. Her future plans include going to graduate school to become a genetic counselor, working in maternal-fetal medicine or pediatrics, and having a family. In her free time, she enjoys exploring new and interesting places, spending time with her family and friends, and taking-in the beauty of nature. She says that she is truly blessed to work with a bunch of amazing students, fellows, and faculty and sends thanks to everyone for graciously welcoming her to the GCTP.



Jami-Lin Williams

Jami has worked part-time at JHSPH since 2013 as a RIAS Coder for Dr. Roter's research on patient-provider communication. Originally from Maine, Jami graduated from Wellesley College in 2011 with a B.A. in English and Spanish. She received her M.A. in Iberian and Latin American Cultures from Stanford University in 2012 before deciding to pursue a career in health sciences. Last year, Jami completed the post-baccalaureate premedical program at Goucher College and began volunteering at the Esperanza Center Clinic for undocumented immigrants. Jami is an avid runner, a dedicated fan of the New England Patriots and she enjoys exploring Baltimore's vibrant arts and food scenes. She is looking forward to supporting the students and faculty of the Genetic Counseling Training Program while gaining research experience in the social and behavioral aspects of healthcare.

Professional Development Seminars

As is our tradition, we hosted two professional development seminars during this academic year. On December 4, supervisor and alumna Kendra Schaa [11] and long-time supervisor Debbie Lantz engaged the students in a discussion about mentorship and supervision skills. On February 26, we were joined by David Michael, JD, Deputy Ombudsman of the Center for Cooperative Resolution of the NIH Office of the Ombudsman. He engaged the students in some case scenarios to consider conflict negotiation in the workplace.

Congratulations to the Class of 2016

On January 15, 2016, in the Cloisters Lecture Hall on the NIH campus, we celebrated the graduation of Claire Anderson, Kyle Davis, and Jenn Kohler from the GCTP. It was a joyous occasion, as family, friends and colleagues gathered to recall fond memories, share in their accomplishments, and anticipate the many great things to come. It was, as always, difficult to say goodbye, but we look forward to hearing from them frequently and to many future collaborations!

The students began the celebration by presenting their thesis research in a symposium. The titles of their presentations were:

Claire Anderson

Are genetic counselors screening adolescents for suicide risk?
A mixed-methods study
Advisor: Lori Erby

Kyle Davis

What counts? The role of numeracy in interpretation of personalized genomic risk information in Coriell participants
Advisor: Bill Klein

Jennefer Kohler

Personal utility in genomics: A mixed-methods study identifying key elements
Advisor: Barbara Biesecker



The graduates. (Pictured are Claire Anderson, Kyle Davis, and Jenn Kohler, left to right)



GCTP Program students and recent alumni. (Pictured are Hannah Wand, Jenn Kohler, Devon Bonner, Celeste D'Amanda, Lydia Hellwig, Rachel Gore, Mike Setzer, Emily Bonkowski, Kyle Davis, Katie Fiallos, Yingyue (Annie) Li, Claire Anderson, and Anna Chassevent, left to right)

Where are they now?

After developing strong relationships during a summer internship, **Claire Anderson** took a job as a genetic counselor at the Ferre Institute, a non-profit genetic counseling program in Binghamton, New York that serves a large rural region. She has very much enjoyed getting to work with the under-served populations in the region. In other news, she

and Jesse are getting married in June at her parents' farm in Ohio. In the meantime, they have been spending their free time getting their own fruit and vegetable gardens going!

Kyle Davis moved to Austin, TX, where he is working remotely as a genetic counselor with Lineagen providing support to providers with questions about genetic testing for developmental delay, intellectual disability, and autism spectrum disorders. He is also providing telephone genetic counseling to clients undergoing chromosomal microarray and sequencing testing. He and Jenny recently bought a house and are settling in. In between work and spending time with Jenny and Gabe, he is also enjoying some time to continue his writing.

Jenn Kohler started her job as a genetic counselor working in the Stanford Center for Undiagnosed Disease shortly after graduation. She is enthusiastic about using the latest genomic technologies to improve and expand the impact of genetics in medicine and is especially passionate about doing so in a way that cares for the whole patient - emotionally and physically.

