



September 7, 2016

I would like to bring to your attention an important technical advance in the way that NHGRI communicates on the web. The NHGRI website, genome.gov, was recently upgraded to have a 'mobile-friendly design.' It is now easy to browse our website using a variety of mobile devices (such as iPhones, Androids, and tablets). This upgrade provides quick and easy access to important information about NHGRI and its programs whether at a computer or on a mobile device. I encourage you to check out this major enhancement to genome.gov.

In the September issue of *The Genomics Landscape*, we feature stories about:

- [Centers of Excellence in Ethical, Legal, and Social Implications Research \(CEER\) Program](#)
- [NHGRI Workshop on Sharing Summary Statistics from Genomic Data](#)
- [Investigational Device Exemption Workshop](#)
- [Genome: Unlocking Life's Code Says Good-Bye to Salt Lake City](#)
- [NHGRI Summer Trainees](#)

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!

Traveling Exhibition	
Current	Next
GENOME UNLOCKING LIFE'S CODE September 30, 2016 - January 1, 2017 Exploration Place Wichita, Kansas See unlockinglifescode.org for details	April 1 - May 29, 2017 Peoria Riverfront Museum Peoria, Illinois

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

~To access past editions, see: genome.gov/2754196~

Centers of Excellence in Ethical, Legal, and Social Implications Research (CEER) Program

Starting at the inception of the Human Genome Project, NHGRI has been at the forefront of research into the Ethical, Legal, and Social Implications (ELSI) of genomic advances. From stand-alone investigator-initiated studies to research embedded within large international genomics collaborations (e.g., [HapMap Project](#), [1000 Genomes Project](#), and [H3Africa](#)), NHGRI has funded in-depth research endeavors that aim to ask and answer questions about individuals' and communities' attitudes about genomics, legal issues associated with genomics, the responsibilities of genomic researchers to their research participants, and numerous other issues. This funding support has gone to investigators from a wide range of disciplines – bioethics, law, behavioral and social sciences, policy, philosophy, and theology.



In 2004, NHGRI launched a new program called the Centers of Excellence in ELSI Research (CEER) Program, with the purpose of developing research teams with the expertise and flexibility to respond rapidly to emerging and evolving ELSI issues.

The CEER Program began with exploratory grants and full-fledged Centers, and has evolved throughout the years. This past May, four new CEERs were funded (see genome.gov/27565088 for details). These Centers focus on studying the use of genomic information in the prevention and treatment of infectious disease; genomic information privacy; communication about prenatal and newborn genomic testing results; and the impact of genomics in American Indian and Alaskan Native communities. The researchers supported by these grants join an already impressive group of CEER investigators (see genome.gov/25522195 for details).

From the early days of genomics to the current explosion of research in genomic technologies and genomic medicine, ELSI research has been a key component of NHGRI's research portfolio. ELSI researchers have answered questions of critical

NHGRI Workshop on Sharing Summary Statistics from Genomic Data



Recently, NHGRI hosted a two-day workshop on the topic of sharing summary statistics from genomic data. Participants were asked to weigh the benefits and risks of sharing this information, given current perspectives from researchers and participant communities about privacy and data sharing. Workshop participants emphasized that summary statistics represent valuable information for use in scientific and clinical discovery. Summary statistics for thousands of genomic research studies are available from the [Database of Genotypes and Phenotypes \(dbGaP\)](#), but only via 'controlled access' due to an NIH policy change in 2008. The NHGRI workshop was convened to initiate a contemporary re-consideration of this policy and to provide recommendations for how NHGRI should proceed with regards to the sharing of such summary-level information from genomic studies. Workshop participants noted the need for public engagement about the risks and benefits of sharing this information, and for appropriate consideration of any risks related to vulnerable populations or sensitive phenotypes. A workshop report has now been released (see genome.gov/27566089), which enumerates key findings.

Investigational Device Exemption Workshop



In June, NHGRI held a workshop to discuss FDA's Investigational Device Exemption (IDE) regulations and how to fulfill them for applicable genomics research projects. While the regulations themselves are not new, they represent new territory for the genomics community. FDA may require researchers to apply for and obtain an IDE to conduct human subjects research involving the use of investigational genomic technologies (such as

importance, informed study designs, and advised the development of public policy and research guidelines. In many cases, ELSI research deals with issues that arise from potential genomic technologies long before they find their way into general use. The CEER Program has provided an opportunity to be forward-looking and to illuminate ELSI issues in a multi-disciplinary manner. Through this Program, unique collaborations have formed, and a research community has solidified and strengthened.



For more information about the CEER Program, visit genome.gov/15014773.

