

July 7, 2015

This is certainly a busy season of meetings for NIH and NHGRI. There have been multiple workshops related to the Precision Medicine Initiative, available on the Precision Medicine Initiative's YouTube channel. In addition, NHGRI has hosted (or co-hosted) several recent meetings—including a major The Cancer Genome Atlas (TCGA) symposium and the Genomic Medicine VIII meeting, both available on NHGRI's YouTube channel (GenomeTV). Many NIH and NHGRI meetings are webcast live, but if you cannot watch them in real-time, I encourage you to take advantage of the video archives that we make available on YouTube.

In this month's *The Genomics Landscape*, I feature a well-established joint program with Johns Hopkins University that trains genetic counselors, a recent report to the NIH Director on the future of the National Library of Medicine, and news from NHGRI activities related to coordinating provider education in genomics and international genomic medicine efforts. See various details below, along with other information items that I hope will be of interest to you.

Specifically, July's *The Genomics Landscape* features stories about:

- The Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program
- New Strategic Vision for the National Library of Medicine
- Report from the Inter-Society Coordinating Committee for Practitioner Education in Genomics Meeting
- Publication from Genomic Medicine VI Meeting: Global Leaders in Genomic Medicine

All the best,



Watch here for current and upcoming locations of the Smithsonian-NHGRI exhibition "Genome: Unlocking Life's Code" as it tours North America!



~To manage your subscription to *The Genomics Landscape*, see: list.nih.gov/cgi-bin/wa.exe?A0=NHGRILANDSCAPE~

~To suggest future topics, send an e-mail to: NHGRILANDSCAPE@MAIL.NIH.GOV~

~To access past editions, see: genome.gov/27541196~

The Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program

New technologies are commonplace in genomics. In recent years, new DNA sequencing methods have allowed clinicians to sequence large panels of genes when screening for various diseases or conditions. The use of these panels is introducing new uncertainties for those being screened. For example, a person with a strong family history of early onset heart disease goes to see a genetic counselor and opts for a multi-gene panel test to assess his or her risk. The person is found to have a genomic variant in one of the genes of uncertain pathogenicity, a common occurrence with panel testing. How does the genetic counselor help the person manage these results? Genetic counselors help people manage uncertainty and make informed choices. They do not only relay information, they also form therapeutic relationships with clients to understand their values and preferences, which is key to successful partnerships.

Since 1996, NHGRI, in partnership with Johns Hopkins University (JHU), has offered a unique program: The JHU/NHGRI Genetic Counseling Training Program (GCTP). The program focuses on education in cutting-edge genomics, in-depth psychological counseling training, and research skills for thesis development and execution. The GCTP aims to produce the next generation of leaders in the field. Graduates earn their degree from the Johns Hopkins Bloomberg School of Public Health.





One goal of the program is to prepare graduates to provide genetic counseling with an emphasis on the psychological and educational needs of their clients. Rotations are required so that the students can learn directly about genetic conditions, their impact on people and families, and the role of genetic counselors. A second program goal is to prepare graduates to conduct social and behavioral research related to genetic counseling, with a required thesis. Lastly, the program aims to enable its graduates to educate healthcare providers, policy makers, and the public about genetics, genomics, and related health and social issues.

The program is unique in its level of interactive and research-oriented coursework, which leads graduates to complete high-quality thesis studies that can be published. It has produced genetic counselors who are collectively broadening the scope of genetic counseling by contributing to research in the field. Additionally, program faculty members provide students with direct supervision throughout their graduate studies. These sessions offer students feedback based on

New Strategic Vision for the National Library of Medicine



NIH Director Francis Collins has approved a new strategic vision for the National Library of Medicine (NLM). Motivated in part by the retirement of former NLM Director Donald Lindberg, a working group of the NIH Advisory Committee to the Director (ACD) recently completed a review of NLM's mission, organization, and programmatic priorities. That working group then developed a strategic vision and set of recommendations for the NLM going forward. The working group concluded that NLM is well-poised to continue being an important international force in disseminating biomedical research information, supporting open science, training future generations of biomedical informaticists, and preserving the historical legacy of biomedical research. In addition, the working group called for NLM to become the epicenter for data science at NIH and across the biomedical research enterprise. For more information, see nih.gov/news/health/jun2015/od-11.htm.

Report from the Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC) Meeting



The Inter-Society Coordinating
Committee for Practitioner Education in
Genomics (ISCC) held its fourth in-person
meeting on May 21, 2015. The committee
facilitates interactions among professional
societies and related organizations to
enhance and increase the understanding
of practitioners in applying genomic
medicine to cost-effective decision making

audiotaped sessions with clients and on interventions, consistent with the development of counseling expertise.

Johns Hopkins Bloomberg School of Public Health provides an established academic home for the GCTP, while NHGRI provides leadership, a majority of the instruction, and funding. The program draws faculty from NHGRI and JHU, and includes tenured investigators, scientists, and healthcare providers. The genetic counseling coursework, student supervision, coordination of clinical rotations, and Accreditation Council for Genetic Counseling accreditation are overseen jointly by NHGRI and JHU. The GCTP is seen by many as an important effort to address new challenges resulting from genomic advances.





On left: GCTP students and recent alumnae. (Pictured left to right are Nina Harkavy, Jenn Kohler, Lydia Hellwig, Celeste D'Amanda, Devon Bonner, Katie Fiallos, Mike Setzer, Megan Bell, Marci Barr, Cari Young, Kyle Davis, and Claire Anderson).