CATCHING UP WITH THE CURRENT STUDENTS

Since we last checked in, the current second year students have been busy with clinic, classwork, and planning for thesis data collection. While it's impossible to distill all of their adventures into a few short lines, this should give you a flavor for what they have been up to.

Devon Bonner spent 8 weeks last summer in sunny southern California completing a cancer rotation at the City of Hope Medical Center. She returned to complete rotations at Children's National Medical Center, that National Human Genome Research Institute, and the National Institute of Neurologic Disease and Stroke. For her thesis research, she is excited to be collaborating with Moffitt Cancer Center and the City of Hope to administer a survey to individuals who have received a variant of uncertain significance in order to examine relationships between the clients' perception of uncertainty related to their result and their recollection and interpretation of the genetic information communicated by their provider at the time of result disclosure. While collecting data this summer, she will also be rotating with Katie Lewis with the NHGRI ClinSeq study.

Celeste D'Amanda worked last summer with Julie Cohen ['09] in pediatric neurogenetics at the Kennedy Krieger Institute. She also completed second year rotations at the National Eye Institute and with the Johns Hopkins Institute for Genetic Medicine. Celeste will be spending her summer completing qualitative interviews for her thesis designed to explore parental expectations and hopes related to Fragile X syndrome clinical trials. She will also spend a couple of weeks exploring the life of a lab counselor at GeneDx.

Katie Fiallos completed a six-week genetic counseling clinical rotation in Santiago, Chile last summer where she was able to combine her Spanish skills with her genetic counseling by conducting sessions in Spanish. She also had the opportunity to experience and come to understand the culture and medical system in Chile. Upon returning to Baltimore, she completed rotations at the Johns Hopkins Institute for Genetic Medicine and Walter Reed National Military Medical Center. This summer, Katie will be conducting free-listing interviews in Spanish for her study exploring Latina's causal attributions of breast and colon cancer and mental models of disease inheritance. In addition, she will be counseling research participants with Ellen Macnamara ['14] in the NIH Undiagnosed Disease Program.

Lydia Hellwig completed an eight week summer rotation at Froedtert Hospital & the Medical College of Wisconsin where she participated in cancer, neurology, and adult counseling sessions, worked on research project regarding panel testing, worked on variant classification, and generated patient education tools. She then completed second year rotations with Katie Lewis ['08] at the NIH ClinSeq study, with Howard Levy at Johns Hopkins, in the pediatric genetics clinic at the Walter Reed National Military Medical Center, and in the cancer department of the Greater Baltimore Medical Center. This summer, Lydia will be collecting data for her thesis that involves a survey of ClinSeq participants to assess if patient perceived uncertainty, risk perception, risk comprehension, and behavioral intentions differ based on the hypothetical variant pathogenicity classification that they receive. In addition, she will be gaining additional clinical experience at the National Human Genome Research Institute.

Michael Setzer spent two months last summer with the Amish community at the Clinic for Special Children in Strasburg, PA. After returning to Baltimore, he completed rotations at the Johns Hopkins Cancer Center, the National



The first year "G-Nomes" at Halloween



First, second, and third year students heading out on the town for Halloween

Institute of Neurologic Disease and Stroke, and at Walter Reed National Military Medical Center. This summer, watch for an opportunity to participate in his thesis study exploring a novel remote method for the study of genetic counseling communication. In addition to collecting data for his thesis, Mike will also gain additional clinical experience at the NIH.

The current first year students (Emily Bonkowski, Anna Chassevent, Rachel Gore, Annie Li, and Hannah Wand) have been busy with classes, clinic, and early thesis question exploration while also just becoming acclimated to life in the program and in the Baltimore/Washington metro area.



Hannah and Emily busy at the NSGC booth for USA Science and Engineering Festival



Rachel and Anna pose between visitors at the NSGC booth for USA Science and Engineering Festival

In addition to all of that, the first and second years each made time to celebrate an early DNA Day by staffing the NHGRI and NSGC booths at the recent USA Science and Engineering Festival, the largest such festival in the country.