NHGRI Summer Trainees



NHGRI 2016 Summer Trainees

Each summer, NIH becomes energized with the influx of trainees from high school to professional levels, who have traveled from far and wide to participate in the [NIH Summer Internship Program](#) (SIP). The SIP provides an opportunity for trainees to spend a summer working at the NIH side-by-side with leading biomedical researchers. The trainees participate in a variety of activities including biomedical research, scientific lectures, career/professional development workshops, and other events hosted by the [NIH Office of Intramural Training and Education](#) and the [NHGRI Intramural Training Office](#). This summer, NHGRI hosted 49 SIP trainees. If you are interested in applying for the 2017 cohort, the [online](#) SIP application will be available in mid-November.

analyses utilizing next-generation DNA sequencing). The workshop audience, which included investigators and institutional review board (IRB) members, learned how the IDE regulations apply to genomics research. Panelists from NHGRI, FDA's Center for Devices and Radiological Health, NHGRI extramural grantees, and various IRBs shared their knowledge about the IDE regulations, provided information about when a study needs an IDE, and detailed how to fulfill IDE requirements. Participants learned about issues to consider when preparing an IDE submission and worked to pinpoint gaps in understanding about IDE regulations. Such a forum for information exchange is important for adhering to regulatory policies and ensuring the safe implementation of genomic medicine. NHGRI will continue to develop more informational resources on this and related topics. For more information about the workshop, see genome.gov/27564792.

Genome: Unlocking Life's Code Says Good-Bye to Salt Lake City



The time has come for [Genome: Unlocking Life's Code](#) to say good-bye to Salt Lake City. To celebrate the traveling exhibition's visit to Utah, I gave a [lecture](#) entitled Human Genomics, Precision Medicine, and Advancing Human Health at the Natural History Museum of Utah in early August. In partnership with a local radio station (KCPW), that lecture has now been made available as a podcast. Also during my visit, I participated in a [podcast](#) interview about genomics and precision medicine at Scope Radio (the University of Utah Health Science Radio Station). The Natural History Museum of Utah was a wonderful host for the exhibition, but it is time for another city to benefit from this educational resource. The exhibition's next stop is Exploration Place in Wichita, Kansas – starting September 30. If you are in the Wichita area between September 30 and January 1, come explore the fascinating world of genome science through the high-tech, hands-on learning that *Genome: Unlocking Life's Code* provides.



**Spotlight on the Precision
Medicine Initiative (PMI)**



nih.gov/precisionmedicine

- The NIH PMI Cohort Program [announced](#) the publication of a recent survey designed to measure public attitudes about the PMI Cohort Program. The findings of the survey were published online in *PLoS ONE* by a team of National Institutes of Health researchers; that paper can be found [here](#). NHGRI's David Kaufman, Ph.D., led the research.
- The PMI Cohort Program Advisory Panel Meeting scheduled for Thursday, September 8, 2016 has been cancelled. Please check the [PMI Cohort Program 'Events' page](#) for upcoming meetings.

Genomics Research

[Sardinian Dog Genome Reveals a Shared Ancestral Homeland with Humans](#)

[Largest Collection of Human Exome Sequence Data Yields Unprecedented Tool for Diagnosing Rare Disease](#)

[NIH Researchers Discover Otulipenia, a New Inflammatory Disease](#)

New Podcast

[Eric Green on Human Genomics, Precision Medicine, and Advancing Human Health](#)

New Videos

[Investigational Device Exemptions \(IDE\) and Genomics Workshop](#)

Funding Opportunities

[New Funding Opportunities for H3Africa](#)

Funding News

[A Look at NIH Support for Model Organisms, Part Two](#)

[Model Organisms, Part 3: A Look at All RPGs for Six Models](#)

[Revised: Projected FY 2017 Stipend Levels for Postdoctoral Trainees and Fellows on Ruth L. Kirschstein National Research Service Awards](#)

Upcoming Videocast

[Seventy-Eighth Meeting: National Advisory Council for Human Genome Research](#) – September 12, 2016

[PLOS Computational Biology Symposium](#) – September 16, 2016

NIH/NHGRI News of Interest

[New Email Updates on the Latest NHGRI Science, Research, News, Upcoming Events, & Website](#)

[NHGRI Funding Opportunities Email List](#)

[Unlocking Life's Code: August 2016 Newsletter](#)

[NIH Names Dr. Diana Bianchi Director of the National Institute of Child Health and Human Development](#)

[NCI Embraces Scientific Road Map to Achieve Cancer Moonshot Goals](#)

[Seeking: Director, Division of Genome Sciences](#)

