

February 5, 2015

You are receiving February's *The Genomics Landscape* a few days later than originally scheduled – but for good reason! I wanted to wait to feature last week's historic announcement that very much involves the field of genomics. I was fortunate to be in the East Room of the White House along with a number of other NHGRI and NIH colleagues to hear President Obama announce the <u>Precision Medicine Initiative</u>. It has been an honor to be part of the extensive planning effort leading up to last week's unveiling, and it will be gratifying to have NHGRI involved in making this important Initiative a reality. I fully expect that future *The Genomics Landscape* editions will feature updates on the Precision Medicine Initiative.

I am also pleased to point out that the Smithsonian-NHGRI exhibition, *Genome: Unlocking Life's Code*, is now open at its second stop on a North American, multi-year tour – in this case, in San Jose, California. Specifically, the exhibition is being featured at The Tech Museum of Innovation through April 27, 2015. For details about the exhibition and future stops on its tour, see genome.gov/27560150 or unlockinglifescode.org.

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

- President Obama's Precision Medicine Initiative
- First Grants for the Genomics of Gene Regulation Project
- Revised NHGRI Informed Consent Resource
- NHGRI Appoints a New Chief of the Education and Community Involvement Branch
- Recruiting a New Chief, Communications and Public Liaison Branch

Finally, the next meeting of the National Advisory Council for Human Genome Research (NACHGR) will be held beginning Monday, February 9. To watch the Open Session, visit genome.gov/GenomeTVLive/ at 10:00 AM ET.

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!



President Obama's Precision Medicine Initiative

Extending on the announcement made in his recent State of the Union Address, President Barack Obama outlined a bold, new Precision Medicine Initiative at a White House event last Friday. This exciting new enterprise will draw on the remarkable advances in multiple domains (particularly genomics!) to increase our understanding of human disease, revolutionize how we approach medical care, and greatly improve human health. The time is ripe for a major focus on precision medicine research – major advances in genomic technologies, electronic health records, technologies for capturing environmental and lifestyle information, data science, and the availability of numerous existing research cohorts will foster the growth of this enterprise.



Current medical practice cannot always account for differences in treatment response, but examples of being more 'precise' in the delivery of medical care for a given individual are now emerging. For example, two people may metabolize the same drug at different rates due to inherited genomic variants that influence drug-metabolizing pathways. Precision medicine approaches use genomic information about a patient to determine the optimum choice of drug and dosage. Other compelling examples of precision medicine are emerging in the arena of cancer treatment. Individual tumors can vary greatly in the genomic changes that produce their cancerous properties. These differences are highly relevant in selecting the appropriate treatment for each patient.

President Obama's Precision Medicine Initiative aims to greatly accelerate the research needed to take advantage of great technological advances and to integrate them into medicine. There is quite a bit of information available about this exciting Initiative. You can start by hearing the President's first announcement during his State of the Union Address at whitehouse.gov/sotu (specifically at 28:58 – 29:56) or his more detailed announcement from last Friday. Meanwhile,

First Grants for the Genomics of Gene Regulation Project



Recently, NHGRI awarded the first set of grants for its new Genomics of Gene Regulation (GGR) project. The goal of GGR is to decipher the language of how and when genes are turned on and off, and how the molecules that regulate this activity work together. Scientists have identified many genomic regions that regulate gene expression, but oftentimes, they do not know which gene(s) an individual regulatory element actually controls. GGR will help to make these connections. Understanding how regulatory elements and genes work together will allow scientists to further understand the potential role of these interactions in human disease. For more information, see genome.gov/27559930.

Revised NHGRI Informed Consent Resource



Informed consent is a fundamental principle of research involving human participants. This week, an updated NHGRI Informed Consent Resource went live on NHGRI's website. This resource is designed to help researchers develop processes and consent documents through which to seek informed consent or participation in genomics-related research. It includes the discussion of topics essential to genomics research, sample language and consent forms, and resources on the relevant Federal (or U.S.) regulations and policies. The updated content in the Informed Consent Resource covers issues related to data repositories, biobanking, data sharing, and return of results. For more information, see genome.gov/27560340. To access the resource, see genome.gov/informedconsent.

last week, Drs. Francis Collins and Harold Varmus published a description of the Initiative in the <u>New England Journal of Medicine</u>. Finally, you can follow the progress of the Precision Medicine Initiative at the White House and the NIH.

A major component of the Initiative will be the establishment of a national, patient-powered research cohort of one million or more Americans. To jumpstart the planning for such a cohort, NIH is holding a workshop, entitled Precision Medicine Initiative: Building a Large U.S. Research Cohort. This workshop will be held on February 11-12, beginning at 8:30 AM on the first day. I invite you to tune in via the webcast at wideocast.nih.gov to view what promises to be an important and engaging discussion.



