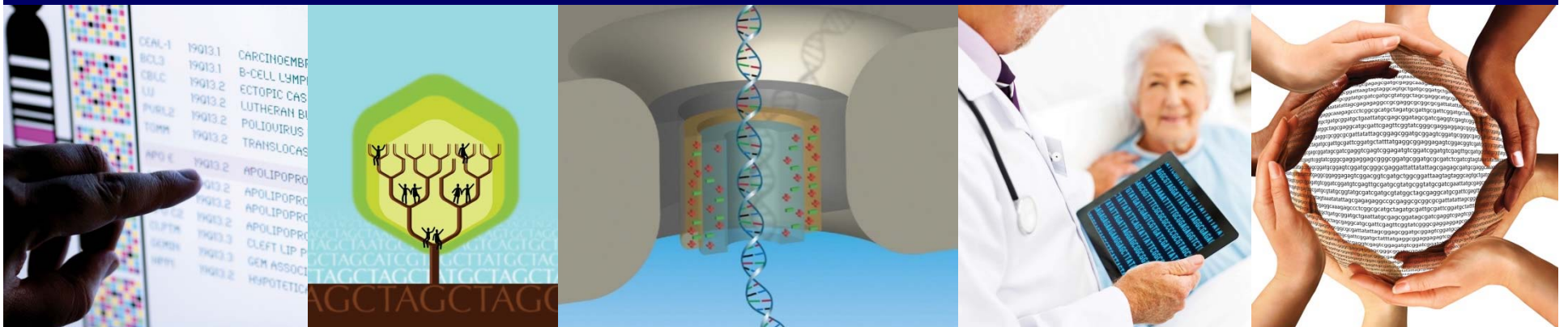


# DIRECTOR'S REPORT

## National Advisory Council for Human Genome Research

February 2018

Eric Green, M.D., Ph.D.  
Director, NHGRI



## Director's Report-Related Documents: February 2018

**Director's Report**



**Director's Report**



No.	Relevant Documents
1	<p>2017 Prince Mahidol Award</p> <p>Prince Mahidol Award</p> <p>Prince Mahidol Award Conference</p> <p>NIH News Release</p> <p>Award Ceremony Video</p> <p><i>Bangkok Post</i> Article</p> <p><i>The Nation</i> Article</p>
2	New Director, Division of Genome Sciences

[genome.gov/DirectorsReport](http://genome.gov/DirectorsReport)



Document #

# Open Session Presentations

- **En Route to a “2020 Vision for Genomics”:  
The Next Round of NHGRI Strategic Planning**  
**Eric Green**
- **Updates from Building 1: Next Generation  
Researchers Initiative and Clinical Trial Reforms**  
**Michael Lauer**
- **Concept Clearance: Novel Nucleic Acid  
Sequencing Technology Development**  
**Michael Smith**

# Open Session Presentations

- **Report: The Human Microbiome Project**  
**Lita Proctor**
- **Report: Recommendations from the 2017  
eMERGE and Beyond Workshop**  
**Sharon Plon**
- **NCBI in a Data-Enabled World**  
**Jim Ostell**

# Director's Report Outline

- I. General NHGRI Updates
- II. General NIH Updates
- III. General Genomics Updates
- IV. NHGRI Extramural Research Program
- V. NIH Common Fund/Trans-NIH
- VI. NHGRI Division of Policy,  
Communications, and Education
- VII. NHGRI Intramural Research Program

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# 2017 Prince Mahidol Award

## Field of Medicine: Human Genome Project



# **New Director, Division of Genome Sciences**



**Carolyn Hutter, Ph.D.**



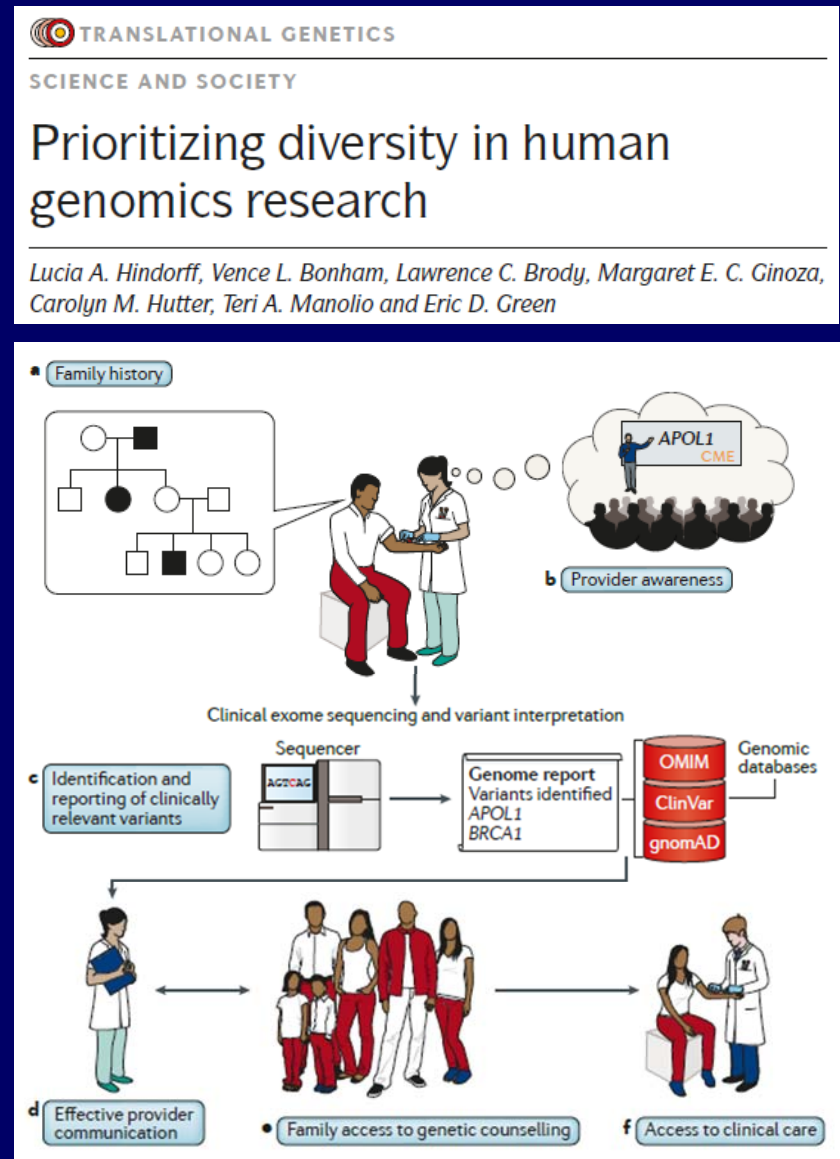
# Departure of NHGRI Program Director



**Lu Wang, Ph.D.**

# NHGRI Perspective: Prioritizing Diversity

- Published in *Nature Reviews Genetics*
- Highlights importance of diversity at all levels of research
- Focuses on lessons learned and near-term recommendations
- Reddit AMA in December



