

## January 7, 2014

Happy New Year!

I start 2014 with mixed feelings. I continue to marvel at the spectacular advances seen in genomics each and every year, to struggle with the ongoing difficult budgetary circumstances for NIH and NHGRI, and to latch on to a few optimistic signs suggesting that our budgetary problems might be finally 'bottoming out' and that things will soon start to improve. I suspect the stories we feature in *The Genomics Landscape* during 2014 will capture elements of these mixed feelings.

To kick off 2014, January's The Genomics Landscape includes stories about:

- <u>A Decade of the NHGRI Social and Behavioral Research Branch</u>
- NHGRI has Lost a Good Friend and Colleague— Dr. Janet Rowley
- Selection of the NIH Associate Director for Data Science
- Welcoming New NHGRI Advisors
- <u>NHGRI-Smithsonian Genomics Exhibition Update</u>
- Genomics News of Interest, New Funding Opportunities, and More

All the best,



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#### A Decade of the NHGRI Social and Behavioral Research Branch



and Behavioral **Research Branch** 

# National Human Genome Research Institute

As mentioned in last month's The Genomics Landscape, the NHGRI Intramural Research Program (IRP) recently reached its 20-year milestone. With its diverse spectrum of research – from genomic technology development to clinical genomics research and everything in between— the NHGRI IRP continues to serve as an important focal point for genomics research at NIH and worldwide. One of the IRP's key contributions to genomics research is the Social and Behavioral Research Branch (SBRB), now celebrating its 10<sup>th</sup> anniversary.

In my former position as the NHGRI Scientific Director, I recognized the need for a social science research program within the Institute's IRP. So, ten years ago, I recruited Dr. Colleen McBride to NHGRI, and she established the SBRB (for details, see genome.gov/11509318). The mission of SBRB is to investigate the social and behavioral factors that affect the translation of genetic and genomic discoveries for health promotion, disease prevention, and healthcare improvements. The Branch's research encompasses four domains: (1) testing the effectiveness of strategies for communicating information about genetic risk; (2) developing and evaluating behavioral interventions; (3) using genomic advances in clinical practice; and (4) understanding the social, ethical, and policy implications of genomics research.

The specific research areas being investigated by SBRB scientists include improving methods for communicating genetic risk to lay populations, establishing best practices in genetic counseling, investigating approaches for integrating genetics into primary care settings, and studying broad issues related to the public dissemination of genomic discoveries. SBRB investigators are also examining the bioethical considerations for the involvement of human subjects in genomics research. One of the Branch's unique resources is the Immersive Virtual Environment Testing Area, which uses virtual reality technology to study social and behavioral hypotheses.

#### NHGRI has Lost a Good Friend and Colleague — Dr. Janet Rowley



Dr. Janet Rowley died of ovarian cancer last month at the age of 88. In addition to being a good friend to many of us at the Institute, she was a wise and valued advisor- serving on our Board of Scientific Counselors at the very beginning of our Intramural Research Program and later on our National Advisory Council for Human Genome Research. The research community has lost a legend. Janet's scientific accomplishments are nicely described in a story written by the University of Chicago at

news.uchicago.edu/article/2013/12/17/j anet-rowley-cancer-genetics-pioneer-1925-2013.

### Selection of the NIH Associate Director for Data Science



In December, NIH Director Francis Collins announced the selection of Philip E. Bourne, Ph.D., as the first NIH Associate Director for Data Science. Dr. Bourne is expected to join the NIH in early 2014. He will lead an NIH-wide priority initiative that aims to enable the biomedical research enterprise to capitalize on the exponential growth in

SBRB has much to celebrate after its first decade. The Branch's anniversary celebration began in June 2013 with a set of paired lectures as part of the NHGRI seminar series commemorating the 10<sup>th</sup> anniversary of the completion of the Human Genome Project. Drs. Caryn Lerman and Alexandra Shields presented talks on "Translating Pharmacogenetics Research to Practice: The Case Example of Smoking Cessation." These two lectures can be viewed on GenomeTV (at <u>youtube.com/playlist?list=PL1ay9ko4A8sm7dBcd-SdY9ib3t9TASWS</u>). SBRB's 10<sup>th</sup> anniversary celebration will culminate with a scientific symposium on January 13 entitled "Translating Genomics through a Social and Behavioral Lens." A video from the symposium will be available on GenomeTV shortly thereafter.



