



December 2, 2015

With 2015 winding down, I want to draw your attention to some important topics that I will be covering in an early 2016 issue of *The Genomics Landscape*. Specifically, I plan to highlight the new awards associated with the re-formulated [NHGRI Genome Sequencing Program](#) (GSP), the plans for which I outlined in the [January 2015 issue](#). Components of the program include the [Centers for Mendelian Genomics](#) and the new Centers for Common Disease Genomics. We are currently seeking input about the future of another component of our GSP, the [Clinical Sequencing Exploratory Research \(CSER\) Program](#), for which we recently issued a [Request for Information](#). We welcome your comments for this, which are due by December 7.

In this month's *The Genomics Landscape*, I highlight NHGRI's efforts in developing a path toward addressing health disparities. See various details below, along with other information items that I hope will be of interest to you.

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

- [NHGRI Develops Path Forward to Address Health Disparities](#)
- [Sustaining Big Data in Biomedicine](#)
- [Genome: Unlocking Life's Code – Native American Family Day](#)
- [DHHS Career Achievement Award Given to Jeff Schloss](#)
- [NHGRI Welcomes the New Chief of the Policy and Program Analysis Branch](#)
- [Bob Blakesley, Director of the NISC Sequencing Group, Retires](#)

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 |
| October 2 - January 3, 2016 | January 18 - April 25, 2016 |
| Oregon Museum of Science and Industry Portland, Oregon | Discovery World Milwaukee Milwaukee, Wisconsin |
| See unlockinglifescode.org for details | |

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

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

NHGRI Develops Path Forward to Address Health Disparities

In September, NHGRI convened a roundtable meeting to discuss the opportunities and challenges associated with the inclusion and engagement of underrepresented populations in genomics research. The roundtable was organized by NHGRI Senior Advisor on Genomics and Health Disparities, [Vence Bonham](#), J.D. Mr. Bonham's role as Senior Advisor dovetails with his research in the Health Disparities Unit, part of the NHGRI Social and Behavioral Research Branch, in which he conducts research at the intersection of public policy, healthcare inequities, and genomics.

At the roundtable, experts from academic and non-profit institutions across the United States joined NHGRI and NIH staff to identify scientific problems brought about by insufficiently diverse ancestral populations in genomics research, as well as the existing barriers that limit underrepresented populations from participating in genomics research. The group also discussed potential solutions to these problems.



NHGRI Roundtable on Inclusion and Engagement of Underrepresented Populations in Genomics Research

Presentations from the attendees highlighted current research examining health disparities. Discussions centered around ways in which NHGRI can encourage population diversity in future research through Funding Opportunity Announcements and the incorporation of environmental and social data. NHGRI has begun to move into genomic medicine research, and working with diverse communities and addressing disparities will be key for ensuring an equitable and productive path forward.

Dr. David Williams of Harvard University shared his thoughts on health disparities at the roundtable: "Most interventions that have been introduced to address health have widened disparity...to, in fact, reduce inequalities in health, we need two things to be happening at the same time: we need to improve the health of all, but secondly – and this is the challenge – we need to improve the health of the disadvantaged more rapidly than the health of the general populations. In order to do that, you need specifically targeted interventions, even with a global strategy to improve health."

At the conclusion of the meeting, NHGRI encouraged continued dialogue and engagement of health disparities researchers and NHGRI. This will be critical to incorporating the needs of diverse communities into future genomics initiatives. The roundtable report will be presented to the National Advisory Council for Human Genome Research on February 8; you can tune into the presentation that day by visiting our [GenomeTV channel](#) on YouTube.

Sustaining Big Data in Biomedicine

PERSPECTIVE

Sustaining the big-data ecosystem

Organizing and accessing biomedical big data will require quite different business models, say Philip E. Bourne, Jon R. Lorsch and Eric D. Green.