# American Indian and Alaska Native Communities and Genomics Research

- New guide to genetics and genomics research for tribal communities
- Discusses key aspects of genetics and genomics research, with examples



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# New Secretary, Department of Health and Human Services



**Alex Azar, J.D.**



# New Director, National Cancer Institute



**Ned Sharpless, M.D.**



# New Director, National Center for Biotechnology Information



**Jim Ostell, Ph.D.**



# New Scientific Director, National Institute on Minority Health and Health Disparities



**Anna María Nápoles,  
Ph.D., M.P.H.**



# Roderic Pettigrew Departs as Director, National Institute of Biomedical Imaging and Bioengineering



**Roderic Pettigrew,  
Ph.D., M.D.**



**Jill Heemskerk,  
Ph.D.**

# Lasker~DeBakey Clinical Medical Research Award



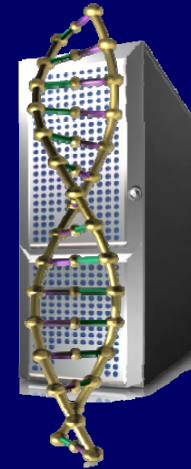
**John Schiller, Ph.D. & Doug Lowy, M.D.**

# Updating Access to Genomic Summary Results



National Institutes of Health  
Office of Science Policy

**Genomic Data Sharing**



- Update the access procedures for Genomic Summary Results (GSR) under NIH Genomic Data Sharing Policy
- Proposed update:
  - GSR from *most* genomic studies to be available through a new 'rapid access' tier
  - GSR from 'sensitive studies' to remain accessible through controlled access

# Delay in Common Rule Implementation

**The Common Rule, Updated** N ENGL J MED 376;7 NEJM.ORG FEBRUARY 16, 2017

Jerry Menikoff, M.D., J.D., Julie Kaneshiro, M.A., and Ivor Pritchard, Ph.D.

For the first time since it was issued in 1991, the Common Rule — the set of federal regulations for ethical conduct of human-subjects research — has been updated. Most of the requirements, many of which increase flexibility, will take effect in 2018, which gives institutions a year to work toward implementation.

The public saw the beginnings of this effort in 2011, when the Department of Health

submitted, from a fairly wide swath of the public, including individuals, institutions, and scientists, proposals and suggestions. These comments, and a report from the National Academies of Sciences, Engineering, and Medicine,<sup>3</sup> led to a long process of deliberation and discussion. The result is a final rule that differs significantly from what was initially proposed.

Most notably, the new rule does not adopt the proposal to

implementing this proposal could significantly harm the ability to do important research, without producing any substantial off-setting benefits. The public response was particularly noteworthy, given that the premise behind the proposal was specifically tied to public sentiment: the NPRM had stated that continuing to allow research on unidentified biospecimens without consent would place “the publicly-funded research establishment in

**DELAYED**

- Interim final rule delays effective date to July 19, 2018
- Institutions can begin implementing some provisions now
- A notice of proposed rulemaking will likely propose a further delay

# New Policy on Certificates of Confidentiality (CoCs)

The screenshot shows the NIH Certificates of Confidentiality (CoC) Kiosk website. At the top, there is a navigation bar with the NIH logo and the text "National Institutes of Health Certificates of Confidentiality (CoC) Kiosk". To the right of the logo, there are links for "Home", "Select Your Funder", "Suggested Consent Language", "CoC Assurance Template", and "CoC Coordinators". A search bar is also present with the text "FAQs | Human Subjects Home". Below the navigation bar, there is an orange banner with the text: "Effective Oct 1, 2017, NIH will automatically issue CoCs to all research funded by NIH that is collecting or using identifiable, sensitive information. New disclosure rules apply to everyone. [Learn more!](#)". The main content area has a light blue background. On the left, there is a section titled "Certificates of Confidentiality (CoC)" with a paragraph of text explaining the purpose of CoCs. Below this text are two buttons: "Learn more about CoCs" and "Extend or Amend CoC". On the right side of the main content area, there is a graphic featuring a shield with "CoC" written on it, and a collage of images related to research, including a scientist in a lab, a DNA helix, and a group of people.

- **New CoC policy to provide additional privacy protections to research participants**
- **Policy covers all applicable ongoing and new research funded by NIH on or after December 13, 2016**
- **Investigators issued CoCs are prohibited from disclosing identifying information about participants**

# Budget Update

FUNDING FEDERAL GOVERNMENT THROUGH MARCH 23

**H R 1892**

	<b>YEA</b>	<b>NAY</b>	<b>PRES</b>	<b>NV</b>
<b>REPUBLICAN</b>	228	8		2
<b>DEMOCRATIC</b>	17	174		2
<b>INDEPENDENT</b>				
<b>TOTALS</b>	245	182		4

**TIME REMAINING 0:00**

**U.S. House**

**C-SPAN**  
c-span.org  
@cspan

# NIH Appropriations

	Fiscal Year 2017 Budget	Fiscal Year 2018 Senate Appropriations Labor-HHS Spending Bill
NIH	\$34.1 B	\$36.1 B
NHGRI	\$528 M	TBD

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# Mourning the Loss of Arno Motulsky



