

Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Training Program

Welcome to the fall 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

Based on feedback from applicants, current students and alumni, we have a new and improved GCTP website hosted on the NHGRI servers. Not only does the website more fully describe the program, it showcases our strengths and distinguishes the JHU/NHGRI program from other genetic counseling training programs. We encourage you to check it out: <http://www.genome.gov/GCTP/>

Congratulations to **Joan Scott, MS**, GCTP Executive Committee member, as she assumes the position of Director of the Genetics and Public Policy Center at the Johns Hopkins University!

Kim Kaphingst, ScD, GCTP Executive Committee member, recently left the Social and Behavioral Research Branch at NHGRI. Our loss is Washington University's gain, as Kim has joined the faculty of the School of Medicine where she will continue her research program in health literacy and communication about genetics and genomics.

Andrea Wray, MS, GCTP faculty member, was appointed Adjunct Assistant Professor in the Johns Hopkins Bloomberg School of Public Health. Congratulations, Andrea!

Introductions

In August 2009, the following members of the class of 2012 arrived. Please give them a warm welcome if you see them in your clinic, around campus or attending classes!



Yue Guan

Yue Guan graduated from Peking University in 2009 with a Bachelor of Science in Nursing, and a Bachelor of Arts in Arts. During her fifth year of medical study, Yue worked as a nurse intern in a comprehensive hospital in Beijing, China. Her current

research interests include reproductive genetics and health attitudes and behaviors related to genetic counseling. In her spare time, she loves travelling with friends and watching television shows like *Lie to Me*.



Leila Jamal

Leila Jamal received her Bachelor of Arts in Philosophy, Politics, and Economics from Oxford University in 2002. She spent the past two years conducting research on the healthcare sector at Harvard Business School. Prior to that, she worked as a management consultant in New York City. Her academic interests include the role of personalized medicine in U.S. healthcare reform and the role of ethnicity in risk perception and provider/patient communication.



Isaac Jones

This is Isaac Jones' second time as a graduate student in the Johns Hopkins Bloomberg School of Public Health. His previous stint was spent studying the evolution of sperm-egg specific interactions. Over the past eight years, Isaac has taught high school in New York City and San Diego and is now very excited about the opportunity to be a student again. He is interested in working at the intersection of genetics, education, and public policy.



Tamandra Morgan

Tamandra Morgan received a Bachelor of Arts in Human Biology with a concentration in genetic diseases and cancer from Stanford University in June 2009. This past summer, Tamandra completed an internship in the lab of Dr. James Yager at the Johns Hopkins Bloomberg School of Public Health, Department of Environmental Health Sciences. Her research interests include understanding the impact of genetic technology on racial/ethnic health disparities.



(Maria) Belen Pappa

Belen Pappa was born and raised in Buenos Aires, Argentina. She moved to the United States to complete her undergraduate studies at the University of Maryland College Park, where she received a Bachelor of Science in Cell Biology and Molecular Genetics in 2008. As an undergraduate, Belen spent two years working as a Howard Hughes Medical Institute Fellow in Dr. Caren Chang's lab focusing on genetic mapping. Currently, she is interested in

pediatric genetic counseling and the impact of counseling interventions on family dynamics.

(Photos: Maggie Bartlett, NHGRI)

GCTP Working Group

In 2007, NHGRI Scientific Director, Eric Green, MD, PhD, asked that we formalize the GCTP Advisory Group into an NHGRI Working Group that reports to the Board of Scientific Counselors (BSC). Lawrence Green, DrPH, member of the BSC, agreed to chair the new Working Group and expanded its membership. Group members include genetic counseling program directors, Caroline Lieber, MS, Sarah Lawrence College and Kelly Ormond, MS, Stanford University, as well as Bob Croyle, PhD, NCI Division of Cancer Control and Population Sciences, Gurnavet Randhawa, MD, MPH, Agency for Healthcare Research and Quality, and Marianne Clancy, Executive Director of the HHT Foundation International. The Working Group meets annually to assess the GCTP's goals and how well they are being achieved; it also serves as a proactive group for considering future opportunities in the training of genetic counselors. The Working Group's recommendations are made to Dr. Green and to David Holtgrave, PhD, Department Chair, Health, Behavior and Society, Johns Hopkins Bloomberg School of Public Health. We're grateful to this group, and all of the individuals who volunteer their time and energy, for their work in support of the GCTP.

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 2011 to describe how they embraced this mandate during their training.



Christy Haakonsen

I spent six weeks rotating with two genetic counselors in suburban Chicago. Two days a week, I was supervised by Luna Okada, MS and Jeannette Israel, MD, at St. Alexius Medical Center in Hoffman Estates, Illinois. I participated in prenatal and pediatric clinics, as well as a cystic fibrosis (CF) clinic that provided care to newborns with CF and carriers. The other two days a week I was supervised by Shelly Galasinski, MS, at Advocate Good Shepherd Hospital's cancer genetics clinic in Barrington, Illinois. In addition to great clinical experiences, this summer provided me the opportunity to live with my grandparents!



Sarah Kalia

I spent four weeks this summer shadowing Miguel del Campo, MD, a geneticist in Barcelona, Spain. I observed pediatric cases at a public hospital and preconception counseling at a private facility. This also gave me the opportunity to compare the emerging field of genetic counseling in Spain with that in the U.S., to see a nationalized health system in action, and to practice my Spanish!



