

# Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Training Program

*Welcome to the Spring 2013 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 pass along a few program updates, congratulate the class of 2013, celebrate DNA Day and catch up with our fantastic alumni. Happy Reading!*

## PROGRAM UPDATES

We have added an exciting new course to our curriculum for the 2013-2014 school year: "Health Judgment and Decision Making" will be taught by GCTP Executive Committee member, Bill Klein, in the 3rd term of next year.

We are also thrilled to have welcomed Morgan Butrick ('10) back to the program, this time in the capacity of course director for the Facilitating Adaptation to Grief and Loss course.

## CONGRATULATIONS TO THE CLASS OF 2013!



(Photo: Maggie Bartlett, NHGRI) Our outstanding graduates!

On January 18th, 2013, in the Cloisters at NIH, we celebrated the graduation of Wei Yi Mu, Dana Petry, Sally Rodriguez and Ilana Solomon from the GCTP. The students began a full day of celebration by presenting their thesis research in a symposium that faculty, friends and family attended. We celebrated their accomplishments and bid a bittersweet farewell. We enthusiastically welcome these new colleagues in the field!

Presentations were titled:

### **Wei Yi Mu**

Challenges of Living with Frontotemporal Dementia:

Understanding the Perspective of the Affected Individual Through Blog Content Analysis

### **Dana Petry**

Likelihood of Use of a New Adult Genetic Risk Assessment Clinic

### **Sally Rodriguez**

Translation and Validation of a Spanish-language Genetic Literacy Screening Tool

### **Ilana Solomon**

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

## ONWARD AND UPWARD!

Our 2013 graduates entered the professional world in full force and with an impressive slate of "first jobs":

**Wei Yi Mu** accepted a full-time position in the McKusick-Nathans Institute of Genetic Medicine at Johns Hopkins.

**Dana Petry** is a cancer genetic counselor in the Institute for Cancer Care at Mercy Hospital.

**Sally Rodriguez** accepted a position in New York, NY with the genetic testing company, Recombine. She joins alumna Neha Kumar ('11) in providing counseling support to families undergoing carrier screening.

**Ilana Solomon** headed westward and practices as a cancer genetic counselor at City of Hope Comprehensive Cancer Center in Duarte, CA.

## SAVE THE DATE!

- On June 14th 2013, the *Genome: Unlocking Life's Code* exhibit will open at the Smithsonian Museum of Natural History, appropriately, in hall 23.
- Last day to schedule the American Board of Genetic Counseling (ABGC) 2013 board certification exam is July 1st, 2013.
- ABGC 2013 board certification examination will be offered August 1st – August 30th, 2013.
- GCTP fall classes start September 3rd, 2013.
- NSGC Annual Education Conference is October 9th-13th, 2013, in Anaheim, CA

- American Society of Human Genetics Annual Meeting is October 22nd-26th, 2013 in Boston, MA.

- January 17th, 2013 is the next GCTP NIH graduation symposium and celebration. Please plan to attend!

## ALUMNI – WHERE ARE THEY NOW?

In this installation of the GCTP newsletter, we catch up with Tricia See ('06), Genetic Counseling Team Leader, General Genetics for InformedDNA, a nationwide provider of genetic services via telephone. Tricia recently visited the GCTP to share her work with the students, and then agreed to a brief interview for this newsletter.

*GCTP: We would love to hear more about InformedDNA and your work there.*

InformedDNA is an independent genetic counseling network providing telephone-based genetic counseling services. Our services cover most sub-specialties and expertise: cancer, reproductive, cardiac, ocular, neurogenetics, pharmacogenetics, and whole genome/exome sequencing. We receive referrals from a number of sources, including providers and directly from patients. I am a senior genetic counselor with the company and serve as team leader for our General Genetics team.

*GCTP: What do you see as the benefits (to your clients and to you) of counseling by phone?*

We offer telephone-based genetic counseling appointments at convenient and flexible hours (evenings and weekends) and allow clients to participate from the comfort of their own home. Clients who have physical or work limitations are able to access our services easily, thereby reducing barriers to following through with a genetic counseling referral. Our services are covered by most insurers and clients are notified of any out-of-pocket costs prior to the appointment.

The benefits to me, as a genetic counselor, in counseling by telephone are twofold: 1. I am able to reach individuals across the United States, from rural to urban settings, and from many cultural and regional backgrounds; 2. I have a great deal of flexibility in my work schedule and am able to maximize time at home with my family outside of working hours (no commute!).

