

Research Activities at the UMGCP

By design, the UMGCP Research Program is structured so that each student's thesis grows out of his/her own interests. The infrastructure supporting the Research Program includes a network of experienced mentors, explicit guidance for students and mentors, focused didactic training, and significant financial resources. During the month of April, the members of the class of 2014 are finalizing data analyses, presenting their findings to our community, and preparing manuscripts.

Julie Frank evaluated the impact of BRCA1/2 testing decisions and results on psychological and management outcomes in a cohort of individuals counseled at the University of Michigan Breast and Ovarian Cancer Risk Evaluation Clinic. Data from over 200 study participants suggest that in the setting of genetic counseling, participants that test positive for a BRCA mutation continue to be worried about their cancer risks one year after receiving genetic services. However, their overall worry frequency is not significantly different from baseline and is comparable to patients without a BRCA mutation and those who do not have testing. Interestingly, participants who receive genetic counseling but who did not receive genetic testing had higher decision regret scores than patients who did receive genetic testing, regardless of test results. Further analysis of these results, including those related to management outcomes, will be important in informing ongoing improvements to cancer genetic services.

Deanna Julian evaluated practices and attitudes related to adoption processes and genetic information through a survey of National Association of Social Workers chapters and follow up interviews. Deanna collected information about participants' genetics background, information collected during the adoption process, and attitudes regarding a vignette about genetic testing. While interview analysis is pending, the survey data revealed that the three most common reasons social workers would order genetic testing include 1) the test results would affect the care of



Christine Hong, Emily Moe, Deanna Julian, Caroline Weipert, Julie Frank, Lauren Hipp, Dana Schlegel.

the adoptee, 2) the perspective adoptive parents have a right to know the genetic information, and 3) genetic testing has positive effects. Further analysis of the survey and interview data will inform efforts for increased collaboration with social workers.

Christine Hong chose to evaluate attitudes of a healthy young adult population in regards to whole genome/exome sequencing and the return of incidental findings. This population is of particular interest as they represent future consumers of this technology. Christine developed and administered a survey tool to examine the opinions of undergraduate students regarding autonomy and choice, the healthcare provider's "duty to warn," results disclosure and handling, and genetic testing in children. Data were collected from nearly 400 UM undergraduate students and will help medical professionals understand preferences towards whole genome/exome sequencing and inform approaches to genetic counseling in the genomic era, especially as related to incidental findings.

For information about the research activities of Lauren Hipp, Emily Moe, and Caroline Weipert, visit the Fall 2013 Newsletter @ <http://hg.med.umich.edu/gcweb/news-letters>. Dana Schlegel's research is described in "Ghanaian Perspectives on Sickle Cell Disease" in this current newsletter.

Supervisor Spotlight: Jessica Everett, MS, CGC



Jess Everett joined the University of Michigan in 2006 as a clinical genetic counselor in the Cancer Genetics Clinic and earned a faculty appointment in Internal Medicine in 2012. Prior to coming to UM, Jess worked in cancer genetics at the University of Cincinnati, where she also earned her genetic counseling degree.

Jess's contributions to the training of our students are multifaceted. In her role of clinical supervisor, Jess is consistently described as an especially empowering supervisor, who provides balanced constructive feedback that enables trainees to achieve high levels of clinical excellence. Jess also teaches multiple components of our cancer genetics class, including lectures related to psychosocial issues and advances in cancer genomics. Jess has served on research committees for multiple

students, most recently for Caroline Weipert's thesis, "Examining the Conceptual Framework Underlying Oncologists' Understanding of Whole Genome Sequencing for Cancer Patients."

As noted in her recent publication, (Everett et al, J Genet Couns. 2014 Mar 1), Jess is a strong advocate for the inclusion of genetic counselors in the development and implementation of whole-genome applications. In fact, Jess has been a key contributor to the vision and development of Precision Medicine at the University of Michigan. Jess's contributions to the UM's NIH funded precision oncology protocol is a testament to how genetic counselors' skills in building alliances, communicating complex genetic information, fostering patient autonomy and facilitating informed decision making are critical in the success of genomics research and the translation of results into patient care. She is a nationally recognized expert on this topic and in 2014 is participating in Institute of Medicine Roundtable discussions.

SAVE THE DATES!!!

Friday May 2, 2014

Genetic Counseling Program Graduation
(Reception Thursday at 7pm)

Monday May 12, 2014

James V. Neel Lecture

“Genes, Genomes, & the Future of
Medicine”

Kahn Auditorium

Speaker: Richard P Lifton MD, PhD

Wednesday & Thursday May 13-14

Victors for Discovery: Biomedicine at
Michigan

Speakers include: Francis Collins, Stephen
Gruber, Elizabeth Nabel, Sean Morrison et al

Friday May 30, 2014

Joint UM/WSU Supervisors Workshop
Detroit, MI

Wednesday, August 27, 2014

Fall Orientation for incoming students
begins

Tuesday, September 2, 2014

Fall classes start

September 26-27, 2013

Department of Human Genetics Retreat
Gull Lake, MI

Friday, October 10, 2014

An Introduction to the UMGCP

Intended Audience: Prospective Applicants
More details to come soon!