Neha Kumar

I observed pediatric genetic counseling for four weeks in Singapore at KK Women and Children's Hospital under the supervision of a group of clinical geneticists. I also had the opportunity to attend birth defects conferences, to observe the work of the National Thalassemia Registry, and to prepare a research proposal inquiring into pregnant women's views of Amnio-PCR. Through my experience, I learned about the unique challenges of living with a genetic condition in Singapore and about the practice of and potential for genetic counseling in Singapore. Having spent many years in South East Asia, I also truly enjoyed being back in that part of the world!



Jane Lee

I saw patients under the supervision of **Colleen Brown ('07)** for 10 weeks in the Cardiovascular Genetics Clinic at the University of California at San Francisco (UCSF). In addition to writing patient letters and learning counseling and case management skills, I also had the unique opportunity to counsel in Mandarin (my native language), assist in patient advocacy efforts, counsel a patient at the bed-side, and present a poster at a patient conference. I also learned by observing Colleen in action—speaking at the Adults with Congenital Heart Defects support group meeting, teaching medical students, and presenting at the Hypertrophic Cardiomyopathy provider conference! In my spare time, I volunteered at the Cystic Fibrosis Family Education Conference and at the Noonan/Costello International Family as a clinic note-taker for families participating in its Clinic Program.



Kendra Schaa

I completed a five-week rotation in Manchester, England, at St Mary's Hospital under the supervision of Lauren Kerzin-Storror, MS. I had the opportunity to observe and participate in a wide variety of clinics, including cardiac, pediatric, cancer, Huntington's disease, metabolic, neurogenetics, and deafness. I worked alongside 26 genetic counselors

and 25 geneticists, giving me the chance to observe a variety of counseling styles and expertise. My rotation introduced me to a different health care system, the National Health Service. Overall, I enjoyed every minute of my time in England and classify this experience as one of the best in my lifetime!

(Photos: Maggie Bartlett, NHGRI)

Save the date!

- NSGC Annual Education Conference is November 12-15, 2009 in Atlanta, GA. Student and alumni reunion at NSGC is November 13, 2009.
- NHGRI annual retreat is November 17-18, 2009 in Gettysburg, PA.
- GCTP graduation for the class of 2010 is Friday, January 22, 2010 on the NIH campus in Bethesda, MD.
- GCTP Research Symposium is Friday, January 29, 2010 on the NIH campus in Bethesda, MD.
- American Board of Genetic Counseling (ABGC) opens scheduling of the 2010 Board Examination on April 1, 2010 for individuals who have been granted Active Candidate Status.

Alumni News

Jennifer Leib ('01) reports that her government relations and public policy consulting firm, HealthFutures, was acquired in May 2009, by Cavarocchi-Ruscio-Dennis Associates. Cavarocchi-Ruscio-Dennis Associates represents for-profit and non-profit organizations in healthcare, science, higher education, municipal government, transportation, and other fields.

Danielle Dong ('05) recently left the University of Virginia Genetics Division in Charlottesville, VA. After the birth of their daughter, Ellie Maria Haberkern on June 17, 2009, Danielle and her husband, Phil, moved to Princeton, NJ, for Phil's post-doctoral fellowship in Princeton University's Department of Religion. GCTP alumni celebrate the baptism of Danielle's daughter in Charlottesville, VA, in late July. Shawn is her godmother!



(Pictured left to right: **Shawn (Sinesky) Lipinski ('04)**, **Danielle Dong ('05)**, Ellie Haberkern, **Julie Chevalier Sapp ('05)**)



Ellie Maria Haberkern, born June 17, 2009, daughter of **Danielle Dong ('05)** and Phil Haberkern.

Sarah (Smith) Zentack ('05) has been busy. She moved to Houston in 2005, Dallas in 2006, and now she's returned to Houston. The great news is that now she and her husband are living in the same house (they lived apart for over a year in the final move) and they're hoping to grow some roots there. She recently started working at Baylor College of Medicine in their Breast Center.

Julie Cohen ('09) recently started a new position at Kennedy Krieger Institute, where she is providing genetic counseling to patients in the Neurodevelopmental Medicine and Muscle Center clinics. She also is working as a prenatal genetic counselor at Franklin Square Hospital. Congratulations to Julie for winning the Best Student Abstract Award at the 2009 NSGC Annual Education Conference! She will be presenting her thesis research on adaptation and quality of life among adults with neurofibromatosis type 1.

Mindy Simonson ('09) shared the news of her new city (Little Rock) and her new job (with the Arkansas Reproductive Genetics Program in the Department of Maternal Fetal medicine at the University of Arkansas for Medical Sciences)! Congratulations, Mindy!

Congratulations!

In the class of 2007, **Colleen Brown, Jamie Dokson, Rachel Silver, and Matthew Thomas** all informed us that they passed the 2009 ABGC Board Examination. In the class of 2008, **Jessica Adcock, Jackie Douyard, Courtney Nichols, and Katie Voss** shared the good news that they passed the 2009 ABGC Board Examination. Congratulations to these alumni for their accomplishment! If you sat for the boards this year, let us know when you receive your results.

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.