Precision medicine offers great promise and, in many ways, represents a cornerstone for the long-term vision of genomics research. I personally – and NHGRI more generally – find President Obama's commitment to this new Initiative both gratifying and inspiring. While many challenges will undoubtedly be faced in the coming days, weeks, and months in making the President's vision a reality, that hard work promises to lead to us into a new and exciting era of medical advances.







NHGRI Appoints a New Chief of the Education and Community Involvement Branch



NHGRI is delighted to announce the appointment of Carla Easter, Ph.D., as the new Chief of the Education and Community Involvement Branch (ECIB) within the Division of Policy, Communications, and Education. Dr. Easter brings to this position outstanding credentials, boundless energy, and infectious enthusiasm. Previously, Dr. Easter served as ECIB's Deputy Chief, during which time she was fundamental to all aspects of the Smithsonian-NHGRI exhibition Genome: Unlocking Life's Code. Dr. Easter succeeds Vence Bonham, J.D., the founding ECIB Branch Chief, who will now focus more of his time in his role as Senior Advisor to the NHGRI Director on Genomics and Health Disparities. For further details regarding Dr. Easter's appointment, see genome.gov/27560073.



Recruiting a New Chief, Communications and Public Liaison Branch

NHGRI is currently recruiting a new Chief of the Communications and Public Liaison Branch (CPLB), part of our Division of Policy, Communications, and Education (DPCE). The CPLB Chief serves as the overall 'communications director' for NHGRI, working closely with the DPCE Director and NHGRI Director in dealing with all aspects of the Institute's communications programs. Specifically, the individual is expected to manage and lead communications and public relations activities that are fundamental to communicating genomics research advances as well as Institute goals, policies, programs, and accomplishments. This individual also works in close collaboration with many other parts of NHGRI and NIH. For further information about this important position, contact Dr. Laura Lyman Rodriguez.

Genomics Research

Ferreting Out Genomic Secrets

Certain Genetic Variants May Influence Progression of Kidney Disease

NIH Researchers Tackle Thorny Side of Gene Therapy

NIH-Funded Study Uncovers Range of Molecular Alterations in Head and Neck Cancers, New Potential Drug Targets

Genome Advance of the Month

Researchers Detect Cancer Precursors in Blood DNA Before Disease Develops

NIH News of Interest

NIH Genomic Data Sharing Policy Takes Effect – January 25, 2015

Rare Disease Day – February 28, 2015

Appointment of Dr. Carrie Wolinetz as Associate Director for Science Policy, NIH

Fellowship Opportunities

ASHG-NHGRI Genetics & Public Policy Fellowship

ASHG-NHGRI Genetics & Education Fellowship

Upcomina Webcasts

National Advisory Council for Human Genome Research – February 9, 2015

Precision Medicine Initiative: Building a Large U.S. Research Cohort – February 11-12, 2015 – Day 1 and Day 2

New Videos

<u>Trans-NIH Workshop to Explore the Ethical,</u> <u>Legal and Social Implications (ELSI) of Citizen</u> <u>Science</u>

Framework for Regulatory Oversight of Laboratory Developed Tests (LDTs) – Day 1 and Day 2

Methylmalonic Acidemia (MMA) Gene Therapy – Charles Venditti and Randy Chandler

Awards

<u>CHANEL-CERIES Research Award 2014</u> – Julie Segre

Rare Voice Award 2014 – William Gahl

<u>National Society of Genetic Counselors</u> <u>Leadership Award 2014</u> – Barbara Biesecker

South African Medical Research Council
Scientific Merit Award 2014 – Charles Rotimi

<u>American Journal of Human Genetics C.W.</u> <u>Cotterman Award 2014</u> – Shurjo Sen

Fundina News

NIH Fiscal Policy for Grant Awards FY2015

Notice of Salary Limitation on Grants, Cooperative Agreements, and Contracts

Ruth L. Kirschstein National Research Service Award (NRSA) Stipends, Tuition/Fees and Other Budgetary Levels Effective for Fiscal Year 2015

Funding Opportunities

NIH Big Data to Knowledge (BD2K) Biomedical Data Science Training Coordination Center (U24)

NIH Big Data to Knowledge (BD2K)
Enhancing Diversity in Biomedical Data
Science (R25)

Metabolomics Core for the
Undiagnosed Diseases Network (UDN)
(U01)

NIH Pathway to Independence Award (Parent K99/R00)

Nuclear Organization and Function Interdisciplinary Consortium (NOFIC)(U54)

Empirical Research on Ethical Issues
Related to Central IRBs and Consent
for Research Using Clinical Records and
Data (R01)

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