# George Cunningham Visionary Award in Newborn Screening



**Jeff Botkin,  
M.D., M.P.H.**



**American Public  
Health Laboratory  
Association**

# Brotman Baty Institute for Precision Medicine Launched



**Jay Shendure, M.D., Ph.D.**

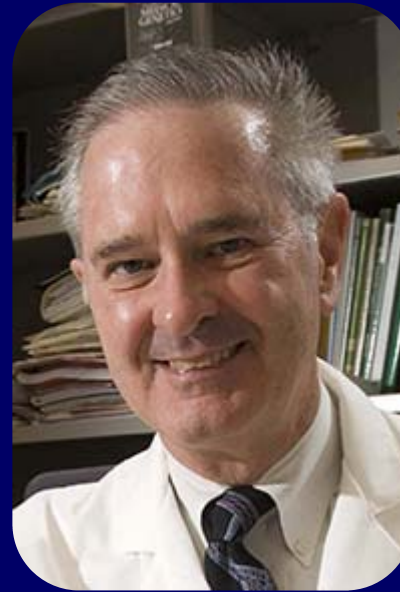
# 2017 ASHG Awards



**Kári  
Stefánsson,  
M.D.**



**Arthur  
Beaudet,  
M.D.**



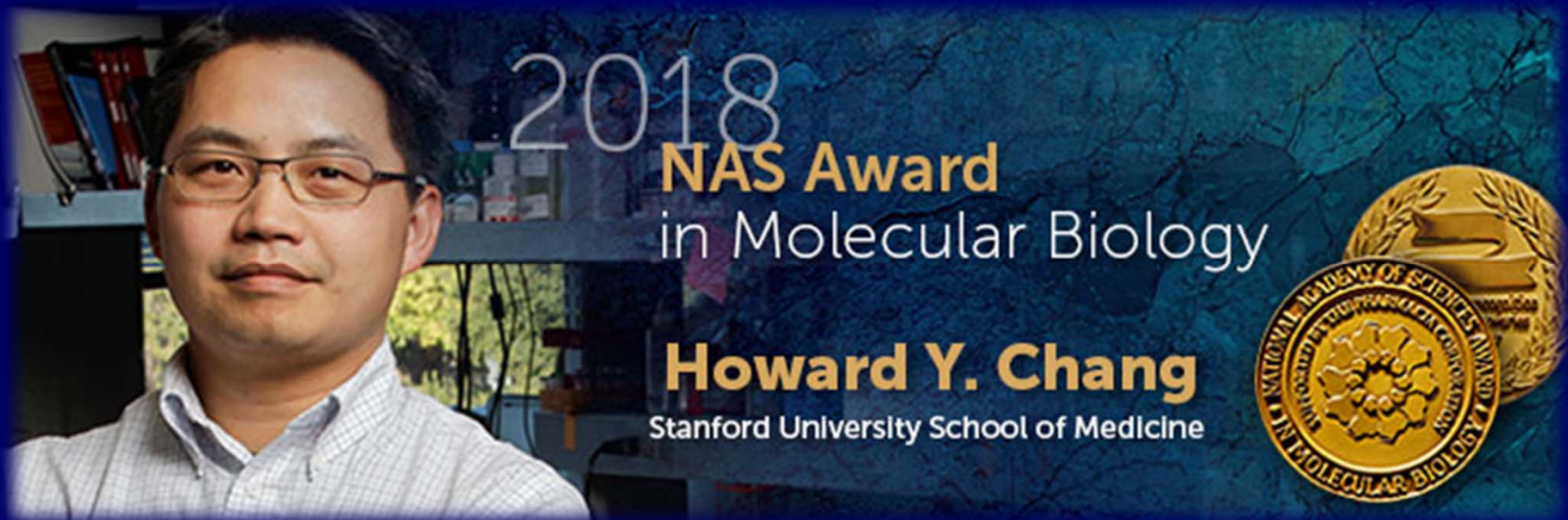
**John  
Mulvihill,  
M.D.**



**Daniel  
MacArthur,  
Ph.D.**



# National Academy of Sciences Award in Molecular Biology



# Elected to National Academy of Medicine

**Cori Bargmann**

**Howard Chang**

**Mark Daly**

**Josh Denny**

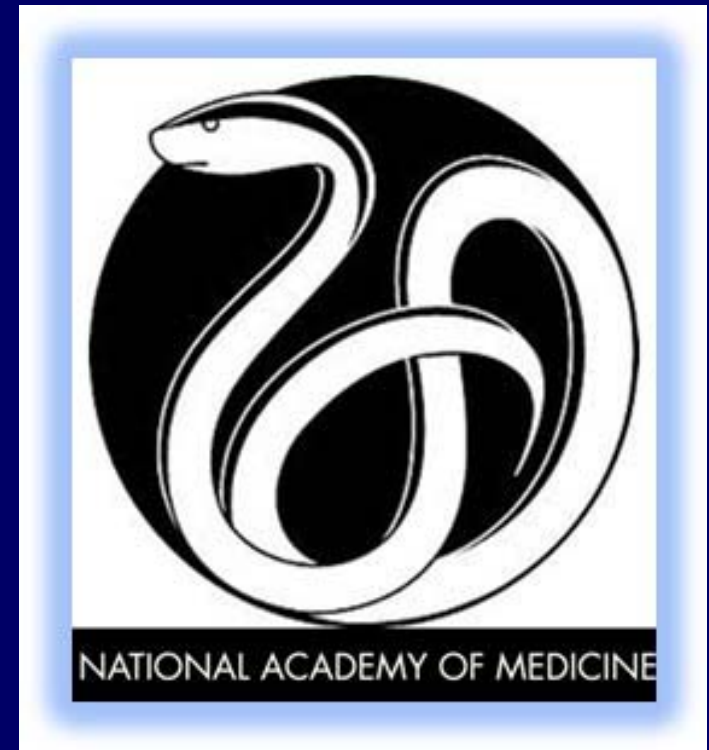
**Karen DeSalvo**

**Evan Eichler**

**Christine Grady**

**Chanita Hughes-Halbert**

**George Koob**



# Elected to AAAS

**Susan Dutcher**

**Joshua Gordon**

**Gail Jarvik**

**Hongzhe Li**

**Mona Miller**

**Bhramar Mukherjee**

**Griffin Rodgers**

**Michelle Southard-Smith**

**Monte Westerfield**



# New Vice President for Genomic Research at AbbVie



**Howard Jacob, Ph.D.**



# 2017 Science Breakthrough of the Year Runners Up

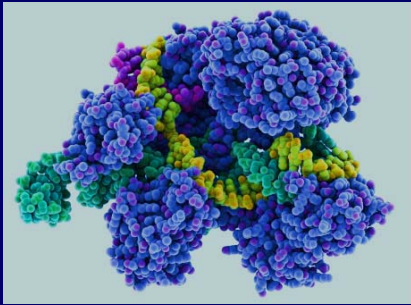


*Pinpoint Gene Editing*

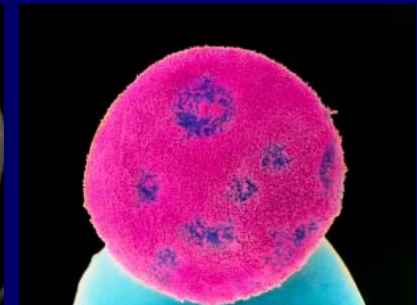
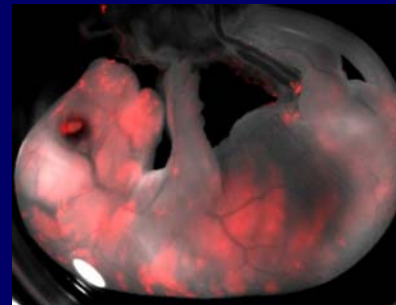
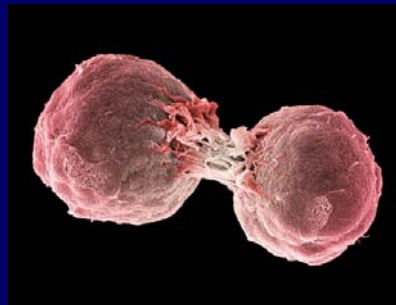
*Cancer Drug's Broad Swipe*

