



August 1, 2017

While August thunderstorms are sure to bring lightning to the DC area, the NIH campus has already experienced some lightning of its own this summer – lightning-fast communications training. Late in June, the finals of the [NIH Three-Minute-Talk](#) (TmT) competition took place within the NIH Intramural Research Program. NIH trainees at the graduate and postdoctoral level competed to communicate in three minutes or less the substance and significance of their research in such a way that can be understood by a broad scientific audience. [Ryan Johnson](#), a postdoctoral fellow in [Julie Segre’s Laboratory at NHGRI](#), spoke about “Genetic Factors that Influence Carbapenem Resistance in Bacteria” and took 1st Place. Congratulations, Ryan!

This month’s *The Genomics Landscape* features stories about:

- [4th ELSI Congress Showcases Societal Implications of Genomics Research](#)
- [Genomic Medicine X Meeting: Research Directions in Pharmacogenomics Implementation](#)
- [New Executive Director of the American Society of Human Genetics](#)

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		
GENOME UNLOCKING LIFE'S CODE	Current	Next
	June 12 - September 11, 2017	September 30, 2017 - January 1, 2018
	The Health Museum Houston, Texas	Science North Sudbury, Ontario
	See unlockinglifescode.org for details	

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4th ELSI Congress Showcases Societal Implications of Genomics Research

In June, nearly 300 people attended a three-day Congress on the Ethical, Legal, and Social Implications (ELSI) of genomics research. The fourth such meeting, entitled [Genomics and Society: Expanding the ELSI Universe](#), was funded by NHGRI through a grant to Columbia University Medical Center, and held on the campus of UConn Health and The Jackson Laboratory for Genomic Medicine in Farmington, CT. This ELSI Congress, traditionally occurring every few years, assembles researchers to discuss societal issues emanating from advances in genomics research. Given the recent [beta launch of NIH's All of Us Research Program in June](#), many discussions centered on important ELSI research opportunities with this new program. *All of Us* is the government-funded Precision Medicine Initiative aiming to enable research on a wide range of diseases and further our understanding of healthy states by enrolling and studying one million research participants.



To that end, the [keynote address](#), given by Stephanie Devaney, Ph.D. (Deputy Director of the [All of Us Research Program](#)), detailed the initiative. Following her talk was a [response](#) by P. Pearl O'Rourke, M.D. (Director of Human Research Affairs at Partners HealthCare) that raised important ELSI issues associated with the *All of Us* program – the kick-off to fruitful discussions for the remainder of the conference.

The many talks, poster presentations, and panel discussions held over the three days covered a range of relevant issues. For instance, how genomics may or may not address health disparities and what other factors contribute to people's health, including access to basic healthcare; issues concerning return of genomic information and informed consent; and, control over access to genomic information and privacy.

There were also talks discussing important issues unrelated to precision medicine. These included presentations on direct-to-consumer genetic testing and third-party tools available on the Internet to help people understand their genomic information; DNA and the law, including its use in the criminal justice system; genetic testing in adoption; and ELSI issues in human microbiome research.

Particularly relevant to NHGRI was a session on embedded ELSI research projects. Over the past decade, [NHGRI's ELSI Research Program](#) has embraced a model where projects are embedded in larger programs, such as the [Clinical Sequencing Exploratory Research \(CSER\) Consortium](#) and the [Electronic Medical Records and Genomics \(eMERGE\) Network](#).

Genomic Medicine X Meeting: Research Directions in Pharmacogenomics Implementation



In May, NHGRI gathered experts to discuss implementing pharmacogenomics at a meeting entitled [Genomic Medicine X: Research Directions in Pharmacogenomics Implementation](#). The Institute surveyed current pharmacogenomics efforts to develop a strategic framework for implementing pharmacogenomics research on a larger scale. A meeting report has now been [released](#).

Recommendations from the meeting emphasized: clinical practice and education related to genetic testing, return of results, variant actionability, quality standards, and reimbursement; bioinformatics related to clinical decision-support tools, electronic health records, drug-gene interaction modules, data infrastructure, and standardized terminology; and research related to data re-use, study design, patient data capture, standardized outcomes, measures of benefit, patient registries, patient diversity, and rare adverse drug response.

For these programs, each site within the network has complementary ELSI studies integrated into parent projects (e.g., on genomic discovery or variant interpretation). For instance, an ELSI research project could identify best practices for informed consent in genomic medicine by taking advantage of the large number of research participants being enrolled in the overarching program.



Participants in the 4th ELSI Congress gather for the conference.

