

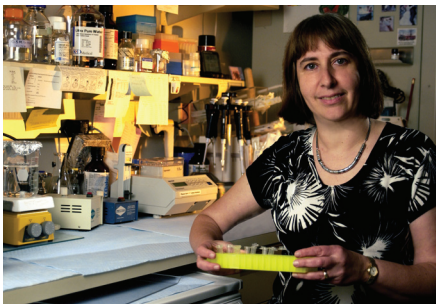
Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Training Program

Welcome to the spring 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, support staff, Executive Committee members and current and prospective students. We hope this letter will keep you up-to-date about our program.

Program Updates

We welcome with pleasure Dr. Ellen Sidransky as the new Medical Director of the Genetic Counseling Training Program (GCTP). As Medical Director, Ellen will



(photo: Maggie Bartlett, NHGRI)

JHU/NHGRI GCTP
Medical Director Ellen Sidransky, M.D.

be serving as an instructor, thesis and faculty advisor to the students, and an Executive Committee member. She is responsible for the GCTP genetics curriculum. In addition to her work as Medical Director, Ellen is a Senior Investigator in the Medical Genetics Branch of the National Human Genome Research Institute (NHGRI), where her research program focuses on the genetics of Gaucher disease.

At its July 2008 retreat, the Executive Committee decided summer clinical rotations will be a formal requirement of the curriculum. Although historically most students have chosen to complete clinical rotations, incoming students will now be required to do so. Summer rotations provide students with expanded opportunities to develop the case management skills that are often part of a genetic counselor's job. The Program will continue to encourage international and innovative rotations outside of the clinic,

which many students have enjoyed in past summers. Additionally, we've removed the clinical rotation requirement for 2nd year students in their 3rd quarter. This has long been a challenging quarter for students to complete a clinical rotation because of a particularly busy class schedule.

Class of 2009

Theses studies

Screening Behavior in Adults with Hereditary Hemorrhagic Telangiectasia: Illness Perceptions and the Health Belief Model

Melanie D. Baxter, Sc.M.
Advisor: Alan Guttmacher, M.D.

Adaptation and Quality of Life Among Adults with Neurofibromatosis Type 1

Julie Snyder Cohen, Sc.M.
Advisor: Barbara Biesecker, M.S.

Testing for Inflammatory Bowel Disease: Predictors of Patients' Appraisals of Medical and Genetic Testing

Gillian W. Hooker, Ph.D., Sc.M.
Advisor: Debra Roter, DrPH, MPH

Cultural Congruence in International Genetics Research: Perceptions of Challenges and Opportunities among Researchers

Mindy Simonson, Sc.M.
Advisor: Rajiv Rimal, Ph.D.

The Role of Hope in Adaptation to Uncertainty: The Experience of Caregivers of Children with Down Syndrome

Megan Truitt, Sc.M.
Advisor: Lori Erby, Ph.D.

Where are they now?

Melanie Baxter returned to Missouri, home to both her and her husband's families. She works as a genetic counselor in the Siteman Cancer Center of Washington University in St. Louis. Her responsibilities are split between providing clinical services and working in the Hereditary Cancer Core, a shared research resource in

the Siteman Cancer Center that is responsible for facilitating cancer genetic research studies.

Julie Cohen, a life long Baltimorean, stayed in Baltimore after graduation and is working part time at the Johns Hopkins Prenatal Diagnosis and Treatment Center as well as part time at the Frederick and Rockville offices of Maryland Perinatal Associates. We can't wait for Julie to start supervising students!

Gillian Hooker transitioned from the role of student to genetic counselor at one of her final rotation sites. Gillian is working as a genetic counselor and project director in the Cancer Control Program at Lombardi Comprehensive Cancer Center. Her position is a mix of counseling and participating in ongoing social and behavioral research at the Center. It's nice to have her just down the street!

Mindy Simonson has returned to her roots in the southwest and is living in Santa Fe, New Mexico while she looks for permanent employment. She hopes to find a job in the southwest. While engaging in her job search, she is enjoying hiking and relaxing with her family.

Megan Truitt accepted a position in the Big Apple. She is providing pediatric and prenatal genetic counseling at Columbia/NY Presbyterian Children's Hospital. She lives on the Upper West Side of Manhattan and enjoys exploring the city in her spare time.



(photo: Bill Branson, NHGRI)

JHU/NHGRI GCTP class of 2009 enjoys a celebratory moment at their graduation, Friday, January 16, 2009, with Program Director Barb Biesecker. Left to right: Julie Cohen, Megan Truitt, Barb Biesecker, Gillian Hooker, Mindy Simonson, Melanie Baxter.



(photo: Bill Branson, NHGRI)

NHGRI Retreat, 2008. Second and third year GCTP students demonstrate a new way of educating clients about chromosomes. Here, students enjoy the grand finale of their interpretative dance. Left to right: Mindy Simonson, Morgan Butrick, Gillian Hooker, Julie Cohen, Amanda (Rowe) Lamb, Melanie Baxter, Amy Turriff, Megan Truitt, Amanda Singleton.

NHGRI Retreat

The annual NHGRI retreat was October 20-21, 2008. Although there had been many previous celebrations of Francis Collins' role at NHGRI, this was an opportunity for NHGRI faculty, trainees and staff to enjoy a roast of Dr. Collins. Eric Green served as Master of Ceremonies and the GCTP chose to demonstrate the changes that have happened in genetic counseling during Dr. Collins' tenure at NHGRI. Students in the classes of 2009 and 2010 choreographed a modern dance performance in which they were chromosomes. Barb Biesecker narrated the performance and Anne Madeo served as a poster board presenter, a la Vanna White. As the picture indicates, it was quite a performance.