*Gene Therapy Triumph*

# 2017 *Nature* Science Events that Shaped the Year

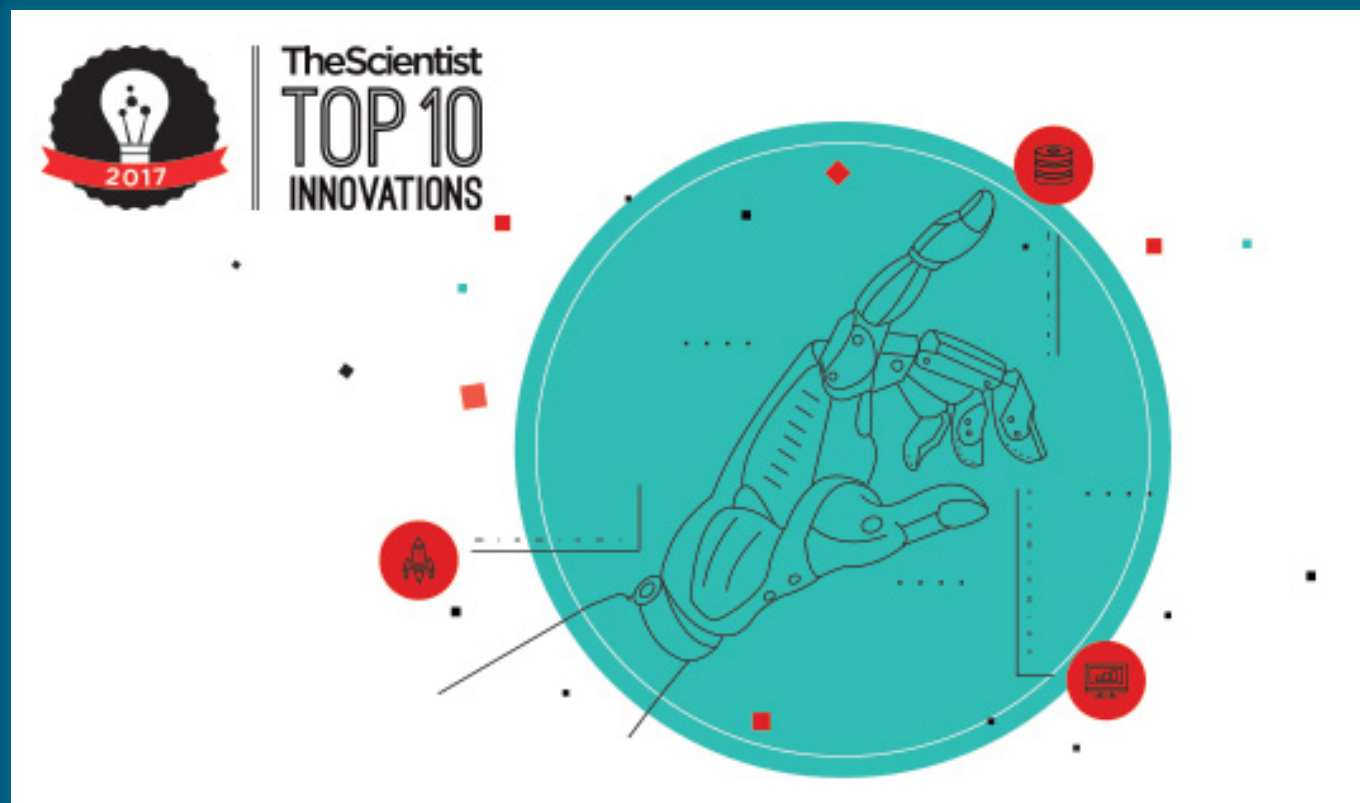


**nature**  
International weekly journal of science



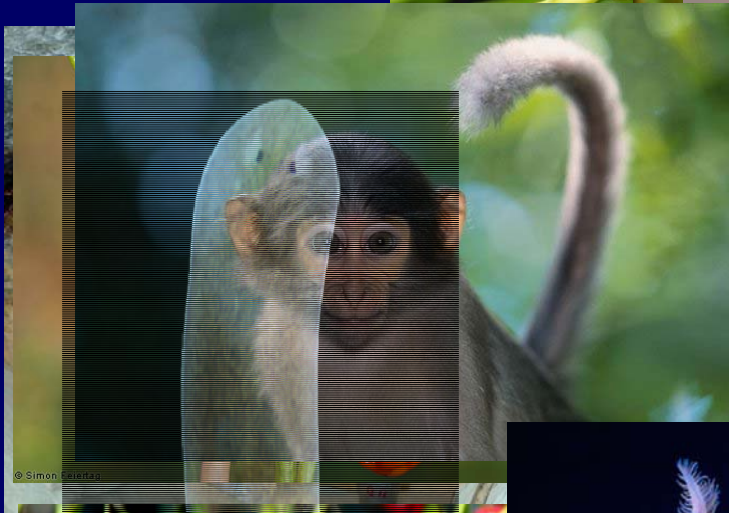
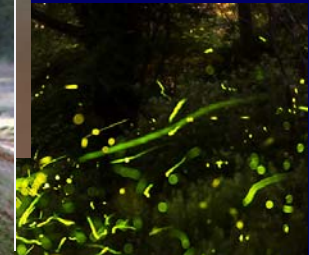
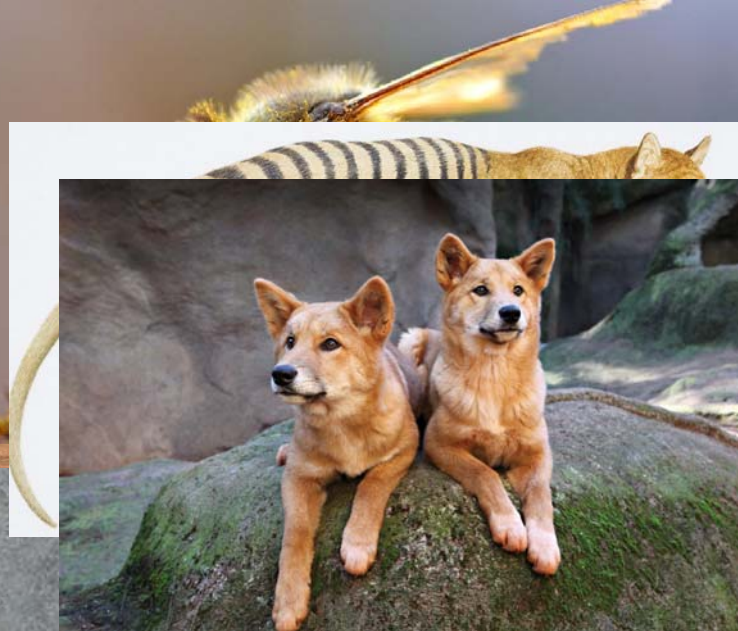
## Genetics Bonanza

