

# Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Training Program

*Welcome to the Spring/Summer 2014 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.*

## PROGRAM UPDATES

### Associate Director

In January, we had a bittersweet transition in Associate Directors. We said good-bye to **Gillian Hooker**, who relocated with her family to Nashville, TN where she now serves as the senior manager for clinical development at NextGxDx. There, she is working to build and maintain an online marketplace for genetic testing and develop tools to facilitate the ordering of genetic tests. She reports that she misses the students and faculty of the GCTP very much, but that the family has transitioned quite well, and are enjoying the music scene and working on their southern accents.

We were excited to welcome long-time GCTP enthusiast, **Lori Erby**. Lori is an alumna of the program and has been teaching the thesis proposal development course series for a number of years. She has relocated her office from Hampton House to the NIH campus, and in spite of taking a brief hiatus immediately after starting the position to have her second baby, reports that she has already been enjoying her increased contact with the students.



Julie Cohen, ScM

### Executive Committee

We would like to welcome **Julie Cohen, ScM** and **Larry Cheskin, M.D.** as the newest members of the Executive Committee. Julie Cohen is an alumna of the GCTP, receiving her degree in '09. She is currently a genetic counselor at Kennedy Krieger Institute in the division of Neurogenetics and is an active clinical supervisor for our students. Larry Cheskin is an Associate Professor in the Johns Hopkins Bloomberg School of Public Health Department of Health, Behavior and Society, with joint appointments in Human Nutrition and in Medicine. He is the Director of the Johns Hopkins Weight Management Center and teaches Clinical and Public Health Behavior Change at the undergraduate campus as well as several nutrition and weight-related graduate level courses. We look forward to the energy that both new members will bring to the group!



Larry Cheskin, M.D.

### Courses

We were fortunate to recruit **Rachel Nusbaum** to take over teaching Cancer Genetics at the end of this past academic year. Rachel, now with GeneDx, was formerly a genetic counselor and clinical supervisor at Lombardi Cancer Center and has

counseled families at risk for hereditary cancer for seven years. She has also been actively involved in several cancer-related research studies. Thanks to Rachel for sharing her enthusiasm and expertise!

## Congratulations to the Class of 2014



The graduates share some memories. (Pictured are Ellen Macnamara and Rachel Shapira, left to right)

On January 17, 2014, in the Cloisters Lecture Hall on the NIH campus, we celebrated the graduation of Ellen Macnamara and Rachel Shapira from the GCTP. It was a joyous occasion, as we recalled fond memories, shared their accomplishments, and anticipated great

things to come. It was, as always, difficult to say goodbye, but we look forward to finding future collaborations.

The students began the celebration by presenting their thesis research in a symposium attended by faculty, family, and friends. The titles of their presentations were:

### Ellen Macnamara

*Experiences of parents of children with undiagnosed multiple congenital anomalies*

### Rachel Shapira

*Adaptation to living with a BRCA1/2 mutation in carriers and their partners*

### Where are they now?

After graduation, **Ellen Macnamara** successfully lobbied for the creation of her dream job as a genetic counselor with the NIH Undiagnosed Diseases Program (UDP). The UDP, organized by the NHGRI, the NIH Office of Rare Diseases



Graduation attendees. Pictured are Barbara Biesecker, Megan Bell, Rachel Shapira, Cari Young, Marci Barr, Claire Anderson, Kyle Davis, Jennefer Kohler, Nina Harkavy, Ellen Macnamara, and Gillian Hooker, left to right)

Research, and the NIH Clinical Center, has been set up to provide answers to patients with mysterious conditions that have remained undiagnosed in spite of previous diagnostic attempts and to simultaneously advance medical knowledge about rare and common disease. After a brief stint covering a maternity leave position, she is now happily working full-time for the UDP and has even agreed to supervise an advanced student as part of a summer rotation.

**Rachel Shapira** is a (half-time) genetic counselor at St. Joseph Hospital Center for Cancer Prevention and Treatment in Orange, CA. In the other half of her time, she works for GeneTestNow.com, a nonprofit initiative in Los Angeles committed to promoting awareness and education about Jewish Genetic Diseases. Occasionally, she works for Progenity, providing genetic counseling to individuals and couples at Jewish genetic screening events. As a throwback to her pre-GC days, she can sometimes be found working for conference services at American Jewish University as a stage manager, or, most recently, Bar Mitzvah event coordinator. She remains active with FORCE, and recently co-presented a session at the annual conference with her husband, Danny.

## CATCHING UP WITH THE GCTP

In this issue, we catch up with our long-time program coordinator at Johns Hopkins, **Mary Ann Dunevant**. Mary Ann has shepherded many of our alumni as well as all of our current students through the transition to Baltimore, course registration, Johns Hopkins administrative processes, and myriad other daily needs of student life. She has been the face of the program for potential applicants wishing to visit campus, sharing her knowledge of our training program as well as fun-facts about life in the city. It probably goes without saying that the Johns Hopkins side of the program simply would not function without her. Mary Ann has also worked for many years with Academic Director Debra Roter doing communication coding of medical visits, including many from the Genetic Counseling Video Project.

**Mary Ann shared the following with us:**

One of my most frequently used phrases when meeting new GCTP students or interviewees is: "Remember, I'm a former English teacher!" I am always eager and excited to hear about

their research interests and thesis proposals, but I want them to be aware that I am not coming from a science background and that they will need to explain to me just like they would explain to a client. I figure that it is good practice for them! In other ways, my previous life as a high school English teacher and middle school Creative Writing teacher helps in many ways. I have become the "go-to" person when a student or faculty member needs some editing of a document, work which I enjoy very much. In my spare time, I am a hiker and a swimmer. My husband and I are "practicing" for retirement by traveling. Early in June we hiked in the Alps in Austria and Italy. We did up to 9 miles a day! Those miles were necessary to burn off the 5 course gourmet meals in the evening! Next trip for me is a "girls' weekend" in August with my daughter in Las Vegas. But I'll be back in time for orientation, and I look forward to getting to know our new class of 2017!