To learn more about SBRB, the Branch's investigators, and their exciting research programs, please visit <u>genome.gov/11508935</u>. NHGRI is privileged to have this impressive cadre of scientists working within the Institute's IRP!

**NHGRI-Smithsonian Genomics Exhibition Update** 



The NHGRI-Smithsonian exhibition, *Genome: Unlocking Life's Code*, is almost halfway through its stay at the National Museum of Natural History, and it continues to receive both numerous and notable visitors (e.g., see former Supreme Court Justice Sandra Day O'Connor above). In September, the exhibition will travel to the Reuben H. Fleet Science Center in San Diego. For its remaining months in D.C., the Smithsonian Associates has organized a series of exhibition-related programs. On January 29, you can learn about how Hollywood gets genomics right at "Genomics, Hollywood Style." On February 6, you can explore "Is Genetic Information Different" when ethical and medical questions related to genomics are debated. For details about the exhibition and related programs, see <u>unlockinglifescode.org</u>. data production and availability. The era of 'Big Data' has arrived, and it is vital that the NIH make a major contribution in coordinating access to and analysis of the many different data types that can, together, create previously unobtainable opportunities for gaining novel insights. For further details, see

nih.gov/news/health/dec2013/od-09.htm.

#### Welcoming New NHGRI Advisors



NHGRI relies extensively on external experts to advise the Institute in setting and achieving its goals for advancing genomics research. I would like to welcome new nominated/appointed members to our two major advisory groups— the National Advisory Council for Human Genome Research (NACHGR; see above photo), which provides advice mostly about our Extramural Research Program, and the Board of Scientific Counselors (BSC), which provides advice about our Intramural Research Program. Eric Boerwinkle, Ph.D., Chanita Hughes-Halbert, Ph.D., Martin Kreitman, Ph.D., and David Page, M.D. have been nominated to become new members of the NACHGR. John Atkinson, M.D., and Gloria Petersen, Ph.D. have been appointed to the BSC. For more information about the NACHGR, see: genome.gov/10000905. For more information about the BSC, see: genome.gov/10000911.



Genomics News of Interest	New Funding Opportunities	Genome Advance of the Month
Presidential Bioethics Committee report on incidental findings <u>bioethics.gov/node/3186</u> With new study, aquatic comb jelly floats into	BD2K-LINCS-Perturbation Data Coordination and Integration Center (DCIC) (U54) grants.nih.gov/grants/guide/rfa-files/RFA-HG-14- 001.html	Pilot study eyes implications of ACMG stance on incidental findings genome.gov/27555648
new evolutionary position genome.gov/27555600	Development of an NIH BD2K Data Discovery Index Coordination Consortium (U24) grants.nih.gov/grants/guide/rfa-files/RFA-HL-14-	Upcoming Webcast
NIH study links family structure to high blood pressure in African-American men	<u>031.html</u>	Genomic Medicine VI Meeting genome.gov/27555775
genome.gov/27555549 Neandertal genome project reaches its goal mpg.de/7666848/neandertal genome projec	Computational Analyses Exploiting Reference Epigenomic Maps (R01) grants.nih.gov/grants/guide/rfa-files/RFA-RM-14- 001.html	New Genomics Videos
Genzyme and NORD establish program to help undiagnosed patients with rare diseases	Validation and Advanced Development of Technologies for the Study of Biological Properties of Single Cells (R33)	Genomic Medicine Lecture Series: "When the Lifeguard for the Gene Pool Goes on Strike youtube.com/watch?v=_z0kEsvCw9k
news.genzyme.com/press-release/genzyme- and-nord-establish-program-help- undiagnosed-patients-rare-diseases	grants.nih.gov/grants/guide/rfa-files/RFA-RM-13- 020.html Exceptionally Innovative Tools and Technologies	Eric Green – "Human Genomics a Decade After the Human Genome Project: Opportunities and
Nanopore DNA sequencing: New approaches to an old challenge genome.gov/27555651	for Single Cell Analysis (R21) grants.nih.gov/grants/guide/rfa-files/RFA-RM-13- 021.html	challenges" individualizingmedicineconference.m ayo.edu/talks/

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