After the summer Public Health Genomics course ends, Emily, Anna, Rachel, Annie, and Hannah will be heading off to exciting summer placements. Stay tuned for all of the details in the fall newsletter!

THE GCTP AT THE NSGC AEC



A sampling of student, alumni, and faculty presenters at the NSGC AEC



Having fun at the reunion!

Faculty, students and alumni participated in an invigorating meeting in Pittsburgh in the fall. In all, twelve members of our alumni presented at the meeting in some fashion (two were involved in plenary presentations, two in pre-conference symposia, two in EBS's, three in platform presentations, seven in the poster session, and one chaired the meeting). We also had one student present a platform presentation and four students present posters. Our program had an incredible showing, and our reunion at the farm to table Six Penn Kitchen was perhaps the best attended to date. Such fun to see everyone!

LEADERSHIP COLUMN

By: Lori Erby

I am pleased to write the inaugural entry for our newest feature, a column devoted to exploring the ways in which our alumni have taken on leadership roles in genetic counseling. Since its inception, the program has set out to train creative and flexible thinkers who are prepared to grow into leaders. During our recent self-study, we challenged ourselves to take stock of our progress in this regard, and several participants suggested that the newsletter would be an ideal forum for furthering the conversation.

In our discussion about leadership, people offered up many ideas. Leaders were seen as those whose thoughts and actions inspire change, who teach others to grow, who build confidence in those around them, who capitalize on their own gifts in a way that allows others to achieve. When considering leaders in genetic counseling, we noted that it was easy to come up with visible examples of leaders – those who move the various organizations (NSGC, ABGC, ACGC, etc) through traditional leadership roles on Boards of Directors or through chairing committees or Special Interest Groups; those who regularly speak in public forums; those who write papers or columns that provide influence. However, we also noted that the less visible leaders are equally important in moving the profession. Those include genetic counselors who have created innovative positions, defining new roles for themselves and their colleagues. They include individuals who have worked quietly for change within their own communities and institutions to promote improved services for our clients. They include individuals who use their voices to further the missions of committees, task forces, and working groups upon which they serve in a “non-leadership” capacity. They also include genetic counselors who have contributed to the broader conversation about the role of genetics and genomics in our society through work with non-genetic counseling organizations. The list could go on. We have witnessed examples of both highly visible and somewhat hidden leadership among our alumni, and we are certain that there are many examples that have yet to come to our attention. We hope to use this column as a forum for sharing your leadership stories in the hope that this may further inspire others to discover their own leadership potential.

Our intention is to highlight the story of one alumnus in each newsletter. We would therefore welcome submissions of short essays reflecting on your personal leadership journey. In what ways have you instigated change? What do you find yourself doing outside of your basic job description (either within your organization or outside) simply because you care? You may not have thought of some of these as “leadership”, but we encourage you to consider the broader ideas presented above as well as your own concepts of leadership as you reflect on the many ways in which your actions might be shaping

the future of genetic counseling. We will also reach out to actively seek these stories if we don't receive submissions, so don't be surprised to hear from us. In doing so, we are hoping to represent leadership of all types and at all stages of one's career development. We look forward to continuing the discussion!

Looking to get involved but feel uncertain about where to start? A primer on genetic counseling organizations

Although far from comprehensive, we highlight here three national organizations through which you can work to shape the future of genetic counseling.

NSGC (National Society of Genetic Counselors) This is our professional organization. Its mission is to “advance the various roles of genetic counselors in health care by fostering education, research, and public policy to ensure the availability of quality genetic services.” There are a number of formal committees, working groups and special interest groups working toward achieving that mission. If you are interested in becoming more involved, reach out to one of the chairs of the group that interests you.

ABGC (American Board of Genetic Counseling) This is the body responsible for genetic counselors' certification and recertification. Its mission is “to protect the public by setting certification standards and provid[e] leadership to promote the value of certified genetic counselors.” There are often committees and task forces looking for volunteers. The Certification Exam Committee currently needs people who are willing to learn the process of writing exam items.