However, this embedded approach to ELSI research raises important questions. For example, how might the direct incorporation of ELSI research projects into parent studies affect the design or the results of the parent studies or the ELSI studies? Is the consent process more difficult than it needs to be? What are the right issues to address through an embedded project model in order to acquire data from real-life scenarios? In reality, the answers to these and other related research questions are being developed both through embedded ELSI research projects in programs like CSER and eMERGE as well as through NHGRI's [Centers of Excellence in ELSI Research \(CEER\)](#).

While many issues were discussed throughout the three days of the meeting, two conclusions were overwhelmingly evident: (1) genomics is moving at a rapid pace; and (2) while pursuing research advances at this pace is essential for better understanding health and disease, we need to consider the societal and ethical implications that go along with them. The ELSI research community must continue to anticipate the directions that the field of genomics is moving in and the speed at which this is happening. And to NHGRI's part, the ELSI research projects and community gatherings funded by the Institute aim to establish how to capitalize on new discoveries in genomics and genomic medicine in a way that is most efficient, least disruptive, and beneficial to all populations and individuals.

New Executive Director of the American Society of Human Genetics



In July, Mona Miller assumed the position of Executive Director of the [American Society of Human Genetics](#) (ASHG). Prior to her appointment at ASHG, Ms. Miller was the Deputy Executive Director for Programs and Finance at the Society for Neuroscience. In her new role, she will guide and implement ASHG's broad agenda.

ASHG is the primary professional organization for human genetics and genomics specialists worldwide, serving scientists, health professionals, and the public. Comprising nearly 8,000 members, ASHG represents researchers, academicians, clinicians, laboratory practice professionals, genetic counselors, nurses, and others with an interest in human genetics. For more information, visit ashg.org/press/201705-ED-Miller.shtml.



Spotlight on the All of Us Research Program



allofus.nih.gov

- The *All of Us* Research Program has established a working group on child enrollment. [The Child Enrollment Scientific Vision Working Group](#) (CESVWG), will provide information and options for scientific goals that should be broadly enabled through the enrollment of children from diverse backgrounds.
- The *All of Us* Research Program [announced](#) its first community partner awards. Four organizations will support the engagement of diverse communities in the *All of Us* Research Program.

Genomics Research

[Eye Microbiome Trains Immune Cells to Fend Off Pathogens in Mice](#)

[NIH and Collaborators Identify the Genomic Cause for Carey-Fineman-Ziter Syndrome](#)

[Scientists Replay Movie Encoded in DNA](#)

[NIH Scientists Find Rare Disease Clues in Cell's Recycling System](#)

[Social Interaction Affects Cancer Patients' Response to Treatment](#)

[Recession Proof – New Research Explains Genetic Roots of Rare Diseases Unique to South Asian Populations](#)

[Another Milestone in the Cystic Fibrosis Journey](#)

[How Kids See the World Depends a Lot on Genetics](#)

[NCI-COG Pediatric MATCH Trial to Test Targeted Drugs in Childhood Cancers](#)

[“Residual Echo” of Ancient Humans in Scans May Hold Clues to Mental Disorders](#)

[Notable Accomplishments in Genomic Medicine](#)

Funding Opportunities

[NHGRI Genomic Data Science Analysis, Visualization, and Informatics Lab-Space \(AnVIL\)](#)

Implementing Genomics in Practice (IGNITE) II: [Pragmatic Clinical Trials Clinical Groups, Pragmatic Clinical Trials Enhanced Diversity Clinical, Pragmatic Clinical Trials Coordinating Center](#)

Funding News

[NIH Implementation of Final Research Performance Progress Reports for Small Business and Innovation Research \(SBIR\) and Small Business Technology Transfer \(STTR\) Awards](#)

[Revision: Guidance on Salary Limitation for Grants and Cooperative Agreements](#)

[Revision to Ruth L. Kirschstein National Research Service Awards \(NRSA\) Predoctoral Stipends, Training Related Expenses, Institutional Allowance, and Tuition/Fees Effective for Fiscal Year 2017](#)

NIH & NHGRI News

[2017 Lasker Clinical Research Scholars Program – Applications Due August 25](#)

[Drs. Collins and Wolinetz Co-Author a Commentary on the Common Rule and the NIH Single IRB Policy](#)

[Here's How Virtual Reality Can Help Fight Disease – Bill Gates Visits NIH](#)

[Unlocking Life's Code: July 2017 Newsletter](#)

New Videos

[Carey-Fineman-Ziter Syndrome](#)

[Genomics and Society: Expanding the ELSI Universe \(4th ELSI Congress\) Plenary Sessions](#)

[PHS Human Subjects and Clinical Trials Information Form Walk-Through](#)

[NHGRI's Oral History Collection: Interview with George Church](#)

Upcoming TV Broadcast

[Discovery Documentary “First in Human” Gives an Up-Close Look at the NIH Clinical Center](#)

