

Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Graduate Program

Faculty and Staff updates

- Anne Madeo joined the Program in June 2008, as the Associate Director. Before joining the Program, Anne worked for eight years as a genetic counselor and protocol coordinator at the National Institute on Deafness and Other Communication Disorders (NIDCD).
- Holly Peay stepped down from her position as the Associate Director in January 2008. Our loss is the National Coalition for Health Professional Education in Genetics' (NCHPEG) gain, as she returned to a position as Project Director there. She and Barb Biesecker continue to collaborate on research.
- Amanda Bergner, program faculty, left to work full-time in the Neurofibromatosis Center at Johns Hopkins Hospital; we were sad to see her go.
- Trish Magyari agreed to once again provide professional supervision, a role she enjoyed for nearly a decade prior.
- We recruited Andrea Wray to teach the Facilitating Family Adaptation to Loss and Disability course. Some of you may remember Andrea as a supervisor when she worked as a genetic counselor at Georgetown University's Antenatal Testing Unit.
- Dr. Francis Collins has stepped down Genome Research Institute (NHGRI) Director. NHGRI is fortunate that Dr. Alan Guttmacher is currently serving as the Acting Director. Sadly, this means that Dr. Guttmacher will step down from his position as Medical Director of the Genetic Counseling Training Program (GCTP) in January 2009.
- Kathryn Foisie started as a National Institutes of Health (NIH) program coordinator in July 2007, and provides administrative support for the GCTP through her position in the Graduate Partnerships Program (part of the NIH Office of the Director).

Welcome to the fall edition of the Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program Newsletter. This newsletter is intended for individuals affiliated with the program, including faculty, clinical supervisors, alumni, current students, support staff, Executive Committee members and prospective students. We hope this letter will keep you up-to-date regarding what's happening in our program.

Program Updates

In January 2008, site visitors from the American Board of Genetic Counselors (ABGC) came to evaluate the Program. This visit was the culmination of an incredible amount of work on the part of Program faculty, supervisors, students, alumni and Executive Committee members. We're pleased to report that the Program received Full Accreditation for the next eight years! Thank you to everybody who completed a survey and shared your thoughts on the program.

The Executive Committee held a retreat in July 2008, to review the comments made by students, alumni, faculty, employers and the ABGC, and consider ways to improve the Program. We'll keep you updated as changes are made!

Introductions

In August 2007, we welcomed the following members of the class of 2010:

Morgan Butrick came to us from the University of Kansas where she majored in Biology. Morgan's classmates cared for her rooftop vegetable garden while she went to UCSF for a cardiovascular genetics rotation with Colleen Brown ('07) in the summer of 2008.

Amanda (Rowe) Lamb is a graduate of Bowdoin College. Prior to starting in the Program, Amanda worked as a research assistant at Georgetown University's Lombardi Cancer Center. She and her husband live in Arlington, VA, so she's been enjoying some long drives on 95! Amanda is already planning her return to the state of Maine (where she completed a summer rotation in 2008) when she graduates.

Amanda Singleton joined the GCTP with an MPH and many years of experience in a Neurogenetics lab investigating Parkinson's Disease at the National Institute on Neurological Disorders and Stroke (NINDS). She has two young children; her oldest just started 1st grade!

Prior to starting in the GCTP, **Amy Turriff** worked on an acute stroke research protocol as a post-baccalaureate intramural research training award (IRTA) fellow with the Stroke Branch of National Institute of Neurologic Disorders and Stroke (NINDS). She graduated from George Washington University where she majored in biology. Amy rotated with Shawn (Sinesky) Lipinski ('04), Matt Thomas ('07) and Pat Allinson at the University of Virginia (UVA) in her summer 2008 rotation.



Scavenger Hunt Team 1. Team 1 impressed us by getting Eric Green, NHGRI Scientific Director, in their photo! (Left to right: Megan Truitt, Amanda Singleton, Morgan Butrick, Eric Green, Mindy Simonson, Kendra Schaa, Christy Haakonsen)



Scavenger Hunt Team 2. Team 2 demonstrates that they're #1 in front of Building 1! (Left to right: Amanda (Rowe) Lamb, Julie Cohen, Melanie Baxter, Sarah Kalia, Neha Kumar, Gillian Hooker, Jane Lee)

In August 2008, we welcomed the following members of the class of 2011:

Christy Haakonsen is originally from Pittsburgh. She graduated from the Pennsylvania State University (PSU) with a degree in Biopsychology. While there, she investigated sex differences that pertain to endocrinology, biology and genetics. Additionally, Christy used qualitative methodology to better understand a PSU initiative that fosters peer-facilitated small group discussions regarding race.

