

# Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Training Program

*Welcome to the Fall 2012 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 2015 and our first ever genetic counseling "exchange" student, summarize exciting new initiatives stemming from this Summer's Retreat and provide updates on the current students and alumni. Enjoy!*

## Welcome, Class of 2015!!

In August 2012, the following members of the class of 2015 arrived. Please give them a warm welcome if you see them in your clinic, around campus or attending classes!



Marci Barr

### Marci Barr

Marci grew up in Allentown, PA, and completed her BA in biology from Franklin and Marshall College in Lancaster, PA in May 2011. She recently completed a one year fellowship at the National Institutes of Health where she was a member of a laboratory that studies genetic modifiers of pain in sickle cell disease. Her primary research project was focused on examining the responses of sickle cell patients to questions about genetic research and informed consent. She is excited to take her studies of the impact of genetics on individuals to the next level as a student in the GCTP. In her free time, Marci enjoys reading, walks in the woods, yoga, exploring new places and traveling.



Megan Bell

### Megan Bell

Megan is originally from South Dakota and graduated in 2011 from Bethel University in St.

Paul, MN with a BS in Biology. During undergrad, she worked in a cancer biology lab studying the effects of HPV on head and neck cancer. Although she has been interested in genetic counseling for several years, her passion for the field was affirmed while interning this past year at Genetic Alliance in Washington, "DC" where she worked with their newborn screening program. Megan is excited for this new adventure and to get to know the Baltimore area.



Nina Harkavy

### Nina Harkavy

Nina graduated from Vassar College in May of 2012 with a BA in Psychology and Correlate in Ecology/Evolution. She served as a mentor in Vassar's Urban Education Initiative and as a crisis counselor for Vassar's The Listening Center (TLC). Her primary interest is in genetic counseling as it applies to assisted reproductive technology. A lifelong New Yorker, Nina is excited to join the JHU community and pursue the degree in Genetic Counseling she has coveted since high school.



Caroline Young

### Caroline Young

Cari graduated from Kenyon College in 2011 with a major in Biology and a minor in Classics. Since then, she has moved from Ohio back home to McLean, Virginia. In the past year, she worked as an intern at the DC Rape Crisis Center learning about the functioning of nonprofits and gaining valuable experience with counseling and advocacy by working on the DCRCC hotline. She is excited to be joining the genetic counseling field and is looking forward to getting to know Hopkins and the NIH.

Orientation to the program was jam-packed this year, and we are grateful to the faculty and students who

participated! We 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, Team Two (shown below) was declared the winner by a narrow margin.



The victors of the 2012 GCTP Scavenger Hunt



GCTP Trivia: Does anyone recognize this office door?



Tatiane Yanes

### Tatiane Yanes

We also had the pleasure of welcoming our first "genetic counseling exchange student", Tatiane Yanes, this Fall.

Tatiane was born in Brazil but moved to Canberra, Australia when she was 11 years old. She completed a BS in genetics and molecular biology from the Australian National University in 2009. She moved to Brisbane the following year, where she worked in a mental health department for two years. She is currently enrolled the Genetic Counselling program at Griffith University and is completing her first rotation at the NIH. In her spare time she enjoys hanging out with friends and family, dancing, and travelling.

## 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 2014 to describe how they embraced this mandate during their training.

### Rachel Shapira

I spent a fascinating summer in a variety of settings. I started out in Maryland at two sites, the Johns Hopkins Comprehensive Neurofibromatosis Center and the Neurogenetics Adult and Pediatric Clinics at NINDS. In August, I visited Myriad Genetic Laboratories in Salt Lake City, UT, where I spent most of my time with the Professional Support Specialists, a fantastic group of genetic counselors providing support to both providers and patients.

### Ellen Macnamara

I spent six weeks this summer in Charlottesville, VA working with the Genetics team at UVA's Department of Pediatric Genetics. While there I got to participate in a wide variety of genetic counseling cases including a day at the Huntington's clinic, time with metabolic patients receiving treatment, and marathon clinics where we traveled to surrounding rural areas. I had a blast working with the large mix of team members at UVA which included pediatric geneticists, four genetic counselors [two alumni!], a nutritionist, and multiple interns and residents. I thoroughly enjoyed my time in Charlottesville and at UVA (as its my alma mater), and spent my free time pretending I was still an undergrad!

## Graduation 2013!

Save the date for graduation on January 18th, 2013 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.

### Weiyi Mu

*"Challenges of Living with Frontotemporal Dementia: The Perspective of the Affected Individual"*

This study aims to qualitatively explore the experience, conceptualization of disease, and coping strategies of persons with frontotemporal dementia (FTD). FTD is the second most prevalent cause of early-onset dementia after Alzheimer disease, and has a significant genetic origin. Participants are adults affected with FTD and caretakers, recruited from on-line blogs and from nearby specialty clinics.

### Dana Petry

*"Likelihood of Use of a New Adult Genetic Risk Assessment Clinic"*

This study aims to identify factors that could drive early use of a regionally based adult genetic risk assessment clinic for common chronic conditions. Participants are being recruited

from the Johns Hopkins Executive and Preventive Health Program.

### Sally Rodriguez

*"Development of a Tool to Assess Spanish-language Genetic Literacy"*

This study aims to develop a Spanish-language genetic literacy instrument, as one does not currently exist. Native Spanish speakers were recruited from Baltimore, Montgomery, and Prince George's counties.