# *The Scientist's* Top Ten Innovations 2017



**Dharmacon** | Edit-R crRNA Library—Human Genome  
**10x Genomics** | Chromium  
**Thermo Fisher Scientific** | Invitrogen TrueCut Cas9 Protein v2

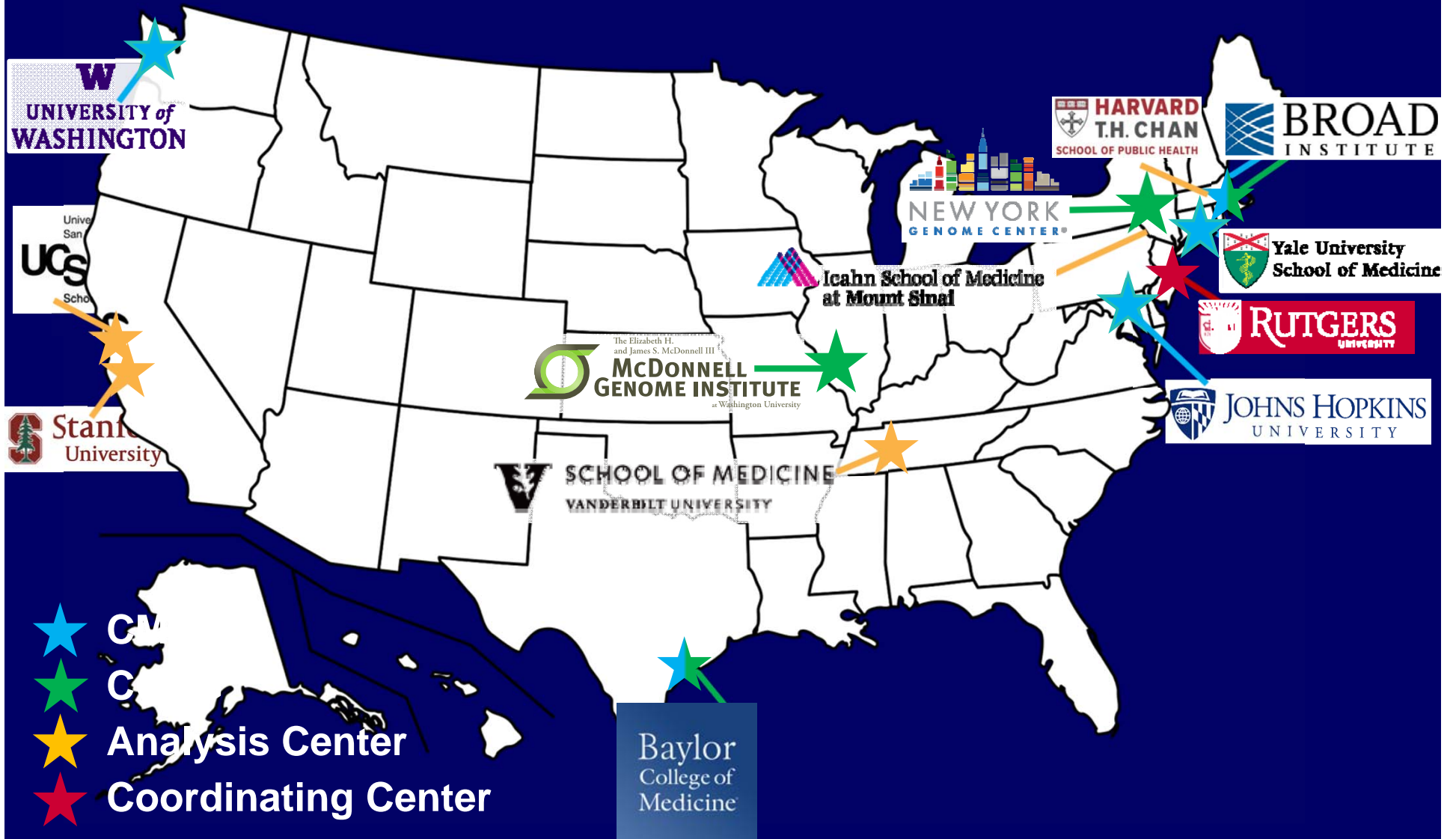
# Genomes In The News...



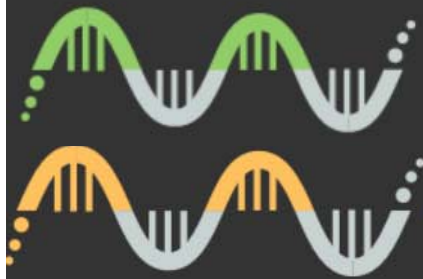
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# Genome Sequencing Program



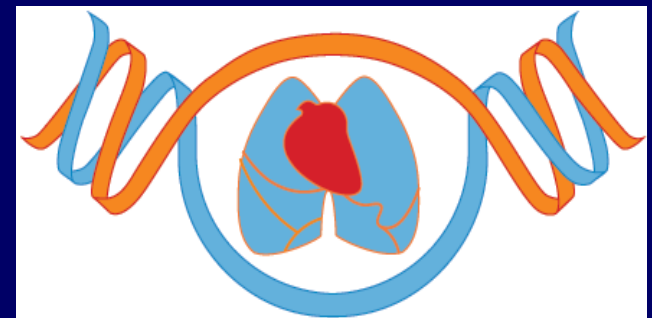
# Genome Sequencing Program



Centers for Common Disease Genomics

Genome Sequencing Program Analysis Centers

- 51,000 whole genomes and 38,000 whole exomes
- Freeze 1 data (20,000 WGS) delivered to the consortium
- Collaboration with NHLBI's TOPMed Program on joint data calls and analyses
- GSP-TOPMed joint analysis workshop at Vanderbilt