## SUPPORT CURRENT STUDENTS AND RECENT ALUMNAE AT THE AEC!

Look for the following oral presentations and posters by current students and recent graduates at the AEC in September:

### Oral presentations

*Genetic Counselors as Choice Architects: Some Considerations for Presenting Genetic Testing Decisions in a Complex Choice Environment* Marci Barr ('15) Beth Fine Kaplan Best Student Abstract Award

*Evaluation of the Quality and Literacy of Commercial Non-Invasive Prenatal Test (NIPT) Websites* Megan Bell ('15) Session 328

### Posters

*The Role of Uncertainty in Coping Efficacy: The Experience of Parents of Children with Undiagnosed Medical Conditions* Ellen Macnamara ('14)

*Adaptation to Living with a BRCA1/2 Mutation in Carriers and their Partners* Rachel Shapira ('14)

*Perceived Obligations by Researchers in Genetics to Return Individual Research Results and Incidental Findings to Participants* Caroline Young ('15)

*The Importance of Suicide Screening in the Genetic Counseling Setting* Claire Anderson ('16)

*De Novo Mutation Rate in the RYR2 Gene: Implications for Genetic Counseling* Kyle Davis ('16)

*Pharmacogenomics: An Analysis of the Baseline Knowledge of ClinSeq® Participants* Jennefer Kohler ('16)

## ALUMNI NEWS

### Professional News

**Ilana Solomon** ('13) reports that she has become faculty for the City of Hope Intensive Course in Cancer Risk Assessment, where she has already taught some of the distance modules and



Mary Ann hiking in the Alps



is in the process of updating a new course. Congratulations on an exciting professional step!

**Tamandra Morgan** ('12) recently accepted a position at GeneDx. She also shared that she recently published a paper entitled "*Using the internet to seek information about genetic and rare diseases: A case study comparing data from 2006 and 2011*", with fellow alumna **Christy Haakonsen** ('11), Program Director **Barbara Biesecker**, and former Executive Committee member **Kimberly Kaphingst** among her co-authors. The manuscript was published in *JMIR Research Protocols*. Congrats to all!

**Morgan Butrick** ('10) is pleased to share that her paper entitled "*Discussing race-related limitations of genomic testing for colon cancer risk: implications for education and counseling*" was recently accepted to *Social Science and Medicine*. Co-authors included **Gillian Hooker** ('09). We're always excited to see alumni collaborations!

**Melanie Baxter** ('09) also reports a job transition; as of March 1, she is now working full-time with InformedDNA, providing telephone-based cancer risk assessment and counseling. And loving it!

After almost twelve years in Cardiology at Johns Hopkins, **Nicole Johnson** ('02) recently took a position with Invitae, a new clinical genetic testing laboratory. Although the lab is based in San Francisco, she'll be working remotely from Baltimore with periodic trips west. We wish her the best!

### On a Personal Note



Gabriel MacLeod Davis

As a first for our program, matriculating second year, **Kyle Davis** ('16), became a first-time father and still managed to finish fourth term. On May 15, 2014, Kyle and Jenny welcomed Gabriel MacLeod Davis to their growing family. We look forward to seeing more of Gabe this year!

**Morgan Butrick** ('10) announced her engagement to Matt Similuk. We can't wait to see wedding photos!



Benjamin Eli

**Julie Cohen** ('09) shared that Benjamin Eli Cohen was born on October 22nd 2013. We're excited to have another GCTP baby in the region!

**Tricia See** ('05) welcomed another baby boy to her family this past fall. Calvin Joseph See was born on November 4, 2013. He's doing great and Tricia notes that Leo is such a good big brother!



Calvin with older brother Leo



Xavia

**Ric, Brook (Waggoner '04) and Zara White** welcomed Xavia to their family on April 16, 2014. So precious!



Graeme Clay and sister Margot

**Kira (Apse) Dies** ('03) shared that her son Graeme Clay was born December 23, 2013. His 3 ½ year old sister, Margot, is quite proud, as you can see.

**Melissa (Barber) Butson** ('00) was blessed with twins Theodore Ansel and Gwendolen Rose on July 12th of 2013. We wish them continued happiness (and sleep!)



Colin and big brother Neal

**Lori Erby** ('00) and her husband Dave welcomed their second son, Colin Robert, on April 24, 2014. Big brother Neal can't get enough of him!

Last but not least, the GCTP class of 2009 recently held a reunion in Taylorsville, KY. Bourbon, babies and belly laughs!



Julie Cohen holding Benjamin, Megan (Truitt) Cho, Melanie Baxter holding Ellie, Melinda Simonson holding Oliver, Gillian Hooker holding Nora, left to right

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](mailto:lori.erby@nih.gov) and Barb can be reached at [barbarab@mail.nih.gov](mailto:barbarab@mail.nih.gov).

### SAVE THE DATE!!!

Alumni Research Symposium Aug 1

First term courses start Sept 2

NSGC AEC Sept 17-20

JHU/NHGRI program reunion Sept 19 -

Look for an upcoming e-mail message with further details

ASHG 2014 meeting Oct 18-22

GCTP Student Graduation Jan 16, 2015