



October 21, 2013

I am pleased to debut a new means of communicating information from the National Human Genome Research Institute (NHGRI) — *The Genomics Landscape*. In response to encouragement that I have received from various stakeholders to provide more regular personal updates about topics of interest, I am starting a monthly email message that aims to disseminate information from the NHGRI Director to the broader genomics community and other interested recipients. Each month, I will endeavor to highlight two to four topics, typically featuring one in greater detail.

In this inaugural *The Genomics Landscape*, I discuss:

- [The Current NHGRI/NIH Budget Situation](#)
- [The New NHGRI-Smithsonian Exhibition *Genome: Unlocking Life's Code*](#)
- [New Developments with HeLa Cells and Genomic Data](#)
- [Draft NIH Genomic Data Sharing Policy](#)

You received this email (and will receive similar ones in November and December) because we have identified you as part of the 'NHGRI constituency.' **To receive *The Genomics Landscape* beginning in January 2014, you will need to 'opt in' through a simple sign-up procedure (see below)**, and I genuinely hope that you do so! Below, you will also find an email address for sending me suggestions for topics to discuss in the future — *The Genomics Landscape* is for you, and I would really like to know what interests you and what information I can provide, so please make suggestions!

I look forward to communicating with you monthly in this way.

All the best,

A handwritten signature in black ink that reads "Eric".

To continue receiving *The Genomics Landscape* each month, you must sign up via the following ListServ before December 31, 2013:
list.nih.gov/cgi-bin/wa.exe?A0=NHGRILANDSCAPE

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

Welcome Fiscal Year 2014! — Or Not?

Today marks the beginning of the third week of Fiscal Year 2014 for the U.S. federal government. Originally, I intended to send out this message on October 1, at the start of the Fiscal Year. But, among its many other effects, the 16-day government shutdown prevented that. Unfortunately, even though the government has reopened, it is going to take many weeks to resolve the numerous problems created by the shutdown. We are well-aware that the shutdown not only affected us as federal employees, but many of you as well, and those of us at NHGRI (and NIH) are working hard to normalize our operations. So, I ask for your patience as we endeavor to undo the damage, but also want to assure you that you can contact us at any time to discuss any shutdown-related problems.

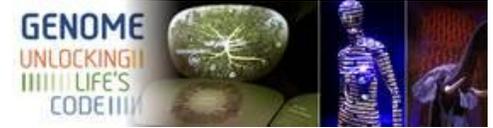
I have worked at the NIH for roughly 19 years, but I am sad to say that the current climate within this large federal institution is the worst that I have experienced in my time here. Words like 'sequester,' 'shut down,' 'continuing resolution,' and 'pessimistic' have become part of our standard lexicon and cast a shadow on the otherwise spectacular opportunities that abound for biomedical research.

While I do not like to admit it, the funding situation for U.S. biomedical research (generally) and NHGRI (specifically) clouds almost everything that I deal with on a daily basis. The profound and continuing uncertainties about funding levels make the job of managing NHGRI and its research portfolio a too-often frustrating task. I would note that none of this would be as frustrating if only genomics research was slow moving, unexciting, and unlikely to have a significant impact on human health; however, in reality, just the opposite is true.

While I have seen individual laboratory budgets squeezed, excellent programs cut, and new initiatives left unfunded, my job is to ensure that NHGRI continues to support the highest quality scientific programs and grantees, so that we can deliver on the promise of genomics. Towards that end, there are a number of specific things that the Institute is doing to balance multiple priorities during a time of suboptimal resources.

In our Extramural Research Program, we continually adjust our grant portfolio to maintain a balance of support for different areas of study, different types of investigators, and different kinds of projects, all while trying to stay on the cutting edge of this incredibly fast-paced area of science. Although the funding outlook is not terribly optimistic and is often unclear until the last minute, we do not hesitate to propose innovative ideas for new initiatives. While we have delayed launching some new programs, we have not abandoned them. If for some reason more funds were to become available, we

Genome: Unlocking Life's Code



The Smithsonian Institution's National Museum of Natural History (NMNH) in Washington, D.C. is currently home to *Genome: Unlocking Life's Code* – a multimedia exhibition developed through a remarkable partnership between NHGRI and NMNH. The exhibition opened in June 2013, and illustrates how the genomic revolution is influencing people's lives and the extraordinary impact it has on science, medicine, and our understanding of the natural world. This collaborative effort — made possible through privately-raised funds — has been extremely gratifying in that it has brought together two powerful scientific institutions to increase the public's awareness of genomics and its significance in the world. In addition, NHGRI and the Smithsonian are holding a series of special conferences and public education programs to complement the exhibition while it is resident at the NMNH until September 2014. After that, the exhibition will travel around North America for 4-5 years. For more information about the exhibition and related programming, visit unlockinglifescode.org.

HeLa and Genomic Data

The National Institutes of Health recently announced that it has reached an understanding with the family of the late Henrietta Lacks to allow biomedical researchers controlled access to genomic data generated from the famous HeLa cell line. The well-known history of this cell line (including the lack of informed

have some phenomenal new ideas in our ‘back pocket’ on which we could swiftly move forward.

