The Genomics Landscape

A monthly update from

the NHGRI Director

June 3, 2014

While the DC area traffic might slow down (ever so) slightly during the summer, NHGRI does not— leaving me with much to talk about. This month, I am pleased to provide information about NHGRI's relatively new Historical Archiving Initiative. I also give updates about the availability of new Genetics/Genomics Competency Center (G2C2) Resources, a recent publication describing the Institute's Ethical, Legal, and Social Implications (ELSI) Research Program, and two recent outreach activities led by the Education and Community Involvement Branch in our Division of Policy, Communications, and Education.

See details below along with other informational items that I hope will be of interest to you.

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

- Capturing the Past: NHGRI Historical Archiving Initiative
- Genetics/Genomics Competency Center (G2C2) Resources
- ELSI Reflections Published in the Annual Review of Genomics and Human Genetics
- Medgar Evers College Genomics Education Outreach Collaborative
- USA Science and Engineering Festival

All the best,

[signature]

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Capturing the Past: NHGRI Historical Archiving Initiative

Starting with NHGRI's original raison d'être— the Human Genome Project— NHGRI has been closely tied to or led a number of very high-profile genomics projects. These efforts have produced massive volumes of documents, notes, emails, slides, photographs, videos, and other materials. As the Institute's scientific portfolio widens, the pace of generating such materials is only growing.

Several years ago, I realized that we were at risk of losing valuable materials that are of historic value because we lacked a systematic approach for archiving Institute resources. I concluded that NHGRI needed to develop an infrastructure for assimilating existing materials and for capturing future materials. In doing so, we would provide historians with a resource with key information about NHGRI activities and the field of genomics. To that end, NHGRI has initiated a 'historical archiving initiative' that aims to: (1) "get our house in order" with respect to archiving, so as to ensure that we do not lose any historically-relevant materials; and (2) foster the pursuit of scholarly work about the history of genomics and NHGRI. The latter will eventually involve making many of the archived materials publically available.

We started this initiative by scanning thousands of historically relevant, hard-copy files. Many of these files are official government records whose disposition must be handled according to well-defined regulations. By generating digital copies, there will be continued access to the information even if the original paper files are archived elsewhere. Meanwhile, existing digital files are being organized in a more systematic fashion and stored on Institute computers. All of these steps are happening while we develop and put into place Institute-wide 'best practices' for retaining and organizing relevant digital files, including handling issues that arise when staff members join and leave the Institute.

Genetics/Genomics Competency Center Resources

The Genetics/Genomics Competency Center for Education (G2C2)— a free, online collection of materials for self-directed learning in genetics and genomics— provides high-quality educational resources for genetic counselors, nurses, physician assistants, pharmacists, and now physicians. The new physician portal includes professionally curated resources, classroom materials, and real-world examples for physicians. For more information about G2C2 and the new physician portal, see g-2-c-2.org/. For more information, see genome.gov/27557663. For details about the framework underlying the new portal, see nature.com/gim/journal/vaop/ncurrent/full/gim201435a.html.

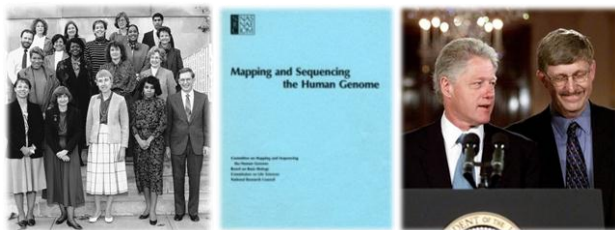## ELSI Reflections Published in the Annual Review of Genomics and Human Genetics

Recently, NHGRI program staff authored an article entitled "The Ethical, Legal and Social Implications Program of the National Human Genome Research Institute: Reflections on an Ongoing Experiment," which was published online in the *Annual Review of Genomics and Human Genetics*. The article reflects on over two decades of NHGRI's ELSI Research Program, detailing its history, growth, and focus and highlighting some of its key components. Originally a stand-alone program, ELSI research has now become embedded within many important NHGRI extramural research projects. It has shaped the ways in which communities are treated in genomics research, and informed policies related to the use of genomic information in the clinic. For the full text of the article, visit annualreviews.org/doi/abs/10.1146/annurev-genom-090413-025327.

In order to make these documents accessible (internally or externally), we plan to develop a database that includes relevant metadata (e.g., annotations regarding confidentiality and document provenance) about the materials and that allows for search capabilities. The database and its curation should enable greater access to historically-relevant materials by staff and other interested parties. As with many other NHGRI programs, we have plans to seek input from the outside community about these historical archiving efforts, including convening a group to help us assess progress.

There are also components of our archiving initiative that will generate new historically-relevant materials. For example, we have started an oral history project that is collecting and recording interviews with NHGRI staff, external scientists, and policy makers who have been involved in the Human Genome Project and other subsequent genomics programs. Another example is the creation of scope and content notes that provide detailed descriptions of archived materials, adding value to the amassed holdings.