For more information contact:

Monica Marvin at monicama@umich.edu

2014 ABGC Board Examination: Continued Success!

Congratulations to recent alumni
Michelle Bailey, Emi Higuchi, Erin Milne,
and Michelle Ernst who recently joined
the ranks of ABGC Certified Genetic
Counselors.

Once again, 100% of our graduates
passed the board
examination of their first attempt!



Ghanaian Perspectives on Sickle Cell Disease

The translation of genetic knowledge to global populations has been a long-standing interest for dual degree student Dana Schlegel (Class of 2014). During the summer of 2013, this interest took Dana around the world to Korle-Bu Teaching Hospital (KBTH) in Accra, Ghana. The Ghana population has an extremely high prevalence of sickle cell disease (SCD); 2% of Ghanaian children are born with SCD and the carrier frequency is 25-30%. In spite of this high prevalence, conventional “Western” treatments are often unavailable, leading to a 50-90% under-five mortality in children born with SCD.

As Ghana prepares to pilot a newborn SCD screening program, Dana conducted a needs assessment of the Ghanaian population with respect to their knowledge of sickle cell disease. She was guided in her research endeavors by Dr. Andrew Campbell (UM Pediatric Comprehensive SCD Clinic).

Dana conducted in-person surveys of 90 Ghanaian patients and interviewed health care providers at the clinic and in the community. Preliminary analysis of Dana’s survey reveals that while study participants mostly understood that SCD “runs in the family” (76.7%) and is inherited from both parents (91.1%), 54.4% did not know if anyone in their family had sickle cell trait, and only 26.7% reported having been tested for SCD themselves. Knowledge of sickle cell disease was significantly higher in female than in male participants.

Dana was struck by the profound impact that a lack of resources and cultural factors, such as religiosity, have on healthcare and genetic services. Specifically, the strong emphasis on religion and child rearing, as well as the actual and perceived limitations on treatment for sickle cell disease present unique challenges to the implementation of a traditional newborn screening program and to utilization of genetic counseling services. However, the local health care providers expressed interest in pursuing genetic counseling in the future, and the needs assessment that Dana conducted provides ideas about particular areas in which to intervene to improve awareness and education about SCD. The experience afforded a unique opportunity for Dana to combine her interests in genetic counseling and global public health and also provided skills and insight that will be of tremendous value as she launches her career.

Dana’s endeavors have been supported by the UM Certificate in Public Health Genetics Program and by the UM Global Public Health Initiative.



Dana Schlegel (far left)
and fellow UM students
in Likpe Todome, Ghana

Come Home to Ann Arbor

Ann Arbor is:

- Ranked #2 in the “Top 10 College Towns.” Livability.com, 2013
- Ranked #2 in the “Best Cities for Young Adults” Kiplinger, 2014
- Ranked #6 in the “Best Cities for Overall Well-Being.” USA Today & Gallup, 2014
- Home to one of “America’s Best Main Streets.” Huffington Post & Fodor’s Travel, 2014
- Ranked #4 in the “Most Walkable Cities.” Governing.com, 2013

The University of Michigan is:

- Ranked #1 as the “Best and Most Collaborative Large U.S. College.” Huffington Post, 2013
- Ranked #4 in the “Top Public Schools.” US News, 2014
- Ranked #15 in “Times Higher Education World Rankings.” 2013
- Home to 100 graduate programs ranked in the top 10 by U.S. News & World Report, 2014

The Growing Michigan Genetic Counseling Community

Fun Fact: The number of clinical genetic counselors working at the University of Michigan has doubled over the last decade!

It is with much pride that we welcome Lauren Hipp to the ranks of clinical genetic counselors at the University of Michigan. Lauren was recruited to the UM Health System to support the ongoing demand for high quality genetic counseling services. Lauren’s expertise, diligence, and smile will be much appreciated by her colleagues Wendy Uhlmann, MS, CGC in the Medical Genetics Clinic and Kara Milliron, MS, CGC in the Breast and Ovarian Cancer Risk Evaluation Clinic. Lauren is a true “Michigan (Wo)Man” who earned her B.S. in Neurosciences from UM in 2010 and who will earn her M.S. in Genetic Counseling from UM on May 2, 2014. We look forward to Lauren’s contributions and are thrilled that she will continue to bleed blue!