Sarah Kalia is originally from Louisiana, but did her undergraduate work at Northwestern University, worked in Madison, WI, for 3 years and then went to Los Angeles where she worked as a Research Assistant in the Cancer Center at the University of California, Los Angeles (UCLA).

Neha Kumar is a citizen of the world! She was born in India, grew up in Brunei, came to the United States for her undergraduate studies at Brown University, and completed a year abroad at Oxford University in England.

Jane Lee spent five years working on the molecular pathogenesis of prostate cancer at Stanford University, but earned her undergraduate degree in molecular cell biology across the Bay at University of California at Berkeley. She is grateful that Stanford gave her the opportunity to publish her research findings, but she still has the Cal spirit inside. Go Bears!

Kendra Schaa graduated from the University of Iowa (go Hawkeyes!), where she worked in Dr. Jeffrey Murray's laboratory on a study whose goal is to identify genetic loci that confer susceptibility to premature birth and its

related complications. Her classmates say that if she weren't a genetic counselor, she would be an interior decorator!

NIH Orientation, 2008

Members of the class of 2009 decided it was time to inject some folly into the NIH Orientation for incoming GCTP students. An NIH based scavenger hunt was planned, with photographic evidence of a team's achievements required each step of the way. Barb, Anne and Kathryn declared the scavenger hunt a tie! (Photographs, pages 1 and 2)

Theses studies from the class of 2008

We hope you were able to see the students' presentations of their thesis studies at the National Society of Genetic Counselors' (NSGC) Annual Education Conference in Los Angeles in October!

The Extent and Patterns of Disclosure within the Huntington Disease Community and the Association with Adaptation to Living at Risk. Jessica Young Adcock, Sc.M. Advisor-Lori Hamby Erby, Sc.M., Ph.D.

Family History of Heart Disease and Barriers to Screening: How Do They Affect Intentions to Get Cholesterol Screening? Courtney Nichols, Sc.M. Advisor-Joan Scott, M.S.

Meaning making among asymptomatic adults with a positive presymptomatic genetic test result for Huntington Disease. Pooja Ramchandran, Sc.M. Advisor-Rajiv Rimal, Ph.D.

Caregiver Adaptation to Autism Spectrum Disorders. Katie Voss, Sc.M. Advisor-Barb Biesecker, M.S.

Disclosure of a Cystic Fibrosis Diagnosis to a Dating Partner. Jaclyn Douyard, Sc.M. Advisor-Kim Kaphingst, Ph.D.

Student Summer Activities

The GCTP has long-encouraged its students to take advantage of the wealth of genetics opportunities available to them locally and globally. We asked Gillian Hooker ('09) and Megan Truitt ('09) to describe how they embraced this mandate during their training.

Gillian Hooker

In the summer of 2007, I traveled to London, England to observe genetic counseling sessions with a group of genetic counselors and doctors affiliated with the Clinical Genetics Department of the University College of London and Great Ormond Street Hospital. My three-week rotation was arranged with the gracious assistance of Bernadette Farren, a genetic counselor who is a long-standing friend and supporter of the GCTP. In previous summers, she hosted Marie (Cudoc) Belgrave ('05) and Jessica (Young) Adcock ('08).

While there, I was exposed to a wide range of clinics, clinicians and patients. I attended several different cancer genetics clinics staffed by a variety of providers. Some of these clinics were conducted as a part of the department's Telemedicine program with consults conducted via live video-feed. One breast cancer clinic was operated in a wing of St. Bartholomew's Hospital, which was founded in 1123 and is the oldest surviving hospital in England. Bernadette arranged for me to spend time in the Huntington's clinic, with the fetal medicine unit and to accompany the physicians on rounds in the Great Ormond Street Hospital. The Clinical Genetics Department is staffed by many expert dysmorphologists who invited me to attend their weekly dysmorphology conferences.

Not only were the conferences informative, they have also been useful to me in several subsequent rotations. Finally, I had the invaluable experience of attending clinics with Bernadette, who is a skilled genetic counselor and nurse from whom I learned a great deal. I am very grateful to her for all of the time and effort she put into making sure my time there was well-spent.

On a more personal note, it was thrilling to spend three weeks "trying on" a new city. I took up residence in the University College dormitories and made a point to take a new route to clinic each day, exploring different neighborhoods in London. Though practical considerations limited my stay to three weeks, I would have gladly stayed for three months.