Lastly, a component of our efforts will involve generating and publishing scholarly works that describe and analyze the history of important NHGRI and genomics programs. Being able to examine the history and circumstances behind key genomics programs and related efforts will be important contributions to the history of science more broadly. Expect to see articles written about human genome variation programs at NHGRI, the $1,000 Genome Technology Development Program, and the Ethical, Legal, and Social Implications Program in the coming months.

From left to right: Early NHGRI (then NCHGR) staff photo, 1988 National Academy of Sciences report about the Human Genome Project, and President Bill Clinton and Francis Collins at a White House press event in 2000.

It is relatively easy for me, as the NHGRI Director, to declare that what NHGRI does is historically important; however, it is more meaningful and relevant for NHGRI to facilitate the collection, organization, and interpretation of historic materials that make this case in a more sophisticated and robust way. Hopefully, this initiative will do just that.

For more information on the NHGRI historical archiving efforts, see genome.gov/27557501.

Medgar Evers College Genomics Education Outreach Collaborative

The Genomics Education Outreach Collaborative (GEOC), a partnership between NHGRI and Medgar Evers College in New York City, recently organized an event at the College for high school students. The students, hailing from six local schools, received a crash course on careers in genomics from NHGRI researchers. These schools have also been involved in testing a genomics curriculum that the GEOC has developed; the curriculum covers topics such as human identity, using genomics to map ancestry, and the difference between genomics and genetics. For more information, see genome.gov/27557596.

USA Science and Engineering Festival

NHGRI staff member, Christina Daulton, volunteers at the USA Science and Engineering Festival.

On April 25-27, 2014, NHGRI participated in the USA Science and Engineering Festival at the Washington D.C. Convention Center. The Festival was attended by more than 325,000 students, parents, and teachers, and included hands-on activities at more than 750 booths. Visitors learned about Science, Technology, Engineering, and Mathematics (STEM) careers at the festival's Career Pavilion, listened to guest speakers like Bill Nye from television's *Bill Nye the Science Guy,* and extracted DNA from strawberries using common household products. More than 40 NHGRI staff members volunteered at the booth during the weekend and interacted with nearly 2,000 visitors. For more details about NHGRI's participation, see genome.gov/27557090.

Genomics News

[Longevity Gene May Boost Brain Power](#)

[Children with Progeria See Lives Prolonged by Experimental Medication](#)

[Scientists Hoping to Ease Interpretation of the DNA 'Book of Life'](#)

[Angelina Jolie Effect: One Year Later](#)

[How Gut Bacteria Help Make Us Fat and Thin](#)

['Aliens of the Sea' Provide New Insight into Evolution](#)

[My No-Soap, No-Shampoo, Bacteria-Rich Hygiene Experiment](#)

[Not Sterile, After All: The Placenta's Microbiome](#)

[The Search for Genes that Prevent Disease](#)

[Gene Panel Helps Predict Alcoholism Risk](#)

Genome Advance of the Month

[The Y Chromosome: Beyond Gender Determination](#)

NHGRI Media Availability

[New Approach to Analyzing Tumor Genome Promises Expanded Results](#)

NIH News of Interest

[Mining the Big Data Mountain: NIH Director's Blog](#)

[Your DNA Enters the Digital Age: Q&A with NIH Director](#)

[Policy: NIH to Balance Sex in Cell and Animal Studies](#)

[NIH Associate Director for Data Science (ADDS): Blog](#)

[NIH Director: Recombinant DNA Advisory Committee](#)

NIH Funding News

[Piloting Modified NIH Biosketches](#)

NIH Funding Opportunities

[Centers of Excellence in Genomic Science (RM1)](#)

[Center for Inherited Disease Research High Throughput Sequencing and Genotyping Resource Access (X01)](#)

[Pharmacogenomics Knowledge Base (R24)](#)

[NIH Science Education Partnership Award (R25)](#)

[IDeA Networks of Biomedical Research Excellence (P20)](#)

Upcoming Webcast

[NIH Common Fund 10-Year Commemoration Symposium](#) – June 19

New Genomics Videos

[NHGRI Advisory Council Meeting](#) – May 19

[The Cancer Genome Atlas 3rd Annual Scientific Symposium](#) – May 12-13

[The Human Genomics Landscape: Bringing Genomic Medicine into Focus](#) – Eric Green

[Genomic Approaches to the Study of Complex Genetic Diseases](#) – Karen Mohlke

[The Search for Mendelian Disease Genes: Opportunities Afforded, Lessons Learned](#) – David Valle

[Pharmacogenomics](#) - Howard McLeod

[Large-Scale Expression Analysis](#) – Paul Meltzer

[Genomic Medicine](#) – Bruce Korf

[Genetic Testing for Neurological Diseases](#) – Kurt Fischbeck

[Uses and Misuses of Clinical Genetic Testing in Psychiatry](#) – Francis McMahon

[Individualized Care, Genome Analysis Are the Future of Medicine](#) – Francis Collins

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