Workshop with Dr. Seymour Kessler

The program was fortunate to host Dr. Seymour Kessler for a workshop November 23-24, 2008. Dr. Kessler's workshops, in which he reviews students' counseling sessions and provides feedback, have been a tradition in the program. Dr. Kessler is considered by many to be the grandfather of genetic counseling. He trained genetic counseling students at the University of California, Berkeley, and he has written extensively on topics in the field. Seymour continues to demonstrate the importance of supervision in promoting personal insight and professional

growth. One of his most significant contributions to the profession is emphasizing the value of compassion in our work.

DNA Day

DNA Day is an opportunity for NHGRI faculty, staff and trainees to work together so that students, teachers and the public can learn more about genetics and genomics! It was created to commemorate the completion of the Human Genome Project in April 2003, and the discovery of DNA's double helix. To

celebrate DNA Day, members of the NHGRI community volunteer as Ambassadors. Ambassadors present current topics in genetics, the work they do, as well as career options in the field to high school audiences. This year, DNA Day was April 24, 2009.

As is tradition, all of the GCTP students volunteered as DNA Day Ambassadors. A popular place to volunteer is the NHGRI DNA Day Chatroom, an internet based "room" in which individuals from around the country are able to ask questions of professionals from a wide variety of genetics backgrounds. Morgan Butrick, Neha Kumar, Amanda Singleton, Amy Turriff and GCTP alumni Kate Reed ('06) and Courtney Nichols ('08), joined many other volunteers in the Chatroom. To see the questions and answers from this year's DNA Day, a transcript can be found at <http://www.genome.gov/27531613>. Sarah Kalia travelled to Houston, TX, to be an Ambassador. Christy Haakonsen and Kendra Schaa could be found at Highland High School in Salt Lake City, UT, where they made four presentations in two different classrooms. Jane Lee stayed closer to home and made presentations in three classes at Oakland Mill High School in Columbia, MD. She reports being "thoroughly impressed by the students and their level of processing... there was a lot of discussion and it even went on amongst the students after the bell rang!" Like Jane, Amanda (Rowe) Lamb stayed close to home and presented at Gwynn Park High School in Brandywine, MD.



Participants in November, 2008 workshop with Dr. Seymour Kessler. Seated: Dr. Kessler; in back, left to right: Jane Lee, Amanda Singleton, Morgan Butrick, Amanda (Rowe) Lamb, Amy Turriff, Christy Haakonsen, Sarah Kalia, Gillian Hooker, Mindy Simonson, Kendra Schaa, Neha Kumar, Melanie Baxter, Julie Cohen.

Save the date!

- Abstracts for the National Society of Genetic Counselors' (NSGC) 28th Annual Education Conference must be submitted by May 15, 2009.
- Genetic Alliance Annual Conference is July 17-19, 2009, in Bethesda, MD.
- Last day to schedule the American Board of Genetic Counseling (ABGC) 2009 board certification exam is August 1, 2009.
- ABGC 2009 board certification examination will be offered August 24 - September 25, 2009.
- NHGRI GCTP new student orientation begins Friday, August 21, 2009.
- Johns Hopkins University (JHU) Bloomberg School of Public Health new student orientation is August 24-26, 2009.
- GCTP fall classes start August 27, 2009.
- National Coalition for Health Professional Education in Genetics (NCHPEG) 12th Annual Meeting is September 23-24, 2009, in Bethesda, MD.
- NSGC Annual Education Conference is November 12-15, 2009, in Atlanta, GA
- NHGRI annual retreat is November 17-18, 2009, in Gettysburg, PA.

Alumni News

Melissa Barber Butson ('00) reports that 2008 was a year full of changes. In June she gave birth to a baby boy, Everett Maxwell, and in August, she and her family relocated to Milwaukee, Wisconsin. September 2008 was

spent at the Brocher Foundation in Geneva, Switzerland working on a project about group harms in large-scale biobanks. So what remained the same in 2008? She's continuing her work on her dissertation in Bioethics from Case Western Reserve University.

Jennifer (Gamm) Ruschman ('02) gave birth to a baby boy, Thomas Joseph Ruschman, on December 7, 2008. He was 8 lbs 10 oz. and 21 inches long and was greeted at home by older siblings, Adam, Jr., Laney and Ashley.

Kira Apse ('03) recently accepted a position as the Tuberous Sclerosis Program Manager at Children's Hospital Boston, where she describes her responsibilities as 50% clinical and 50% research. You'll find her in her new job after Memorial Day.

Marie (Cudoc) Belgrave ('05) and her husband welcomed Colin Michael on October 29, 2008. Marie has continued to work (although from home now) for Dr. Evelyn Karsons private prenatal practice, which allows her to spend time with Colin every day. She reports enjoying motherhood and that Colin keeps her on her toes. Looking at that smile, he couldn't be other than a perfect angel!



Colin Michael Belgrave, sporting a special onesie made for him by the GCTP class of 2005.

Colleen Brown ('07) shares the news of her engagement to Thomas Caleshu. They met doing triathlons and fundraising for the Leukemia and Lymphoma Society. Colleen and Thomas got engaged in the San Juan Islands off of Washington state and plan to return there in the fall of 2010 for their wedding.

Rachel (Jacobsen) Silver ('07) and David Silver welcomed their daughter, Charlotte Paige, at 1:45 am Friday, April 24, 2009. It seems like the perfect way to celebrate DNA Day!

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