ACGC (Accreditation Council for Genetic Counseling) This is the body responsible for accrediting genetic counseling training programs. Its mission is to “advance quality in genetic counseling education by developing standards, and by evaluating and accrediting programs.” The most direct routes toward having a voice within the ACGC are to volunteer with the program review committee or to serve as a site visitor.

ALUMNI NEWS

Professional News

Yelena Kemel ('99) shares that she returned to Memorial Sloan Kettering Cancer Center in February (where she used to work as a clinical cancer genetic counselor) as a Program Manager for the newly established Niehaus Center for Inherited Cancer Genomics. In this role, she will be supporting the operations of the growing genomics research program as well as working on building the institutional germline variant knowledgebase and curation of germline data for ongoing research projects. She reports that she is happy to work again with many of her former colleagues, and is excited to return to her walking commute!

Lori (Hamby) Erby ('00) was elected to the Board of Directors of the American Board of Genetic Counseling in January, 2016. Thanks to alum **Matt Thomas ('07)**, 2015 Chair of the ABGC Nominating Committee for the encouragement!!!

Kira Dies ('03) was named to the Professional Advisory Board of the Tuberous Sclerosis Alliance and reports that she has her first published book chapter, entitled "Genetics of neurocutaneous disorders: Basic principles of inheritance as they apply to neurocutaneous syndromes" in the Handbook of Clinical Neurology. <http://www.ncbi.nlm.nih.gov/pubmed/26564068>

Sarah (Smith) Zentack ('05) is happy to report that, after 710 days and 19,900 miles of bicycling, she and her husband Scott made it to Ushuaia, Argentina, the southern-most city in the world. She says that it was such an amazing experience that, upon returning home, they decided for an encore tour to Europe, where they rode for 3 months from Oslo, Norway to Rome, Italy. They are now Stateside, and Sarah has settled in with a job at InformedDNA, where she is co-workers with her classmate **Tricia (Gasser) See ('05)**!

Meredith Weaver ('06) is currently serving as the President of the Accreditation Council for Genetic Counseling after her election to the Council in 2014.

Matt Thomas ('07) reports that he did a brief interview for a public radio segment, *With Good Reason*, on cardiovascular genetics. Check out his wisdom at: <http://withgoodreasonradio.org/episode/health-in-the-heart-and-mind/>

Colleen (Brown) Caleshu ('07) shares the accomplishments of a very busy and inspiring year! She is currently vice chair of the NSGC Education Committee, is on the ClinGen cardiovascular domain working group and on an American Heart Association writing committee regarding secondary findings. She presented at the ASHG meeting in October, gave invited talks at American College of Cardiology and American Heart Association meetings, and was co-author on a 2016 paper on the role of genetic counselors in cardiac care that was published in *Cardiology in Review*. While doing all of this, she was promoted to Lead Genetic Counselor and now leads a team of six genetic counselors. Check out one of her media appearances in which she promotes the need for genetic counselors in cardiac care: <https://www.youtube.com/watch?v=weFEzEqXUHg>

Courtney (Nichols) Berrios ('08) received the Research SIG Grant Award at the end of 2015, with funding for her project entitled, "Do Quality of Life and Illness Perceptions in Individuals and Parents of Individuals with Hirschsprung Disease Impact Interest in Reproductive Genetic Counseling and Testing?" Her survey was scheduled to launch earlier this year. Courtney also reports that she has recently accepted

a position as a research genetic counselor in the Center for Pediatric Genomic Medicine at Children's Mercy Hospital, which means that she will be returning to her hometown of Kansas City, MO this summer. This of course means big changes for her and her husband, but they're very excited for a new adventure!

Gillian Hooker ('09) reports an exciting new challenge – she has joined the leadership team at NextGxDx as the Vice President of Clinical Development. Congratulations!

Amanda Singleton ('10) reports that, after 5 years with GeneDx, she has transitioned from her position as the cardiology program manager to a position as cardiology specialist on the whole exome sequencing team.

Christy (Haakonsen) Smith ('11) has started a new position at the Institute of Genetic Medicine at Johns Hopkins seeing general genetics patients. She reports that she also continues to serve as the co-chair of the NSGC Cancer SIG Research Subcommittee and has stayed involved in the EDS community by organizing monthly meetings with local providers to discuss relevant cases and co-morbidities in patients.