# Genome Sequencing Program

Centers for Mendelian Genomics 

*Finding the genes underlying human Mendelian conditions*

- **>2,600 conservative or suggestive genes implicated**
- **Public list of phenotypes and genes**
- **65 presentations at 2017 ASHG Meeting**
- **>400 publications co-authored with researchers and patient families**
- **Data are included in driver projects for GA4GH**



# Technology Development Program



## Advanced Genomic Technology Development Meeting

- **Grantee Meeting: May 30-31, 2018**
- **Public Meeting: June 1, 2018**



# ENCyclopedia Of DNA Elements (ENCODE)



**February 2018 in Palo Alto, California**

**Document 28**




# ENCyclopedia Of DNA Elements (ENCODE)

## ENCODE Enabling Gene Therapy Clinical Trials

### An Erythroid Enhancer of *BCL11A* Subject to Genetic Variation Determines Fetal Hemoglobin Level

Daniel E. Bauer,<sup>1,2,3</sup> Sophia C. Kamran,<sup>3,4</sup> Samuel Lessard,<sup>5</sup> Jian Xu,<sup>1,3</sup> Yuko Fujiwara,<sup>1</sup> Carrie Lin,<sup>1</sup> Zhen Shao,<sup>1</sup> Matthew C. Canver,<sup>3</sup> Elenoe C. Smith,<sup>1</sup> Luca Pinello,<sup>6</sup> Peter J. Sabo,<sup>7,8</sup> Jeff Vierstra,<sup>7,8</sup> Richard A. Voit,<sup>9</sup> Guo-Cheng Yuan,<sup>6,10</sup> Matthew H. Porteus,<sup>9</sup> John A. Stamatoyannopoulos,<sup>7,8</sup> Guillaume Lettre,<sup>5</sup> Stuart H. Orkin<sup>1,2,3,4\*</sup>

### Functional footprinting of regulatory DNA

Jeff Vierstra, Andreas Reik, Kai-Hsin Chang, Sandra Stehling-Sun, Yuanyue Zhou, Sarah J Hinkley, David E Paschon, Lei Zhang, Nikoletta Psatha, Yuri R Bendana, Colleen M O'Neil, Alexander H Song, Andrea K Mich, Pei-Qi Liu, Gary Lee, Daniel E Bauer, Michael C Holmes, Stuart H Orkin, Thalia Papayannopoulou, George Stamatoyannopoulos, Edward J Rebar, Philip D Gregory, Fyodor D Urnov  & John A Stamatoyannopoulos 

### Sangamo And Bioverativ Announce FDA Acceptance Of IND Application For ST-400 -- A Gene-Edited Cell Therapy Candidate -- To Treat Beta- Thalassemia

INVESTORS & MEDIA

INVESTORS & MEDIA / NEWS RELEASE

NEWS RELEASE

[<< Back](#)

CRISPR Therapeutics Submits First Clinical Trial Application for a CRISPR Gene-Edited Therapy, CTX001 in  $\beta$ -thalassemia

-Phase 1/2 trial in  $\beta$ -thalassemia expected to begin in 2018-

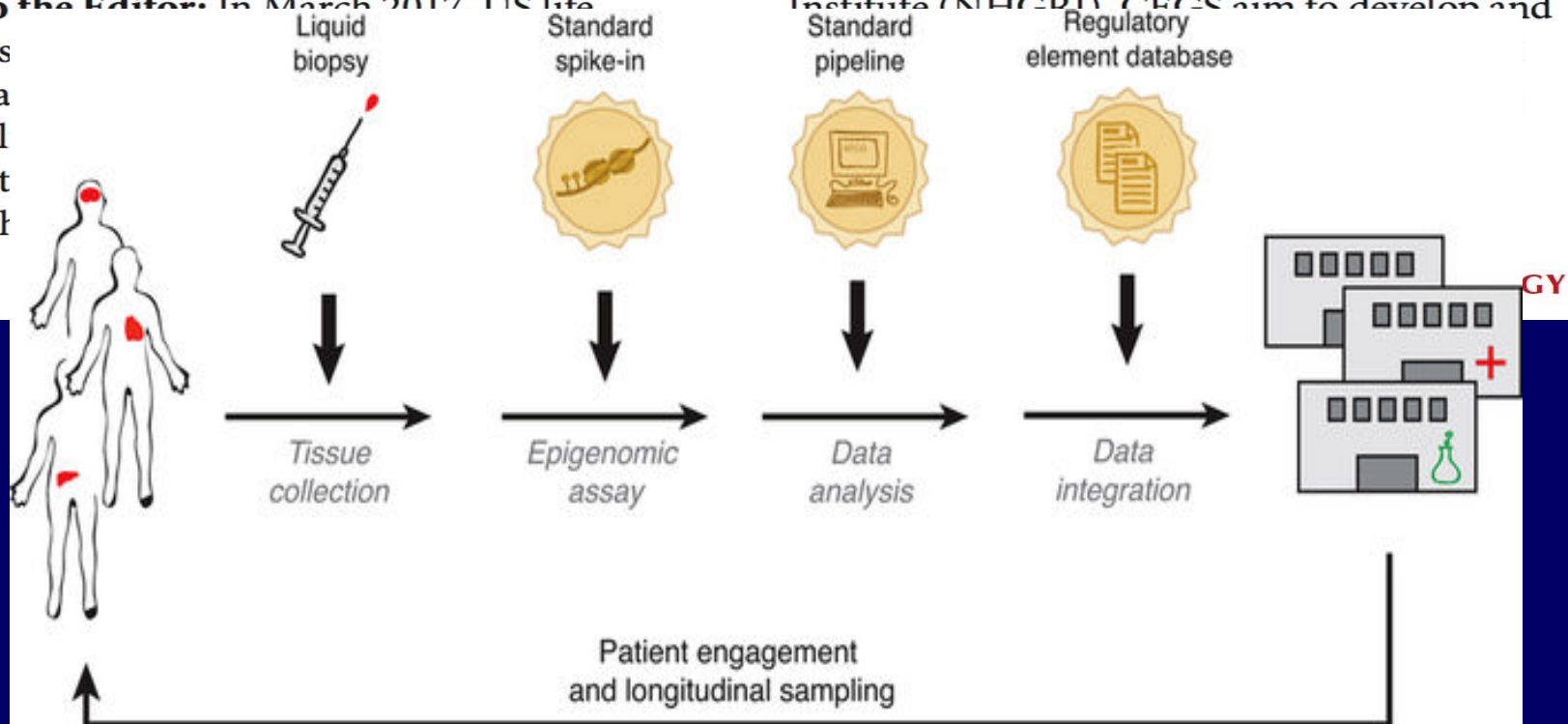
# Centers of Excellence in Genomic Science (CEGS) Program

