

# Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Training Program

*Welcome to the Fall 2011 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. In this issue, we introduce our new associate director and the class of 2014. The current second year class shares stories of their summer experiences outside of the DC-Baltimore area and we provide a small preview of our third years' theses in anticipation of their upcoming graduation. And to close, we pass along news from our alumni, including a special article describing the accomplishments of Pooja Lodaya ('08) in India. Happy reading!*

## Program Updates

We bid a fond farewell to past associate director, Anne Madeo, in June. Please welcome our new associate director, Gillian Hooker, who arrived in August. Gillian is an alumna of the program who had been working as a genetic counselor and research faculty with the Fisher Center for Familial Cancer Research at Georgetown University. She comes to us with expertise in molecular genetics, social science research and in clinical practice skills. Gillian has already been a terrific addition to the program!!



Gillian Hooker (Photo: Maggie Bartlett, NHGRI)

## Introductions

In August 2011, the following members of the class of 2014 arrived. Please give them a warm welcome if you see them in your clinic, around campus or attending classes!



### Haley Eidem

Haley grew up fishing the lakes of Minnesota and graduated from St. Olaf College in June 2010 with a Bachelor of Arts in Biology. She spent the past year working at the National Human Genome Research Institute as a post-baccalaureate fellow with the ClinSeq™ study, a large-scale medical sequencing pilot. Haley enjoyed learning about the implementation of large-scale sequencing in a clinical

research setting and the genetic counseling issues accompanying the return of results. She is very excited for the opportunity to spend more time at the NIH as a part of the GCTP!



### Jenny Gordon

Jenny graduated in 2010 with her Ph.D. in Bioengineering from the University of Maryland, College Park while working as a research engineer at the National Institute of Standards and Technology in Gaithersburg, MD. Her most recent research experience involved engineering hybrid cell attachment surfaces for facilitating the growth and function of embryonic mouse stem cells and human liver cells. She is excited to transition to the genetic counseling field and is particularly interested in how cultural and generational attitude differences affect patient-provider communication.



### Ellen Macnamara

Ellen graduated from the University of Virginia in May 2011 with BAs in Biology and Cognitive Science. For the past year, her research involved identifying proteins specific to the egg and ovaries for clinical and diagnostic purposes. Additionally, Ellen was a member of the Resident Staff Program at UVA as an RA and an SR where she spent time counseling and mentoring first-year students. She looks forward to continuing her education in Genetic Counseling.



### Rachel Shapira

Rachel is thrilled to be a grad student at Johns Hopkins and a fellow at NHGRI studying genetic counseling. She graduated from Wesleyan University in 2000, where she was the first student to major in both Theater and the Science in Society Program. Since then, she has lived in Chicago, and her interests have remained diverse. She worked in theatre as a production stage manager as well as elsewhere in the nonprofit sector. Rachel became interested

in genetic counseling through her experiences in a breast cancer family and in the larger HBOC community, particularly with the organization FORCE (Facing Our Risk of Cancer Empowered). Her decision to pursue the career was clinched after attending the annual FORCE conference and being laid off from her job at Google (the best thing that ever happened to her) in the same week.



GCTP students demonstrating their favorite principles of genetics.

Orientation to our joint program was jam-packed this year, and ended with a scavenger hunt to introduce the first year students to the sites and sounds of the NIH campus. After a fierce competition between our two student teams to visit the most sites and take the most creative pictures, and much deliberation by the faculty judges, it was decided that the scavenger hunt award would be shared jointly by the teams.

## 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 2013 to describe how they embraced this mandate during their training.



### Weiyi Mu

I spent the first part of my summer observing clinical genetics and the NICU at two children's hospitals in Shanghai, China. With the influx of Southern Chinese migrant workers in the past decade, Shanghai is expanding its newborn screening program, currently at four disorders. I witnessed the hectic schedule of a weekly pediatric genetics (or, "hereditary diseases") clinic and discussed the idea of

genetic counseling in China with Chinese geneticists. The last six weeks of my summer were spent rotating at Children's National Medical Center with the neurogenetics team, seeing patients for a variety of myopathies, storage disorders, leukodystrophies, and undiagnosed neuropathies. I was also involved with the national 49,XXXXY conference, sponsored by the Focus Foundation. I am very grateful for two enriching and eye-opening summer experiences!