In the November 5 issue of *Nature*, I co-authored a Perspective entitled "Sustaining the big-data ecosystem" with NIH Associate Director for Data Science Dr. Philip Bourne and National Institute of General Medical Sciences Director Dr. Jon Lorsch. The paper focused on the need to find more efficient models for storing, organizing, and accessing biomedical data, given the growing amounts of data being generated and the restricted research budgets in most countries. Different business models will be necessary, and coordination of various stakeholders, both public and private, will be key for moving forward. For the full text of the Perspective, visit nature.com/nature/journal/v527/n7576_suppl/full/527S16a.html.

Genome: Unlocking Life's Code – Native American Family Day



Last month, the [Native American Youth and Family Center](#) (NAYA), together with NHGRI and the Oregon Museum of Science and Industry, hosted a cultural night at the *Genome: Unlocking Life's Code* exhibition. The event was attended by nearly 250 American Indian and Alaska Native people, and offered participants the opportunity to explore the museum, experience the exhibition, and hear from a Native storyteller about ancestry, origins, and identity. In addition to the cultural night, NAYA brought students from their school and after-school programs to the exhibition during the day as part of their curriculum on genetics.

Based upon the recommendations from the roundtable, NHGRI is developing future plans in the area of genomics and health disparities. Evaluating NHGRI-funded research in terms of disparities will help to identify areas in which we can start to make an immediate difference. Further, NHGRI is well-poised to provide valuable input for the greater NIH efforts regarding genomics and disparities, as many NIH-wide programs have major genomic components.

NHGRI plans to build further collaborations with other NIH Institutes and Centers to address many of the questions highlighted at the workshop. Already, NHGRI works closely with staff at the National Institute on Minority Health and Health Disparities, the National Heart, Lung, and Blood Institute, the National Cancer Institute, the National Institute of Diabetes and Digestive and Kidney Diseases, and elsewhere across NIH to identify projects in which health disparities issues can be investigated and recommendations can be formulated.

As a further commitment to this area of study, NHGRI recently established the 'Genomics and Health Disparities Lecture Series' to enhance opportunities for showcasing how innovations in genomics research and technology can address health disparities. The inaugural lecture was given by Dr. Carlos Bustamante. For more details about the inaugural lecture and archived video, see genome.gov/27561525. For more information on the roundtable, visit genome.gov/27563294.



DHHS Career Achievement Award Given to Jeff Schloss



On November 17, Dr. [Jeff Schloss](#), Director of the [Division of Genome Sciences](#) within the NHGRI Extramural Research Program, received a Department of Health and Human Services (DHHS) 2014 Career Achievement Award. For 19 years, Jeff has established and overseen novel initiatives that aim to develop new DNA analysis technologies. In particular, he has led NHGRI's signature program in DNA sequencing technology development. This latter has been a key contributor to the remarkable reduction in DNA sequencing costs by nearly a million-fold over the last ~15 years. His program is arguably the most successful technology development effort in the history of NIH. In addition, he has promoted interdisciplinary research through trans-NIH and trans-federal activities. For more information, see genome.gov/27563316.

NHGRI Welcomes the New Chief of the Policy and Program Analysis Branch



NIH National Human Genome Research Institute
Department of Health and Human Services

This week, Cristina Kapustij, M.S., was named the new Chief of the [Policy and Program Analysis Branch](#) (PPAB) within the NHGRI [Division of Policy, Communications, and Education \(DPCE\)](#). Prior to joining NHGRI, Ms. Kapustij worked as a Program Manager at the Institute for Human Genetics, University of California San Francisco, where she directed policy responses to potential changes in state and federal legislation, coordinated activities with the U.S. Food and Drug Administration, and researched the ethical, legal, and social implications related to DNA sequencing from newborn blood spots. In her new role as PPAB Chief, she will oversee policy development and analysis, legislative, and federal interactions, as well evaluation of NHGRI research and policy priorities. NHGRI is excited to have Ms. Kapustij join our policy group at such an exciting time for genomics.