## Challenges and recommendations for epigenomics in precision health

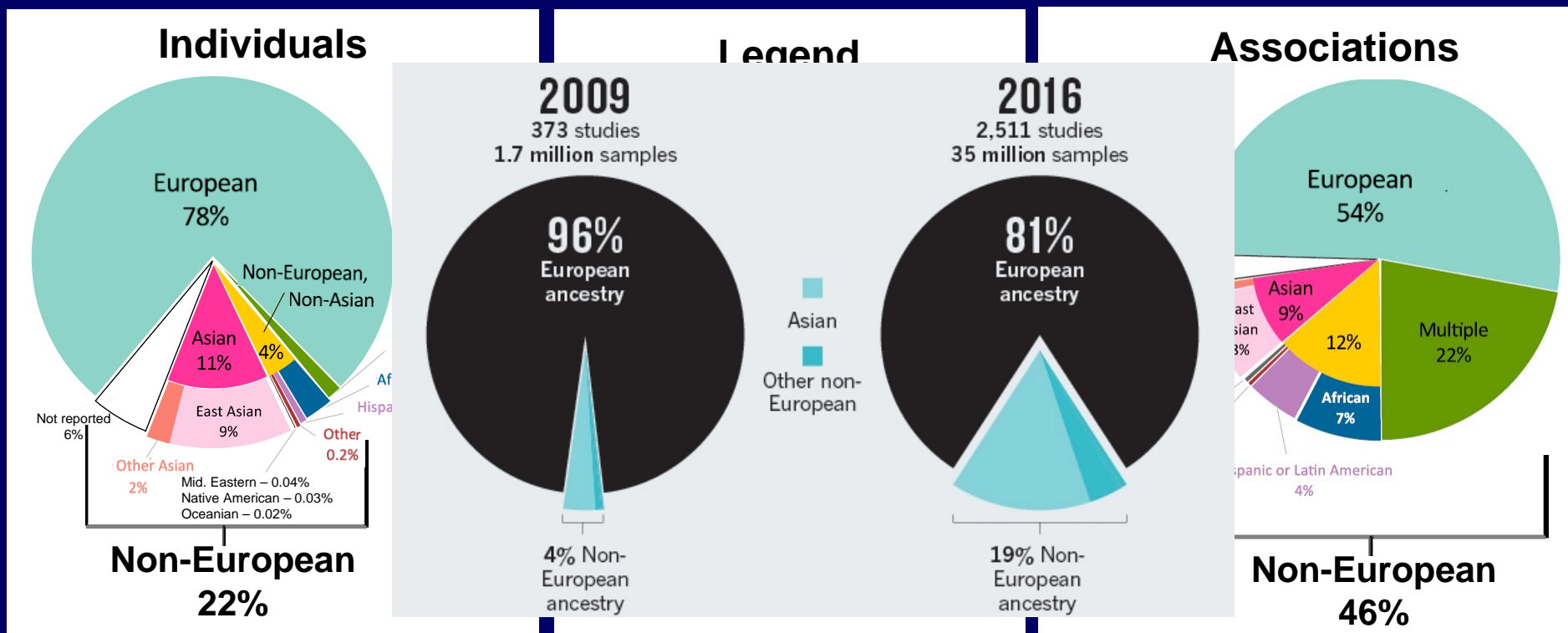
To the Editor: In March 2017, US life

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Institute (NHGRI). CEGS aim to develop and



# Ancestry in the GWAS Catalog



- Bias toward European participants remains (78%)
- Non-European populations contribute disproportionately more associations

# PhenX Toolkit: Chinese Translations

- Dr. Jim Zhang, Shanghai Jiao Tong University
- 294 protocols from 21 PhenX research domains

1. What race or races do you consider yourself to be? Please select one or more.

· 6 · 标准健康问卷和人体测量方法

1. What race or races do you consider yourself to be? Please select one or more.

**MEASURE:** Race #010600

## Definition:

Question asking the respondent his or her race. U.S. Office of Management and Budget (OMB) standards for the classification of federal data on race and ethnicity state that "race and ethnicity may be thought of in terms of social and cultural characteristics as well as ancestry."

## Purpose:

Race is used to stratify study populations and to associate those populations with physical, geographic, biological, social, and cultural characteristics (e.g., African Americans). Race is a social and epidemiological factor, and individuals of some races are at greater risk for certain diseases.

[ ] OTHER  
99 [ ] DON'T KNOW  
77 [ ] REFUSED

# eMERGE and Beyond: The Future of EHR and Genomics Workshop



- **Develop better phenotyping methods and technologies**
- **Build pipelines to automatically interpret/reinterpret genomic variants and to integrate data into EMRs**
- **Promote shareable electronic clinical decision support**
- **Generate evidence for genomic medicine**

*Article*

## **Ethical Considerations Related to Return of Results from Genomic Medicine Projects: The eMERGE Network (Phase III) Experience**

Robyn Fossey <sup>1</sup>, David Kochan <sup>1</sup>, Erin Winkler <sup>2</sup>, Joel E. Pacyna <sup>3</sup>, Janet Olson <sup>3</sup>, Stephen Thibodeau <sup>4</sup>, John J. Connolly <sup>5</sup>, Margaret Harr <sup>5</sup>, Meckenzie A. Behr <sup>5</sup>, Cynthia A. Prows <sup>6</sup>, Beth Cobb <sup>6</sup>, Melanie F. Myers <sup>6</sup>, Nancy D. Leslie <sup>6</sup>, Bahram Namjou-Khales <sup>6</sup>, Hila Milo Rasouly <sup>7</sup>, Julia Wynn <sup>8</sup>, Alexander Fedotov <sup>9</sup>, Wendy K. Chung <sup>10</sup>, Ali Gharavi <sup>7</sup>, Janet L. Williams <sup>11</sup>, Lynn Pais <sup>12</sup>, Ingrid Holm <sup>13</sup>, Sharon Aufox <sup>14</sup>, Maureen E. Smith <sup>14</sup>, Aaron Scrol <sup>15</sup>, Kathleen Leppig <sup>15</sup>, Gail P. Jarvik <sup>16</sup>, Georgia L. Wiesner <sup>17</sup>, Rongling Li <sup>18</sup>, Mary Stroud <sup>19</sup>, Jordan W. Smoller <sup>20</sup>, Richard R. Sharp <sup>3</sup> and Iftikhar J. Kullo <sup>1,\*</sup>

