

Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Training Program

Welcome to the Spring 2015 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 2018!

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!



Emily Bonkowski

Emily Bonkowski grew up in the small town of Genoa, Illinois. She graduated from the University of Chicago in 2011 with a degree in Biological Sciences and a concentration in Neuroscience. While in college, she pursued research in human molecular genetics as well as human behavioral pharmacology and volunteered in a clinic for uninsured residents

of Chicago and on a Global Medical Brigade trip to Honduras. After graduating, she worked in a medical genetics lab in the Department of Neurology at the University of Washington in Seattle, investigating the genetic causes and mechanisms of rare neurodegenerative diseases and movement disorders. For the last three years, she has volunteered as a phone worker and trainer on the King County Crisis Line, and has also spent time volunteering with Planned Parenthood and as a summer writing tutor for the UW Genomics Outreach for Minorities Project. After shadowing genetic counselors and attending Medical Genetics case conferences, she's excited to combine her interests in science and research with her motivation to serve patients, their families, and the community as a genetic counselor.



Anna Chassevent-Jenks

Anna Chassevent-Jenks was born and grew up in Vancouver, Washington. For her undergraduate degree she traveled across the U.S. to South Carolina to attend Anderson University where she majored in psychology. Anna was first drawn to genetics in early high school through participating in the "Designer Genes" Science Olympiad competition where

her team placed in the top three in the state. Through working on her graduate research degree at Clemson University in Healthcare Genetics she realized that her true passion is in helping patients directly through genetic counseling. In her time at Clemson University, she co-taught a genetics course for nurses and was integral in establishing a hereditary cancer screening clinic at the health center on campus. She was also engaged in involving undergraduate nursing students in clinical genetics research.



Rachel Gore

Rachel Gore is a native of Massachusetts and has spent her life living in and around the Boston Area. She graduated with a BA in Biology from Clark University in Worcester, MA. During her time at Clark, Rachel conducted genetics research as part of a team investigating growth and development pathways in a *Drosophila* model. She volunteered as a peer health counselor for the CHOICES Health Center, and led a discussion group as a teaching assistant for a Medical Ethics Course. These experiences cemented her interest in genetics and cultivated a passion to pursue a career as a genetic counselor. For the past two years, Rachel has been working as a Medical Assistant at an Internal Medicine practice in Boston, where she has loved the opportunity to apply her academic interests working with patients in a clinical setting.



Yingyue (Annie) Li

Yingyue (Annie) Li was born and raised in Cangzhou, China. She graduated from Hebei University in 2010 where she majored in Biotechnology and minored in International Trade and Economics. She initially envisioned herself as a biomedical scientist, and enrolled in the graduate program of Biochemistry at the University of Iowa. The training equipped her with a deep understanding of how genetic abnormalities contribute to carcinogenesis, however, she realized that her true passion is to translate the latest discoveries in human genetics to patient care. She graduated with a Masters in Biochemistry in 2012 and then worked as a research assistant at the University of Iowa Hospital and Clinics (UIHC), while volunteering at Family and Internal Medicine at UIHC and the Crisis Center of Johnson County. She shares that interview day at Johns Hopkins was one of the amazing moments in her life, as she can see how perfectly the program matches her long-term professional goals.



Hannah Wand

Hannah Wand got her B.S in molecular biology at the University of Pittsburgh where she was an HHMI fellow in Jon Boyle's lab, researching the molecular genetics of *Toxoplasma gondii*. Following her graduation in 2013, Hannah joined PJ Utz's lab at Stanford to research autoimmune diseases. She has always been an active volunteer in the community and currently spends her time working with the Hospitalized Elder Life Program in San Francisco. In her free time, Hannah likes to be outside hiking or getting an adrenaline rush from trying new activities like ziplining! She unwinds with dancing, reading, or Netflix marathoning. Currently, she is making plans to travel for her summer off. She's excited to return to the east coast and begin her genetic counseling training!

Congratulations to the Class of 2015

On January 16, 2015, in the Cloisters Lecture Hall on the NIH campus, we celebrated the graduation of Marci Barr, Megan Bell, Nina Harkavy, and Cari Young 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 future collaborations!