On right: Rising second year students. [Pictured clockwise are Devon Bonner (top), Mike Setzer, Lydia Hellwig, Katie Fiallos, and Celeste D'Amanda].

The GCTP annually receives between 80 and 100 applications; 4 to 5 students are admitted each year, with a total of 69 trainees participating in the program since its beginning. In the past, approximately half of the graduates have gone to work in research settings, with the other half working in clinical settings. Recently, there has been an increasing shift to commercial settings, reflecting the growth of clinical genomics and genetics as a service industry.

Melissa Richter, a laboratory psychologist who founded the world's first genetic counseling graduate program, once said "When a genetic problem hits, it hits at the very gut of people, at the questions of what am I and what do I leave to the world. It requires so much intelligence to be able to deal with that." (1)

Genetic counseling as a discipline has been around for nearly 40 years. The JHU/NHGRI GCTP is leading the way in producing the next generation of leaders in the field and in preparing new genetic counselors for meaningful careers helping clients make informed choices about challenging genetic issues regarding their health and their genetic legacy. For more information, visit genome.gov/10001156.

(1) "Degrees Offered in Genetic Counseling," New York Times, Dec. 6, 1970, p.71."

and clinical care. They heard about patient safety and genomic medicine, genetic counselors' roles in education, point-of-care education models, and interprofessional education; they also discussed next steps for healthcare professional education and funding priorities. To view the meeting report and supporting materials, visit genome.gov/27562015.

Publication from Genomic Medicine VI Meeting: Global Leaders in Genomic Medicine



For a number of years, NHGRI has held a series of Genomic Medicine meetings that bring together genomics researchers, clinicians, and other experts involved in the implementation of genome medicine programs. Participants in the Genomic Medicine VI: Global Leaders in Genomic Medicine meeting recently published a summary of that gathering. The Global Genomic Medicine Collaborative (G2MC) was formed as a first collaborative step in coordinating international efforts in genomic medicine. G2MC has already formed a steering committee and working groups to address specific topics. The group is also organizing a meeting in Singapore that will be held this November. The paper, "Global implementation of genomic medicine: We are not alone," can be found in the June 3, 2015, issue of Science Translational Medicine. For more information, see genome.gov/27561782.







Spotlight on the Precision Medicine Initiative



nih.gov/precisionmedicine

- ➤ NIH invites input about the Precision Medicine Initiative (PMI) through the NIH Feedback Site. New topics for feedback will be posted every few weeks through the end of August 2015.
- ➤ NIH has launched a new feature on the PMI website called "Faces of the Precision Medicine Initiative." At that site, members of the community give their thoughts about the PMI; see nih.gov/precisionmedicine/multimedia/videos/index.htm.
- On July 27-28, 2015, tune in live at <u>videocast.nih.gov</u> to watch the PMI public workshop on mHealth.
- Eric Green was interviewed for a PMI feature in *The Lancet*.
- > Workshop Summary: Digital Health in a Million-Person PMI Cohort

Genomics Research

NIH Researchers Pilot Predictive
Medicine in Study of Healthy People's
DNA

A New Role for Zebrafish: Larger Scale Gene Function Studies

Health Disparities in U.S. Still Persist According to Report

<u>Stanford Researchers Suss Out Cancer</u> <u>Mutations in Genome's Dark Spots</u>

Reclassifying Brain Tumors with Precision

<u>Vulnerabilities in Genome's 'Dimmer</u> <u>Switches' Should Shed Light on</u> Hundreds of Complex Diseases

Precision Oncology: Creating a Genomic Guide for Melanoma Therapy

<u>LabGenius: The Next Step Toward a</u>
<u>Digital Laboratory</u>

Genome Advance of the Month

<u>Genomics Holds Promise of</u> <u>Treatments for Inherited Blindness</u>

Funding Opportunities

NHGRI Genome Sequencing Program Analysis Centers

High Quality Human and Non-Human Primate Genome Sequences

<u>Lasker Clinical Research Scholars</u> Program

NIH Transformative Research Awards

NIMHD Transdisciplinary Centers for Health Disparities Research Focused on Precision Medicine

Oncology Resources for Consensus on Quantitative Imaging Methods and Precision Medicine

NIH Pathway to Independence Award

NIH News of Interest

NIH Names Walter Koroshetz Director of the NINDS

NIH Director's Statement Regarding Dr. Sally Rockey's Departure

GM8: Looking Across Genomic

Medicine's Gaps and Opportunities

New Videos/Recordings

The Cancer Genome Atlas 4th Annual Scientific Symposium

<u>Genomic Medicine 8: NHGRI's Genomic</u> Medicine Portfolio

<u>From The Moth: Why I Teach</u> – Eric Lander

<u>From the Smithsonian Future is Here</u> <u>Festival: Future of Precision Medicine</u> – Eric Green

Funding News

ASSIST for R01s & Career Development
Awards and Cooperative Agreements

Enhancing Reproducibility through Rigor and Transparency

<u>Consideration of Sex as a Biological</u> <u>Variable in NIH-Funded Research</u>

<u>Publication Reporting for Progress Reports</u> <u>and Renewal Applications</u>

Applicant Responsibilities in Maintaining the Integrity of NIH Peer Review

Rock Talk: What are the Chances of Getting Funded?

