

Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Training Program

Welcome to the Fall/Winter 2014 edition of the Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program Newsletter. This newsletter is intended to highlight achievements and events in the Hopkins/NHGRI community. In this issue we introduce the class of 2017, highlight a professional development opportunity offered by an alumnus, and provide updates on the current faculty, staff, students and alumni. Enjoy!

WELCOME, CLASS OF 2017!!

In August 2014, the following members of the class of 2017 arrived. Please give them a warm welcome if you see them in your clinic, around campus or attending classes!



Devon Bonner

Devon Bonner

Devon was born and raised in Bradenton, FL. She graduated from the University of South Florida in 2011 with a BA in Psychology. During her undergraduate education, she participated in a research internship at the All Children's Hospital in St. Petersburg, FL, where she was first exposed to the genetics community through a study investigating skin-picking in children with Prader-Willi Syndrome. She also completed a clinical internship performing biopsychosocial assessments on patients admitted to the Manatee Glens crisis stabilization unit in her hometown as well as a summer internship in the USF Biology department. After graduation, Devon became the lead research coordinator for a study investigating the etiology and health outcomes of breast cancer in a registry-based sample of young African American women at Moffitt Cancer Center and continued to pursue a BS in Biomedical Sciences. It was through her experience working with families affected by hereditary breast cancer and genetic counselors across the state that she realized her passion for genetic counseling and community-based participatory research initiatives.



Celeste Schepp D'Amanda

Celeste Schepp D'Amanda

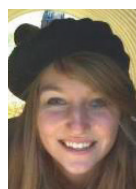
Celeste hails from Rochester, New York, and graduated from Bennington College in 2013, where she was inspired to study biology and chemistry after becoming interested in biomedical sciences through her experiences as a hospice volunteer. While at Bennington, she became fascinated by genetics and enjoyed working in several laboratories. After graduating, she continued her volunteer work in hospice, where she had the opportunity to provide company, comfort care, and advocacy for the dying.



Katherine (Katie) Fiallos

Katherine (Katie) Fiallos

Having lived in Michigan most of her life, Katie considers herself to be a true Michigander although she was actually born in Columbia, Maryland, not far from Baltimore. She graduated from Kalamazoo College in 2008 with degrees in Spanish and International Studies. After graduation, Katie returned to Quito, Ecuador where she had studied abroad her junior year of college. In her four years there, she interned with the United Nations, taught English as a foreign language, immersed herself in the culture and married Gabriel, a native of Ecuador. While in Ecuador, Katie came back to her passion for genetics, and after researching a career in genetic counseling, determined that it contained just the right mix of science and direct patient contact that she was looking for. Katie returned to the states and spent two years taking pre-requisite classes, shadowing genetic counselors, and volunteering at a shelter crisis line. During this time, she also worked with a professor at Eastern Michigan University in his genetics lab.



Lydia Hellwig

Lydia Hellwig

Lydia was born and raised in Shorewood, Wisconsin. She graduated from Johns Hopkins University in 2014 where she majored in Molecular and Cellular Biology and Sociology and Minored in Psychology. Lydia found her passion for genetics at an early age, fascinated by the Human Genome Project when she was very young. Her love of genetic counseling has only grown since then. She has worked in the genetic counseling department through the Human Molecular Genetics Center at the Medical College of Wisconsin. There she worked with genetic counselors in both clinical and research roles. Lydia also volunteered with a peer listening and crisis intervention group at Johns Hopkins, and worked in a biochemistry lab at the School of Medicine.



Michael Setzer

Michael Setzer

Michael was born and raised in Sayre, Pennsylvania. He received a B.S. in technical writing and communication with an additional major in biological sciences from Carnegie Mellon University in 2014, graduating with College Honors. While attending school, Michael was a staff writer and the Science and Technology editor for CMU's student newspaper, The Tartan. He served as a patient support volunteer at the Hillman Cancer Center and worked with individuals with Prader-Willi syndrome at The Children's Institute in Pittsburgh. As a senior, he also served as a mentor to first-year students in CMU's Mellon College of Science. He performed research in both the departments of English and biological sciences at

Carnegie Mellon. His senior honors thesis utilized historical and rhetorical analysis to make recommendations regarding public communication for genetic screening programs.