We are also continuing to reach out to our partners in an effort to leverage resources and promote common interests in these tight times. In particular, we look across NIH for partnerships with other Institutes or Centers; in fact, the majority of our recent new initiatives have involved developing a co-funding partnership with another NIH Institute. NHGRI also participates extensively in a number of trans-NIH initiatives, again leveraging our resources with those amassed centrally. The new Big Data to Knowledge (BD2K) initiative (bd2k.nih.gov) is a great example of that, and something that I will make sure to discuss more in a future installment of *The Genomics Landscape*.

Our Intramural Research Program has also made significant cuts and adjustments to deal with the consequences of the sequester. These have included not replacing staff who have departed the Institute and altering the budgeting process so as to provide our intramural investigators more flexibility in the use of their funds. In terms of the general operations at the Institute, we have felt the tightening of the budget just like other organizations across the country, and have had to deal with it by reducing travel, meetings, the immediate hiring of staff, and other expenditures. Most of these actions are being pursued in close choreography with other components of NIH.

In short, we are doing our best analyzing budgets and developing scenarios for different circumstances — and preparing for events that then do not happen. ‘Fiscal constraint’ (especially when final decisions are uncertain) is actually quite expensive with respect to the amount of time spent by the scientific leaders both within and outside the Institute in analyzing, debating, and executing sharply curtailed operating plans.

But what about the future? We are currently operating under a Continuing Resolution that extends through mid-January, but are also trying to accommodate the possibilities of another government shutdown if the federal budget issues cannot be resolved and/or additional sequester cuts that would lower our funding even further. Probably the only thing that we can be certain about is continued uncertainty regarding funding levels for the Institute, as well as the rest of NIH. As we did last year and in the days and weeks leading up to the eventual sequester, NHGRI will start the fiscal year conservatively, plan for multiple contingencies, and hope for the best possible resolution. While I may wish for different fiscal circumstances, I remain personally committed to continue fostering the most creative and innovative genomics research, while continually explaining its importance for human health to anyone who will listen.

consent from Henrietta Lacks, the widespread use of the cells, and the substantial publicity associated with the identity of the family) represents a unique situation that allows us to learn important lessons about research policy development. NIH worked closely with the Lacks family to develop an innovative policy solution that meets the needs of the family while giving researchers appropriate access to this important genome data. For further details, see www.nih.gov/about/director/statement-hela-08072013.htm

Draft NIH Genomic Data Sharing Policy Released for Public Comment

The NIH is seeking public comments about its new draft Genomic Data Sharing Policy that promotes broad sharing of large-scale human and non-human genomic data generated from NIH-supported research. The draft policy is an update to the 2007 policy for sharing Genome-Wide Association Study data (commonly known as "the GWAS Policy"). This update describes the responsibilities of investigators and institutions for submitting genomic data to NIH databases and the use of controlled-access data from databases such as the database for Genotypes and Phenotypes (dbGaP). I encourage you to review the draft policy and provide comments during the public comment period, which closes November 20. In addition, there will be **one or more** public webinars to discuss the draft policy and to hear public feedback in the coming months. Please visit www.federalregister.gov/a/2013-22941 or gds.nih.gov for more information.



New Funding Opportunities

Genomics of Gene Regulation (U01)
grants.nih.gov/grants/guide/rfa-files/RFA-HG-13-012.html

DNA Sequencing Core for an Undiagnosed Diseases Network (U01)
grants.nih.gov/grants/guide/rfa-files/RFA-RM-13-018.html

Centers of Excellence for Big Data Computing in the Biomedical Sciences (U54) – see bd2k.nih.gov/ for more information about the NIH Big Data to Knowledge (BD2K) initiative
grants.nih.gov/grants/guide/rfa-files/RFA-HG-13-009.html

New Videos on GenomeTV

National Advisory Council for Human Genome Research – September 9, 2013 Open Session
www.youtube.com/playlist?list=PL1ay9ko4A8sn216H9y_gS99NsZU1gW7t4

Human Microbiome Science: Vision for the Future – July 24-26, 2013 Conference featuring cutting-edge work in NIH-supported microbiome research
www.genome.gov/27554404

BioCenturyTV's program on the Genome Revolution (show 152) featuring Dr. Eric Green www.biocenturytv.com/player

Genomics News of Interest

Latest *Genome Advance of the Month* features the use of Y chromosome sequence data to explore human evolution
www.genome.gov/27555170

NHGRI researchers help identify new metabolic disorder caused by faulty gene expression www.genome.gov/27554999

New NIH grants to investigate disease-related variations in genetic makeup through the NHGRI's Population Architecture Using Genomics and Epidemiology (PAGE) program
www.genome.gov/27554930

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To suggest topics for future messages, please send an e-mail to NHGRILANDSCAPE@MAIL.NIH.GOV.