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

Marci Barr

Testing for hereditary cancer predisposition: The impact of the number of options and a provider recommendation on decision making outcomes

Advisor: Debra Roter

Megan Bell

Where does hope fit in? The relationship between hope, uncertainty, and coping efficacy in mothers of children with Duchenne/Becker muscular dystrophy

Advisor: Holly Peay

Nina Harkavy

Physicians' experiences with and attitudes toward non-medical sex selection through preimplantation genetic diagnosis

Advisor: Lori Erby

Cari Young

Genetics researchers' perceived obligations to return incidental findings and individual research results to participants

Advisor: Barbara Biesecker



GCTP Program students and recent alumnae. (Pictured are Nina Harkavy, Jenn Kohler, Lydia Hellwig, Celeste D'Amanda, Devon Bonner, Katie Fiallos, Mike Setzer, Megan Bell, Marci Barr, Cari Young, Kyle Davis, and Claire Anderson, left to right)

Where are they now?

Marci Barr started her job in the Genomics Medicine Institute at Geisinger Health System in Pennsylvania soon after graduating. Her position is centered around the return of clinically actionable results uncovered in the course of opportunistic screening of the exome sequences of biobank participants for 27 conditions. She is working with a team of genetic counselors, medical geneticists, researchers and other healthcare providers to test out a care delivery model and to do research related to many aspects of the project. So far they have over 30,000 exome sequences in the pipeline and are working toward a goal of 250,000, so there is a lot of work to be done!

Although she was sad to leave the east coast, after graduation **Megan Bell** moved back to her hometown of Sioux Falls, SD to begin a position at Sanford Health with a new genomics initiative for internal medicine called Imagenetics. She provides genetics education to internal medicine and primary care physicians, as well as genetic counseling for their patients for a variety of hereditary and multifactorial conditions. It has been an exciting few months jumping into the field and she has thoroughly enjoyed starting to bridge the gap between genetics and primary care.

Nina Harkavy is working with high-risk prenatal patients in a maternal-fetal medicine private practice, returning to the practice with which she interned as an undergrad when she was applying to genetic counseling graduate programs. She works with three other genetic counselors and one maternal-fetal medicine specialist. She is very excited to be counseling in the prenatal setting and very happy to be back in New York. She reports that she continues to recruit physicians to complete additional qualitative interviews for her thesis research with the hope of publishing in the future.

Following her passion for research, **Cari Young** took a job working at the Parent Project Muscular Dystrophy (PPMD) with Executive Committee Member, Holly Peay. She has



The graduates share some memories. (Pictured are Nina Harkavy, Megan Bell, Marci Barr, and Cari Young, left to right)

spent her recent months leading community engagement efforts and collaborating on the development of a survey for a benefit-risk study in partnership with a pharmaceutical company and assisting in data analysis and manuscript writing for a clinical trial conducted by PPMD and CureSMA. She is looking forward to the PPMD conference in Washington, DC next month.

Best Wishes to Chris Anderson

On May 22, we will be saying goodbye to **Chris Anderson**, the GCTP program coordinator on the NHGRI side of the program. Chris will be attempting to learn the art of relaxation in retirement; an art that I believe will require quite a lot of practice, given what I have come to know about her in my time as the Associate Director. Her quick problem-solving skills and warm smile will be sorely missed by program administrators and the students alike.

Sequencing Workshop Pilot

With the rapid increase in clinical and research-based exome sequencing, we identified a need for more intensive training in sequencing. On March 23-24, Drs. Les Biesecker, Jennifer Johnston, and David Adams, in conjunction with genetic counselors Rachel Nusbaum, Megan Cho, and Julie Sapp offered a 1.5 day workshop for the current students that provided an overview of sequencing technologies, provided hands-on experience with variant interpretation, and offered insight into the roles of genetic counselors. There was agreement that the workshop offered extremely valuable exposure, and we are in the process of determining how to incorporate a similar experience on a regular basis.

DNA Day

In celebration of DNA Day, the second year students showed off their public speaking skills while teaching a high school biology class in the Montgomery County Public School system. They had the opportunity to promote the profession of genetic counseling while engaging with a number of bright future scientists and healthcare professionals.



Teaching for DNA Day. (Pictured are Claire Anderson, Jenn Kohler, Kyle Davis, left to right)



The rising second year students enjoy the sun while looking forward to their summer activities. (Pictured (clockwise) are Devon Bonner (top), Mike Setzer, Lydia Hellwig, Katie Fiallos, and Celeste D'Amanda)

End of the term

On May 15, the students completed the last day of classes for the spring term, rounding out another successful year. The rising second year students will be departing soon for their summer rotations, and the rising third year students will be busy with their thesis research. More on both fronts in the fall!