PROGRAM UPDATES

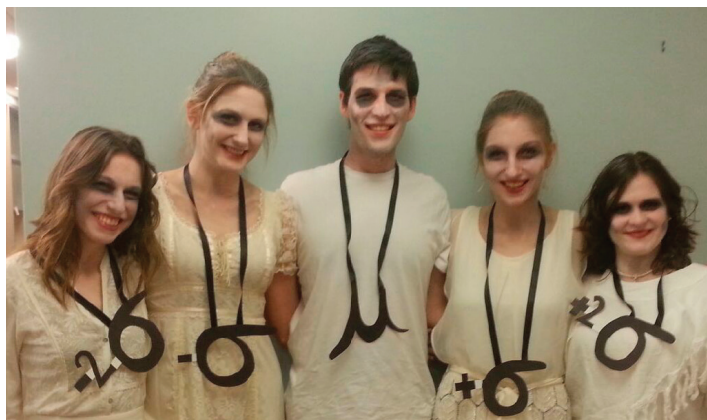
Orientation

Orientation to the program was jam-packed this year, and we are grateful to the faculty and students who participated! The returning students helped to end the day with the traditional scavenger hunt to introduce the first year students to the sights and sounds of the NIH campus. After a fierce and creative photo competition between our two student teams and much deliberation by the faculty judges, the Team Two photo (shown below) was declared the winner based on creative use of available technology.



Team 1 photo: An office of goofy faces

The first year students have already made their mark, starting what they hope will be a new Halloween tradition. See if you can guess what first-year related topic their costumes represent. (answer provided at the end of the newsletter)



Guess the first years' costume

Summer Activities

The GCTP has long-encouraged its students to take advantage of the wealth of genetics opportunities available to them locally and globally over the summer. We asked the class of 2016 to describe how they embraced this mandate during their training.

Claire Anderson spent the summer rotating at the Ferre Institute, a non-profit genetic counseling program in Binghamton, NY that serves a large rural region. Claire saw clients with genetic counselors Luba Djurdjinovic and Lindsey Morse and also spent time shadowing the teratogen specialist, Mark Roth. Claire enjoyed traveling with Luba to see clients throughout upstate NY and learned a great deal about the unique opportunities and challenges afforded by working in a non-profit setting.



Team 2 photo: Mixed up students

Kyle Davis spent his summer in and around Portland, Maine, where he worked at the Maine Medical Center's cancer and prenatal clinics. In the cancer clinic, he worked with fellow JHU/NHGRI alumna Amanda Lamb ('10). In between his time in clinic, he participated in the Myriad Summer Internship in Salt Lake City and even found time to go boating, swimming, kayaking, and explored the many diners of Maine with his family and new baby.



Kyle with new baby Gabe

Jennefer Kohler spent this past summer rotating at the Pacific Fertility Center (PFC) in San Francisco. There she counseled clients about the benefits and risks of pre-implantation genetic screening (PGS) as they decided whether adding such a procedure to their IVF cycle was right for them. She also learned a great deal about the fast-paced fertility clinic environment, even getting to spend a day in the lab watching fertility procedures first-hand. Rotating at the PFC gave Jennefer the chance to gain clinical experience in an exciting and specialized area.

GCTP at the AEC

Faculty, students and alumnae enjoyed sharing their academic and professional endeavors both formally and informally in New Orleans. Thanks to Chris Anderson for finding the Oceana Grill for our reunion – the food and the environment were wonderful!



Images from the AEC

Congratulations to Program Director **Barbara Biesecker** on receiving the Natalie Weissberger Paul National Achievement Award! Barb gave an inspirational acceptance address at the AEC, challenging us to consider the therapeutic counseling goals that we can achieve with our clients.

PROFESSIONAL DEVELOPMENT SEMINAR

On November 7, 2014, we were fortunate to have **Matthew Thomas ('07)** in residence to present a professional development seminar about his recent effort to create a new position within UVA. We had a very engaging discussion, and Matt generously agreed to describe his career experience in writing for the newsletter. Perhaps it will inspire some readers to advocate for change, as well!

Creating a New Position

Just like those of us who received inspiration for our grad school thesis through a patient encounter, I began my transition from a pediatric/general genetic counselor to a cardiovascular one after working with a family who lost their wife/mother to a potentially avoidable sudden death. The patient had an extensive family history of aortic dissection, and no obvious emphasis was placed on screening her for the same treatable disease.