*GCTP: What are the challenges and limitations, and how do you work around these?*

The limitation we face in providing telephone-based genetic counseling is the lack of nonverbal cues. Since I am not face-to-face with clients, I rely heavily on setting concrete expectations during contracting and using my counseling skills to perform an accurate psychosocial assessment.

*GCTP: What are the future challenges and opportunities for telephone counseling?*

I believe there are many future opportunities for telephone-based counseling! Our company aims to reach more and more clients who could benefit from genetic counseling services and allow ALL providers (regardless of geographic location or specialty) the ability to utilize genetics expertise for their patients. By reducing barriers, we hope to make genetic counseling available to all persons who could benefit from such services.

## DNA DAY!!

In anticipation of the upcoming opening of the Genome exhibit, GCTP students had the opportunity to celebrate DNA day at the Smithsonian National Museum of Natural History with hundreds of students from several DC area high schools. Students were involved in tweeting throughout the day and running activity stations in the museum to help high school students explore their own genetics.



GCTP students teamed up with student from the University of Maryland Program to help DC high school students celebrate DNA Day



Nina Harkavy and Marci Barr ready to educate visiting high school students

Every year, DNA Day is a day of outreach, when students, teachers and the public can learn more about genetics and genomics. It is held every year in April to commemorate the completion of the Human Genome Project in 2003.



## ALUMNI NEWS

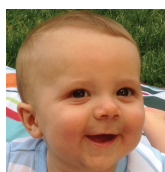
Recently, following the New York Times op-ed from actress, Angelina Jolie, regarding her surgical decisions following BRCA testing, a number of our alumni were called upon to speak to the media about genetic counseling and testing for hereditary cancer. **Christy Haakonsen ('11)** was interviewed by Baltimore stations, WJZ/channel 13 and Fox 45. **Amanda Lamb ('10)** appeared on a news piece on WCSH in Portland, ME and **Melanie Baxter ('09)** was interviewed by the Cape Girardeau, MO NPR station, KRCU. We are proud to have these women representing our field!

**Kira Dies ('03)** wrote to pass along the reference for her recent publication: Dies, KA et al, Schizencephaly: association with young maternal age, alcohol use, and lack of prenatal care. *J Child Neurol* (2013) pp. 198.



Zara Alexis White

Ric and **Brook (Waggoner) White ('04)** welcomed Zara Alexis into their family on March 1, 2013.



Beckett Owen Sapp

Welcome to Beckett Owen Sapp, born to Eric and **Julie Sapp ('05)** on November 12, 2012.

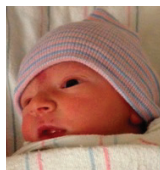
**Sarah Zentack ('05)** wrote to share two updates: "Personal update: My husband and I quit our jobs, sold/donated our stuff and are riding our bicycles from Houston to Tierra del Fuego. We have a website chronicling our adventures, misadventures and everything in between: [www.wanderwheels.com](http://www.wanderwheels.com). Professional update: I left my position at Baylor College of Medicine in Houston, and picked up a contract gig with InformedDNA (w/ **Tricia Gasser See ('05)** that is more conducive to our new nomadic lifestyle :-)"



*Sarah Zentack, into the great wide open.*

**Rachel (Jacobsen) Silver ('07)** and family welcomed baby Molly Claire Silver on May 8, 2013.

**Jamie Dokson ('07)**, and her husband James Peacock, welcomed their first child, Kyle Anderson Peacock, on May 18, 2013.



Jackson Alexander Caleshu

Congratulations to Thomas and **Colleen Caleshu ('07)** on the May 26th birth of Jackson Alexander Caleshu.

**Belen Pappa ('12)** wrote to share the news that she was recently appointed to the faculty at George Washington University and also co-authored a paper on genetic counseling in mitochondrial disease: Vento, JM and Pappa MB, *Neurotherapeutics* (2013) pp. 243-250.

**Tamandra Morgan ('12)** wrote to share that she was invited to present her thesis work at the Conference to Eliminate Health Disparities in Genomic Medicine, held May 29th-30th in San Francisco, CA.

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).



*(This picture didn't quite make it in time for last Fall's news letter, but we couldn't not include it.)* Alumni and faculty celebrating the fall wedding of Megan Truitt ('09) and Sung Woo Cho