**Dana Petry**

I spent my summer in Austin, Texas, which is where I'm from. I completed a seven week rotation with a prenatal genetic counselor at Darnall Army Medical Center at Fort Hood. I mostly counseled couples planning a pregnancy or currently pregnant with significant family histories for various genetic diseases. Due to the military setting, I was fortunate to work with an extremely diverse set of clients presenting with a wide array of unique concerns. I worked very closely with the genetic counselor, as she was the only one on base. In my free time I enjoyed the warm weather, live music, and eclectic Austin life!



**Sally Rodriguez**

I spent eight weeks this summer rotating in neurogenetics at Columbia-Presbyterian Medical Center in NYC. During my time there, I participated in genetic counseling sessions for a variety of neurodegenerative disorders, including Alzheimer disease, Frontotemporal dementia, Huntington disease, Parkinson disease, and spinocerebellar ataxias. The team I worked with included two genetic counselors, various neurologists and neuropsychiatrists, and social workers. I also helped facilitate a biweekly support group for caregivers of people with neurodegenerative disorders. Outside of clinic, I thoroughly enjoyed my time in NYC sight-seeing and overwhelming my taste buds!



**Ilana Solomon**

I spent eight weeks this summer at Cedar Sinai Medical Center in Beverly Hills, California. I was enrolled in their genetic counseling summer rotation program under the pediatrics subdivision. I worked alongside five genetic counselors, three geneticists and other pediatric support staff in three separate clinics.

They included a skeletal dysplasia/connective tissue disorder clinic, metabolic clinic and general adult/pediatric clinic. This variety and intensity of this rotation gave me invaluable experience. I was able to learn from an amazing team and participate in weekly case conferences. I even volunteered at the Little People of America National Conference! I spent my free time soaking up the SoCal sunshine and spending time with friends.

*(Photos: Maggie Bartlett, NHGRI)*

**Get Ready For Graduation!**

Save the date for graduation on January 27th, 2012, where our third year students will present their theses (titles listed below) and we will celebrate them and their research accomplishments!

**Yue Guan**

Parental Illness Representations of G6PD: the Impact on Management Strategies

**Leila Jamal**

Informed consent for whole genome sequencing: Perspectives of research participants across the health spectrum

**Tamandra Morgan**

Family Communication of Hereditary Cancer Risk Among African Americans



The Class of 2012 at last year's NSGC meeting.

**Belen Pappa**

The Role of Family Functioning in Promoting Adaptation in Siblings of Individuals with Duchenne Muscular Dystrophy (DMD)

We would also like to congratulate Leila Jamal on winning the Beth Fine Kaplan Student Abstract award. At the 2011 NSGC Annual Education Conference, she presented a project she began working on as a first year in the program titled "Does family history influence anxiety and depression levels among arrhythmogenic right ventricular dysplasia/cardiomyopathy (ARVD/C) patients?"

**Where are they now?**

**Pooja (Ramchandran) Lodaya:**

**Blazing New Trails**

In this issue we'd like to highlight Pooja (Ramchandran) Lodaya, '08, for her exciting efforts to forge new paths for genetic counselors in India.

Pooja returned to India shortly after completing her training in the program and began work as a genetic counselor for infertility clinics at four different hospitals across the city, and also established her own private practice, providing services to families across the genetic counseling spectrum ([www.poojalodaya.com](http://www.poojalodaya.com)). She has also been part of Cancer Patients Aid Association (an NGO that works with individuals with cancer and their families) as their honorary genetics consultant.

Having developed her own unique and inspiring model for genetic counseling in India, it is not surprising that other organizations are also starting to seek out her expertise.