My goal was to prevent events like this from happening again at the University of Virginia by filling an unmet (and unfunded) need to serve patients with inherited cardiovascular conditions. Although I had multiple encouraging meetings with hospital administrators, showed examples of successful programs across the country, and joined some interested cardiologists in clinic to pilot the service, I was unable to create a new position after many months of trying.

As I began to grow frustrated with the slow pace of change, our hospital sent an annual call for internal grant applicants that I typically ignored, but a cardiologist emailed to encourage me to quite simply "give it a shot." The internal grant, known as the Buchanan Endowment, provides support for new clinical programs that can achieve profitability after three years using a venture capital application process and method of funding. The business development phase of the program took four months, a team of six, and many late nights with the financial justification grounded in something we've all become familiar with: downstream revenue. Simply stated, I argued that with the proper support, a genetic counselor (me) can successfully recruit at-risk family members to receive their necessary cardiology screening at our hospital. In early February I was notified that I received the award and funding for my new program began on July 1.

I am grateful for the longstanding mentorship, support, and friendship from alumni I worked

with for years at UVA, **Shawn Lipinski ('04)** and **Danielle Dong ('05)**, along with leaders in cardiovascular genetics who continue to graciously share their expertise to help get my program up and running (**Colleen Caleshu, '07; Nicole Johnson, '02**).



Matthew Thomas speaks in Professional Development Seminar

GRADUATION 2015!

Save the date for graduation on January 16th, 2015 at the Cloisters on the NIH campus, where our third year students will present their theses (topics listed below) and we will celebrate their many accomplishments in the program.

The Graduates will present research seminars on their theses.

Marci Barr

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

This study used a hypothetical vignette to investigate whether changes in the presentation of genetic testing choice, specifically whether the number of genetic testing options, the way in which these options are presented and inclusion of a personalized provider recommendation, can influence choice in the context of hypothetical hereditary cancer predisposition testing. Findings suggest that individuals may be more likely to undergo cancer genetic testing when presented with three options instead of two. Additionally, some participants may change their testing decisions after a provider recommendation depending upon whether they would prefer all possible genetic information or only clinically actionable information. However, the overall effect of provider recommendation was not significant. This type of recommendation may have the largest potential for impact among individuals with testing choices that do not match their information preferences.

Megan Bell

“Where Does Hope Fit In? The Relationship Between Hope, Uncertainty, and Coping Efficacy in Mothers of Children with Duchenne/Becker Muscular Dystrophy”

Embedded within a larger study of well-being, this study explored the relationships between uncertainty, hope, and coping ability in mothers of children with Duchenne or Becker muscular dystrophy. Participants are biological mothers of at least one child with one of these diagnoses who were part of an already established cohort. Early analysis suggests that hope is a factor in shaping uncertainty appraisals and facilitating coping efficacy. Guiding mothers with low hope to other uncertainty management and reappraisal strategies may be helpful in overall adaptation.

Nina Harkavy

“Physicians’ Experiences with and Attitudes Toward Non-medical Sex Selection Through Preimplantation Genetic Diagnosis”

This qualitative study explored the experiences of healthcare providers with preimplantation genetic diagnosis and non-medical sex selection. The Moral Experience framework guided the projects’ focus on the potential concerns of healthcare providers as well as their feelings and behaviors evoked by lived and hypothetical experiences around non-medical sex selection. Also of interest was how healthcare providers feel that decisions about NMSS are made and their preferences as to how they should be made. Although the interviewees differed in their self-reported strength of opinions on NMSS (from “not strong” to “very strong”), all described personal opposition to NMSS. Reasons have included: concerns about gender inequality, harm to couples (e.g. cost, health), and an ethical “slippery slope” to other non-medical uses of PGD. Participants have so far been evenly divided as to the extent to which their personal opinions are aligned with their professional feelings. On both sides, physicians cited patient autonomy, nonmaleficence, and perceptions of accepted practice. Finally, participants have described a lack of awareness of their colleagues’ professional opinions, but a desire to understand how others are thinking and practicing.