### Ilana Solomon

*"Living in Lynch Syndrome Limbo: Exploring the Meaning of Uncertain Genetic Test Results"*

This qualitative interview study aims to describe perceptions of the process of receiving a VUS for Lynch Syndrome, including the nature of the disclosure, their understanding of the result itself, and their reactions and to describe participants'



The Class of 2013

perceptions of the process of receiving a VUS, including the nature of the disclosure, their understanding of the result itself, and their reactions.

## Thesis Presentations at the NSGC Annual Education Conference

All four of our recent graduates will be presenting their theses at the NSGC Annual Education Conference in Boston this year.

On Thursday, October 25th, from 6 – 7:30 pm Yue Guan will present her poster, *"Parental Disclosure of G6PD and Its Relationship to Child Health in a Chinese Population"* and Barb Biesecker will present Leila Jamal's poster, *"Informed Consent for Whole-Genome or Whole-Exome Sequencing: Insights from Participants Across the Health Spectrum."*

On Friday, October 26th at 3:15 pm, Tamandra Morgan will give a talk on her thesis work, *"Comprehension of Family Communication of Hereditary Cancer Risk Among African Americans."*

And on Saturday, October 27th at 2 pm, Belen Pappa will give a talk on her thesis, *"The Role of Family Functioning in Promoting Adaptation Among Siblings of Individuals with Duchenne Muscular Dystrophy"*.

## 2012 Program Reunion at the AEC

The reunion of alumni, students and faculty will be held on

Thursday, October 25th at 7:30 pm at Geoffrey's Café in Boston. Hope to see you there!

## 2012 Executive Committee Retreat

On June 13th, we held the biennial program retreat at the NIH Natcher Conference Center (lunch catered by Barb and Gillian!). Members of the Executive Committee attended along with faculty and recent program alumni. Rachel Shapira represented the students. There were a number of important outcomes from the retreat that relate to long-term objectives for the program:

1. We plan to expand our interview process to include local alumni.
2. We designed a mentorship program between local alumni and the incoming first year students. Mentors were assigned a student and asked to contact them for an initial meeting. The students and their mentors will decide the shape and extent of the relationship.
3. We also broke into small groups and reviewed courses that are required in the program but not by an accrediting body. There were ten courses that were considered and ranked. There was near consensus among the four groups and six courses are now electives or recommended rather than required. This will introduce greater choice and flexibility for the students.

All in all it was a very enjoyable and productive retreat. As you may have discerned, our recent alumni played a prominent role in informing the process and their input was key to achieving these important outcomes!

## NHGRI/JHU Research Symposium

On Friday, November 2nd, 2012 we plan to hold a day-long research symposium at the NIH on studies of genetic counseling and our clients, highlighting excellence in research. We will begin with a few overseas studies, followed by several alumni presentations and faculty studies. Over a working lunch and at the end of the day there will be sessions to identify key research questions in the profession and to suggest designs that can build on evidence that is beginning to unfold. Area alumni have been invited to attend. Clinical supervisors who are interested in research are also encouraged to attend.

## ALUMNI UPDATES

**Yelena Kemel ('99)** wrote to share that she recently left her position at Memorial Sloan-Kettering Cancer Center in January to join GenPath Diagnostics/Bioreference Laboratories in New Jersey.

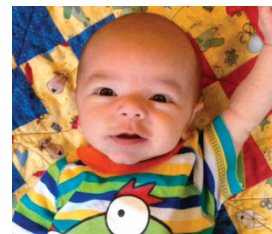
Congratulations to Dave and **Lori Erby (Faculty member and class of '00)** on the birth of David Neal Erby (Neal) on

Oct. 4, 2012! To go with the new baby, Lori and Dave also found a new home in Carroll County, MD

**Danielle Dong ('05)** announced the birth of Brendan Conrad Haberkern on July 29th. Brendan is doing great and big sister, Ellie, age 3, is also well. Danielle and her husband are living in Brookline, MA and Danielle is working for Genzyme for the Lysosomal Storage Disease Registries. Congratulations and Welcome to the GCTP community, Brendan!



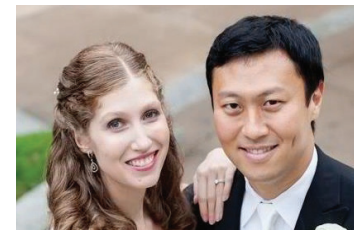
David Neal Erby



Brendan Conrad Haberkern

**Jackie Schienda ('08)** recently left her position at Tufts University to join the Cancer Genetics and Prevention Program at Dana Farber Cancer Institute.

On September 8th, 2012 **Megan Truitt ('09)** wed Sung-Woo Cho in Baltimore, MD. Congratulations, Megan and Sung-Woo!



(Photo: The Blonde Photographer)  
Megan and Sung-Woo

**Melanie Baxter ('09)** has moved from St. Louis to be closer to family. Her husband accepted a position as senior copywriter at Red Letter Communications in Cape Girardeau, MO. Melanie created a part-time position with the Saint Francis Cancer Institute in Cape Girardeau, making her the first genetic counselor in the Southeast Missouri region, and she is also working part-time as a project coordinator for the Heartland Regional Genetics and Newborn Screening Collaborative. She is slotted to teach the Cancer Genetics course for the UAMS Genetic Counseling Training Program this upcoming spring semester. The transition to small town Missouri has been smooth, though they are staying with family until they sell their condo in St. Louis. Hopefully there will be news of a new house in the next edition!

**Neha Kumar ('11)** wrote to share news of her new position at Recombine, genetic testing start-up company in New York City ([www.recombine.com](http://www.recombine.com)).

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).