This year, Pooja was approached by the Indian direct-to-consumer testing company, NutraGene (<http://www.nutragene.com/>), to be part of their team as a genetic counselor. NutraGene is the first and only CLIA approved direct-to-consumer lab in India that has a genetic counselor available to discuss test results with each client. NutraGene is based in Delhi, and genetic counseling services will be delivered to patients via the telephone. Pooja reported that their services went live in August.

Starting in January 2012, Pooja will also serve on the educational board of the Indian Society for Prenatal diagnosis and Therapy (ISPAT) and will be conducting short courses on genetics and genetic counseling targeted to OB-GYNs and nurses. In describing this opportunity, Pooja shared that she is “excited for the future where we could possibly reach out to other specialists (pediatricians, oncologists, etc) to truly incorporate medical genetics and genetic counseling as an integral part of medicine in Mumbai and, hopefully, India.”

Pooja, we applaud your trail-blazing efforts and cannot wait to see where the years ahead take you!

## Alumni News

### Student Thesis Publications

Work from three more student theses has made it to the presses!

Butrick, M.\*, Roter, D., Kaphingst, K., Erby, L. H., Haywood, C., Jr., Beach, M. C., et al. (2011). Patient reactions to personalized medicine vignettes: an experimental design. *Genetics in medicine : official journal of the American College of Medical Genetics*, 13(5), 421-428.

Truitt, M.\*, Biesecker, B., Capone, G., Bailey, T., & Erby, L. (2011). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient education and counseling*. epub ahead of print

Turriff, A.\*, Levy, H. P., & Biesecker, B. (2011). Prevalence and psychosocial correlates of depressive symptoms among adolescents and adults with Klinefelter syndrome. *Genetics in medicine : official journal of the American College of Medical Genetics*. epub ahead of print

### Other Alumni Updates



Jenn Lieb

**Jenn Lieb ('01)** shared news of her recent engagement to David Hodges. They are planning on a spring wedding in DC next year.

**Alissa Bovee Terry ('06)** wrote with news that she and her husband, Steve, welcomed a daughter into their family on July 22.

Avilene Elizabeth weighed 6lbs 11oz and is having fun with her big brother Fletcher, who is now 21 months.

Congratulations to **Meredith Weaver ('06)** on the birth of her daughter, Danica Alison Piquado, 6 lb 12 oz, 20 in., born on October 11, 2011!



Matt Thomas

**Matt Thomas ('07)** wed Shannon Mabry on July 8, 2011 in Charlottesville, VA.

**Courtney Nichols ('08)** said “I Do” to Jay Berrios on February 26th in Kansas City, MO.



Courtney Nichols Berrios

**Melanie Baxter ('09)** and her husband, Michael, announce the arrival of their daughter, Ellie Glenn Baxter. She is their firecracker baby, born July 4th, 2011, weighing 7 lb 7 oz and was 20.25 inches long.



Ellie Glenn Baxter

Congratulations to **Megan Truitt ('09)** on her engagement to Sung-Woo Cho. They are planning a September 2012 wedding.

**Morgan Butrick ('10)** has recently started work at Georgetown Lombardi Cancer Center as a cancer genetic counselor.

Congratulations to **Amy (Turriff) McMullen ('10)** on her marriage to David McMullen. The ceremony took place on October 15th on the Chesapeake Bay.

**Neha Kumar ('11)** wed Mohammad Monsur in a series of ceremonies this year. Neha and Monsur are settling into marriage in Springfield, NJ.

**Kendra Schaa ('11)** accepted a position with the Department of Veterans Affairs in May. She is working on the Genomic Medicine Program with a team in Washington, DC. Her primary responsibilities include education and communication efforts for VA's recently launched Million Veteran Program.

We invite you to continue sharing your personal and professional news with us so that we can update the JHU/NHGRI GCTP community. Gillian can be reached at [hookerg@nih.gov](mailto:hookerg@nih.gov) and Barb can be reached at [barbarab@mail.nih.gov](mailto:barbarab@mail.nih.gov).