Cari Young

“Genetics Researchers’ Perceived Obligations to Return Incidental Findings and Individual Research Results to Participants”

Based on survey data collected by researchers at the Genetics and Public Policy Center, this study describes genetics researchers’ perceived obligation to return individual research results and incidental findings to their participants and examines whether these views are in line with their current reported practice. Genetics researchers varied in the extent of their perceived obligation to return individual research results and incidental findings to their participants. Results showed that the use of clinical samples was predictive of higher perceived obligation to return results, while work setting was also predictive of feelings of obligation. The majority of genetics researchers (60%) do not return any incidental findings or individual research results to their participants. Further analysis revealed

that those with higher perceived obligation and those with more interaction with participants were more likely to return results.

ALUMNI NEWS

Professional News

Yue Guan ('12) was recently awarded a competitive Gordis Teaching Fellowship to teach "Introduction to Public Health Genomics" at the Johns Hopkins Homewood campus during the spring 2014-2015 semester.

Christy Haakonsen ('11) recently accepted the role of co-chair for the Cancer SIG research subcommittee. We look forward to seeing the products of her leadership!

Amanda Singleton ('10) shared that she was recently promoted to Senior Genetic Counselor and Lead Cardiology Genetic Counselor at GeneDx. Way to go!

Cindy James ('99) was the deserving recipient of this year's Jane Engelberg Memorial Fellowship (JEMF) for her project entitled "How does family history influence psychosocial adaptation in individuals with inherited cardiomyopathies and their at-risk family members?".

Cindy also shared that her involvement in the Johns Hopkins Genetic Counselors collaborative research group has led to a publication entitled "Informed consent for exome sequencing research in families with genetic disease: The emerging issue of incidental findings". Among the co-authors are several of our recent/current Johns Hopkins clinical supervisors: Amanda Bergner, Crystal Tichnell, Brittney Murray, Carrie Blout, and Aida Telegrafi. Congratulations on a successful year of research!

On a Personal Note

The class of 2013 has lots of exciting news to report.

First, congratulations to **Ilana Solomon ('13)** and Hector Alvarez on their recent marriage!



Ilana and Hector on Jul 26, 2014



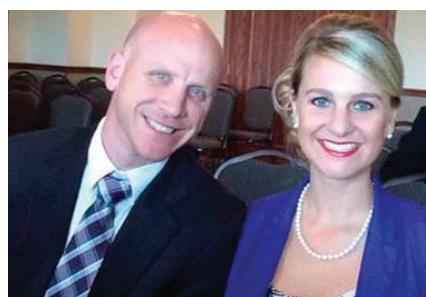
Wei Yi and Zachary, October 18, 2014

We also offer congratulations to **Wei Yi Mu ('13)** on her marriage to Zachary Cordner!

Yue Guan ('12) welcomed baby Jason Zheng (Chinese name: Jiashun Zheng, 郑嘉顺) at 5:22pm on September 4th, 2014. He weighed 7lbs, 4 oz and was 19.3 inches long. All are doing well!



Jason Zheng



Christy and Jake

Christy Haakonsen ('11) announced her engagement to Jacob (Jake) Smith. They are planning a fall, 2015 wedding. We can't wait to see pictures!!!



Morgan and Matt

Congratulations to **Morgan Butrick ('10)** and Matt Similuk on their marriage on September 20, 2014!

Finally, we wanted to give a shout out to program coordinator **Mary Ann Dunevant** and Johns Hopkins academic coordinator **Barbara Diehl**, both of whom received awards for their tasty concoctions at the Second Annual Hopkins United Way Chili Cook-off.

Mary Ann took home third place in the "with meat" category with her "Orioles Tribute" and Barbara won a second place in the "meatless" category for her "410.900 Chili Practicum".



Mary Ann (third from left) and Barbara (third from right)

SAVE THE DATE!!!

Research peer mentoring meetings – we are holding monthly conference calls for alumni interested in discussing research projects (no idea is too early!) The next call will be: January 5 from 3-4 EST

GCTP Student Graduation Jan 16, 2015 at the Cloisters on the NIH Campus

NSGC AEC Call for Speakers closes Jan 19 – Have a topic of potential interest to your colleagues? Consider submitting a proposal for a pre-conference symposium, plenary speaker, or EBS

Third term courses start Jan 20, 2015

Halloween picture answer: “Paranormal” Curve

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.