CATCHING UP WITH THE GCTP

Rochester Healthcare Achievement Award

As many of you may remember from the August, 2014 Alumni Research Symposium, **Jessica (Sparrin) Salamone** ('02) has been working for the last couple of years to dramatically change genetic counseling referrals and service delivery at a high volume breast imaging center. She was instrumental in setting up a triage and referral process and now provides genetic counseling and testing to 800-1000 individuals identified through her center each year. She has also worked to increase community awareness through a community lecture series on breast cancer risk. We are pleased to report that her efforts have recently been formally recognized. Jessica is one of 24 honorees selected as a recipient of the Rochester



Jessica Salamone speaking at the 2014 Alumni Research Symposium

Business Journal's 2015 Healthcare Achievement Award. Her work at Elizabeth Wende Breast Care, LLC is featured in the March 20 issue of the Rochester Business Journal. Nominations for this honor are made by community members, which serves as a testament to the high quality of care that Jessica delivers. Congratulations, Jessica!

ALUMNI NEWS

Professional News

Cindy James ('99) recently received a grant from the Barth Syndrome Foundation to conduct a mixed methods study exploring women's psychological adjustment to being a carrier for a Barth syndrome mutation and subsequent reproductive decision-making. Congratulations!

Belen Pappa ('12) shared that she has co-authored a chapter on urea cycle disorders in the fifth edition of Rosenberg's Molecular and Genetic Basis of Neurological and Psychiatric Disease. She is also co-author on a recent publication in the *Journal of Inherited Metabolic Disease Reports* entitled "*Widening phenotypic spectrum of AADC deficiency, a disorder of dopamine and serotonin synthesis*". We look forward to reading these!

Two of our alumnae have recently had their thesis studies published in a special issue of *Health Psychology* on Health Disparities in Genomic Medicine. **Kendra Schaa's ('11)** paper is entitled "*Genetic counselors' implicit racial attitudes and their relationship to communication*", and **Sally Rodriguez's ('13)** paper is entitled "*Translation and validation of a Spanish-language genetic health literacy screening tool*". Check out the entire issue!

On a Personal Note



Andrew Munro
Whitworth

Jackie Schienda ('08) shared the best Christmas present ever – she gave birth to Andrew Munro Whitworth on December 24, 2014. Congratulations!

Amanda Lamb ('10) is pleased to announce the birth of Nola Cesarina Lamb on February 20,

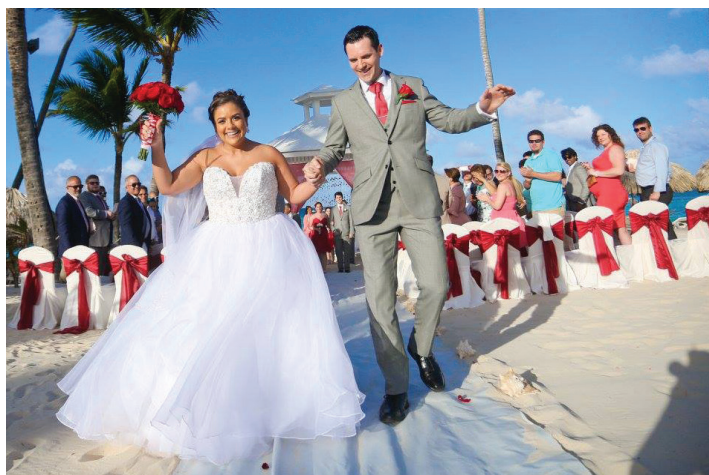


Nola Cesarina Lamb

2015. Amanda and Colin are (understandably) completely in love!

Leila Jamal ('12) reports that she and Chad Hochberg will be getting hitched on May 24, 2015 at Revolution Brewing Company in Chicago! They will then be moving to Baltimore so Leila can continue her PhD and Chad can start his internal medicine residency at Hopkins. We look forward to photos in the fall edition!

Sally Rodriguez ('13) is happy to share that she and Ben Schweitzer were married on April 11, 2015 in Punta Cana.



Sally Rodriguez and Ben Swweitzer

We invite you to continue sharing your personal and professional news with us so that we can update the JHU/NHGRI GCTP community. Lori can be reached at lori.erby@nih.gov and Barb can be reached at barbarab@mail.nih.gov.