Megan Truitt and her camper partying in their togas at MDA camp

Megan Truitt

This summer I spent a week volunteering at a camp for children with neuromuscular disease. Every summer the Muscular Dystrophy Association sponsors camps across the country where children get to experience typical sleep-away camp activities. Our week's schedule was packed full of fun activities including a talent show, fishing, arts and crafts, a toga party, pool time, karaoke, and much, much more.

One of my favorite moments during the week took place the day that Harley Davidson riders came to visit. The campers got to enjoy pizza, t-shirts collected from around the country, bandanas, temporary tattoos, and best of all, free rides around the field in the side car of a Harley. During a quiet moment off to the side while waiting for the rest of the campers to have their turn, I found myself in an ideal position to observe the campers' facial expressions transform into wide eyes and huge smiles as they zoomed towards me during the initial take-off of the ride.

I was sometimes sad thinking that these kids' lives weren't like this all the time; that those big grins would ever have to leave their faces. Then I thought back to what I had heard so many times before – that for these children, this week was the same or better than Christmas – and after all, waiting for Christmas to come around isn't so bad.

My camper had never been to camp before, but even on the first day she began excitedly planning her future summers there, suggesting

potential camp themes and discussing where she would keep her name tag button at home in anticipation of a growing collection. She asked me if I would be able to come back for more summers, too – I told her, I hope so.

Alumni Updates

Yelena Kemel ('99) continues to work as a cancer genetic counselor at Memorial Sloan Kettering Cancer Center in New York City, where she has been for the past five years.

Jennifer Leib ('01) followed up on her American Society of Human Genetics (ASHG)/NHGRI policy internship and experience on the Hill by starting her own government relations and public policy consulting firm, Health Futures. She reports that they focus on policy related to predictive and personalized medicine and encouraged everybody to learn more by checking out their web page, www.healthfutures.com.

Krista Redlinger-Grosse ('01) sounds like she's very busy. In addition to working three days a week at the University of Minnesota, Fairview in a maternal fetal medicine clinic and a pediatric metabolism clinic, she also has three children (ages 5, 3 and 1)!

Kira Apse ('03) wed Jeremy Dies on August 23, 2008 in Boston, MA. She reports that they enjoyed a great honeymoon in Greece!

Shawn Lipinski ('04) has been with the UVA Department of Pediatrics Medical Genetics Division since 2004. She is a pediatric genetic counselor and coordinates the UVA Lysosomal Storage Disease (LSD) Program. In the last 4 years, she has expanded UVA's LSD Program and coordinates care for patients throughout the state of Virginia. She and husband, Mike, a Fellow in Cardiovascular Medicine at UVA, are expecting their first baby in early January 2009.



The University of Virginia Department of Pediatrics, Medical Genetics Division is home to three of the GCTP's alumni: Shawn Lipinski ('04), Danielle Dong ('05), and Matthew Thomas ('07).

Danielle Dong ('05) just re-joined the UVA's Department of Pediatrics Medical Genetics Division after a year of living abroad in Prague, Czech Republic. She and her husband, Phil, spent the last year living there for his doctoral research. Danielle returned to UVA in August 2008, and will be working with Shawn in the LSD Program and in the Pediatrics Genetics clinics.

Tricia (Gasser) See ('05) and her husband bought a house in Berkeley, CA, and have relocated to the West Coast! She's now working at the Memory and Aging Center at the University of California San Francisco Medical Center. If you want to contact her or are in the area, her office phone number is 415-476-2906.

Congratulations to **Meredith Weaver** ('06) and Paul Piquado on their marriage! The ceremony took place October 3, 2008, in Washington, DC. Meredith and Paul met in Meredith's first semester in the Program!

Rachel (Jacobson) Silver ('07) reports that she has joined the ranks of homeowners. She and her husband, David, purchased a house in Toronto that they hope to move into in November or December. Additionally, Rachel is expecting a baby in the spring!

Matt Thomas ('07) joined Danielle and Shawn at the UVA in 2007, working as a pediatric genetic counselor. He has become an integral part of the Division, traveling to satellite clinics throughout the state of Virginia. He and his girlfriend, Shannon, just bought their first house in Charlottesville in May 2008.

Jaclyn Douyard ('08) works at Tufts Medical Center in Boston, MA, where she does a bit of everything: pediatric, adult, abnormal prenatal, preconception and cancer. She and her husband (Jon) bought a house in Stow, MA, in January, 2008.

We invite you to continue sharing your personal and professional news with us so that we can update your fellow alumni! Anne can be reached at Anne.Madeo@nih.gov and Barb can be reached at barbarab@mail.nih.gov.