Neha Kumar ('11) was interviewed last month for a story about genetic counseling and testing on NPR. She represented the profession well! If you missed it, you can find it here: <http://www.npr.org/sections/health-shots/2016/04/18/473066953/more-people-seek-genetic-testing-but-there-arent-enough-counselors>

Leila Jamal ('12) was a co-presenter of a January, 2016 NSGC/ASHG webinar entitled "The germline debate: Can we, should we, and will we use genetic engineering to alter the DNA of our children?" The webinar is available on the NSGC website for free for members.

Tamandra Morgan ('12) reports that she has almost completed her first year of medical school at the University of Illinois at Chicago. She was excited for their Medical Genetics course this Spring and is hoping to take part in clinical genetics research this summer.



Tamandra at her white coat ceremony

Yue Guan ('12) defended her final oral exam in December 2015 and then started working at the University of Maryland as a research fellow/genetic counselor with the Personalized Diabetes Medicine Program (PDMP) to identify patients most likely to have highly penetrant genetic diabetes and to return customized multiplex gene panel sequencing results for patients enrolled in the clinical trial. She is really excited to be involved in genetic counseling for study patients, study design and grant application, as well as teaching and mentoring

genetic counseling students.

Dana Petry ('13) recently started a new position as genetic counselor at the Johns Hopkins Breast Center. We look forward to sending students to her!

Cari Young ('15) finished up her first policy fellowship rotation at NHGRI in the fall and has moved to the second rotation on Capitol Hill working for Senator Sheldon Whitehouse as part of his healthcare team. She will be there until the fall before moving on to ASHG.

On a Personal Note



Naomi and Rachel Fung

Karen Tam ('04) announced two new additions to their family. She and Derek welcomed twin girls, Naomi and Rachel Fung, to their family in December 2015. Needless to say, it has been a tiring and challenging adventure into parenthood, but they also say that it is pretty incredible to watch them grow, change and discover.

Tricia (Gasser) See ('05) – is pleased to announce that they welcomed baby Lucien Gunnar on July 14, 2015. Such a cutie!



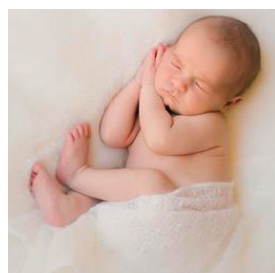
Sydney Cole Peacock

Jamie Dokson ('07) shared that they welcomed a new addition to their family, Sydney Cole Peacock, in October, 2015. She joined big brother Kyle, age 2.5. Congratulations!



Lucien Gunnar See

Jessica Young Adcock ('08) is thrilled to announce that Logan Daniel was born March 30th. He weighed 8lbs, 8oz and was 21.5". In other exciting news, they are also in the midst of relocating back to Texas, near Dallas. We wish their family the best.



Logan Daniel Adcock

Belen Pappa ('12) and Vincent are excited to share the news of their engagement. He popped the question in Paris on July 19th 2015, and they are planning their wedding for December 2016 in Belen's hometown in Argentina.



Vincent and Belen in Paris

Dana Petry ('13) shares that she and Jimmy Wienke were married on September 19th, 2015 in Austin, TX. It was everything that they hoped for!

Marci Barr ('15) shares that she and G.W. Schwartz were married on April 10th, 2016 in Jekyll Island, Georgia. They don't yet have their pictures back, so watch for those in the fall.

We invite you to continue sharing your personal and professional news with us so that we can update the JHU/ NHGRI GCTP community. In addition, we look forward to reading your brief essays on your own leadership journey. Lori can be reached at lori.erby@nih.gov and Barb can be reached at barbarab@mail.nih.gov.

SAVE THE DATE!!!

Alumni research calls occur on the first Monday of each month at 3pm – Hope to hear you!

NSGC AEC in Seattle, Sept 28-Oct 1

ASHG 2016 meeting in Vancouver, Oct 18-22

GCTP Student Graduation Jan 20, 2017