Bob Blakesley, Director of the NISC Sequencing Group, Retires



NISC
NIH Intramural Sequencing Center

After nearly 16 years at the [NIH Intramural Sequencing Center](#) (NISC), Dr. [Bob Blakesley](#) will retire from federal service in the coming month. Bob directs the Sequencing Group at NISC, which is responsible for high-throughput generation of DNA sequence data using state-of-the-art automated instrumentation. As NISC's Former Director, I recruited Bob to NIH and then worked closely with him for many years. During his tenure, he provided leadership in industrializing many aspects of NISC's DNA-sequencing pipeline and contributed to numerous, influential research projects, such as the [Encyclopedia Of DNA Elements \(ENCODE\) Project](#), [ClinSeq](#), and the [NIH Undiagnosed Diseases Program](#). He also served as an icon for the NISC facility, having given more tours of the center than he can probably count. For more information, see genome.gov/27563314.

Spotlight on the Precision Medicine Initiative (PMI)



nih.gov/precisionmedicine

- The White House recently released a set of [Privacy and Trust Principles](#) to guide the U.S. [Precision Medicine Initiative](#)® (PMI). These principles will provide a foundation for protecting participant privacy as well as building and sustaining trust in PMI activities.
- NIH has launched a search for the [PMI Cohort Program Director](#). This new NIH leadership position will lead the development, implementation, evaluation, and maintenance of the PMI Cohort Program. Applications must be received by December 24.
- The NIH Director, Dr. Francis Collins, recently released a [statement](#) that provides updates on the PMI Cohort Program.
- On November 16, the NIH released initial PMI [Funding Opportunities](#).

Genomics Research

[TCGA Study Reveals New Clues to the Genomic Diversity of Prostate Cancers](#)

[Kidney Cancer's Genomic Drivers Revealed](#)

[Analysis of Genetic Neurologic Diseases Identify Genes that Affect Brain Structure, Function](#)

[Big Data Study Reveals Possible Subtypes of Type 2 Diabetes](#)

[Batten Disease May Benefit from Gene Therapy](#)

[GQT: Making the Most of Genomic Big Data](#)

[Genome of Sézary Syndrome Points to Potential Treatment Targets](#)

[Study: Drug May Delay, Prevent Blindness for Millions](#)

[DNA Repair Factor Linked to Breast Cancer May Also Play a Role in Alzheimer's Disease](#)

Funding Opportunities

[Precision Medicine Cohort Program Funding Opportunities](#)

Funding News

[Significant Changes: FY2016 NIH Grants Policy Statement](#)

[NIH Offers Niche Assessment Program to HHS SBIR and STTR Phase I Awardees](#)

[NIH & AHRQ Announce Transition to New Research Training Table Formats for 2016 and Upcoming Release of the xTRACT System](#)

[NIH & AHRQ Announces Upcoming Changes to Post-Award Forms and Instructions](#)

[Inclusion of Children in Clinical Research: Change in NIH Definition](#)

[Simplification of the Vertebrate Animals Section of NIH Grant Applications and Contract Proposals](#)

[NIH & AHRQ Announce New Form for PHS Awarding Component and Peer Review Requests](#)

[Transition to Payment Management System \(PMS\) Subaccounts: FY 2016 Supplements](#)

[ASSIST Now an Option for Fellowship Grant Applications](#)

Request for Comments

[Maximizing Impact of a Potential Future Program in Clinical Sequencing](#)

[Strategies to Enhance Diversity in the Physician-Scientist Workforce](#)

[Common Rule Comment Period Extended](#)

NIH News of Interest

[Director, NICHD Vacancy Announcement](#)

[PMI Cohort Program Director, Vacancy Announcement](#)

[Dr. Francis Collins on Charlie Rose Show](#)

[Charting a Course for Genomic Sequencing in Patient Care](#)

[The Public Health Evidence for FDA Oversight of Laboratory Developed Tests: 20 Case Studies](#)

New Genomics Videos/Webinars

[ENCODE/Roadmap Epigenomics Tutorial](#)

[NIH Gabriella Miller Kids First Pediatric Research Program Webinar](#)

[Newborn Sequencing in Genomic Medicine and Public Health \(NSIGHT\) Public Webinar](#)

[Family Health History Day](#) - Eric Green