- **Examined the Institutional Review Board (IRB) process at 9 academic institutions**
- **Information can help investigators more effectively engage with IRBs**





# Clinical Genome Resource

## Phase 2

- **Multi-PI Teams**

J. Berg, K. Goddard, M. Watson, & M. Williams

C. Bustamante & S. Plon

H. Rehm, D. Ledbetter, & C. Martin

- **Goals**

Accelerate curation and expand to new disease areas

Develop quantitative approaches to enhance the  
ACMG sequence variant interpretation guidelines

Define consent and disclosure recommendations





# Clinical Genome Resource

## Collaborations



### Hematology Curation

- Myeloid Malignancies
- Genetic Platelet Disorders



### Child Health Curation

- Brain Malformations
- Mitochondrial Disorders
- Maturity Onset Diabetes of the Young

# Clinical Sequencing Evidence-Generating Research Program

## CSER Working Groups

- **Clinical Utility, Health Economics, & Policy**
- **ELSI & Diversity**
- **Education & Return of Results**
- **Survey Measures & Outcomes**
- **Patient, Community, & Clinical Stakeholder Engagement**
- **Sequence Analysis & Diagnostic Yield**

# Newborn Sequencing In Genomic medicine and public Health (NSIGHT)



John Francis Peters for TIME

Elizabeth and Tristan Holbrook spend time with their newborn daughter Grace, Rady Children's Hospital, San Diego, CA, July 18, 2017



John Francis Peters for TIME

Dolores Seban with her daughter Sebastiana Guadalupe Manuel, Fallbrook, CA, July 24th 2017

*Time* ( October 2, 2017)

# Computational Genomics and Data Science Program



## NHGRI Meeting of the AGR and MODs Spring 2018

- Assess the progress of the AGR
- Discuss future directions of the AGR and MODs

### External Scientific Panel

Mark Johnston (U. Colorado)

Owen White (U. Maryland)

Valerie Reinke (Yale U.)

Hugo Bellen (BCM)

Jim Ostell (NLM)

Bill Pavan (NHGRI)

# 4<sup>th</sup> iDASH Genomic Privacy Challenge



October  
2017

- **Challenge tasks: (1) de-duplicating patient identifiers, (2) secure GWAS, (3) machine learning with genotype & phenotype data**
- **Industry partners: Microsoft Research & Intel**
- **Wang et al. paper in *Genomic Medicine* (2017): “A community effort to protect genomic data sharing, collaboration and outsourcing”**

# Small Business Grants



<u>Small Business</u>	<u>Phase I</u> Proof of Principle	<u>Phase II</u> Pre- Commercialization
Innovation Research (SBIR)	<b>19</b>	<b>13</b>
Technology Transfer (STTR)	<b>5</b>	<b>1</b>

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# Human Microbiome Project

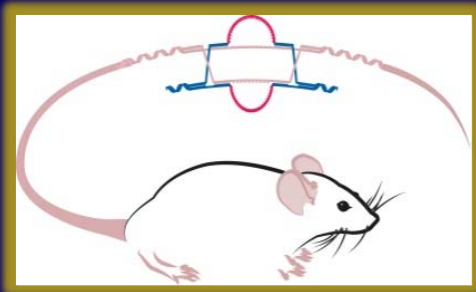
2007-2017, \$215M

Community Resource Effort



Open Session Presentation

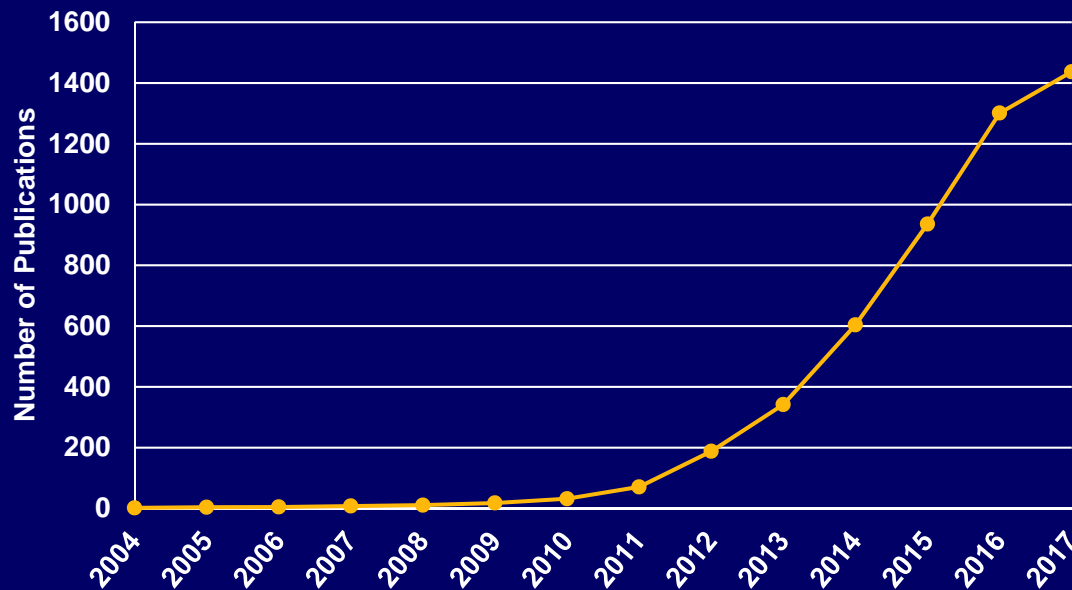
# Knockout Mouse Phenotyping Project (KOMP2)



- **KOMP-CMG Joint Meeting at ASHG 2017**
- **Articles in *Nature Communications***
  - “A large scale hearing loss screen reveals an extensive unexplored genetic landscape for auditory dysfunction”
  - “Identification of genetic elements in metabolism by high-throughput mouse phenotyping”

# Knockout Mouse Phenotyping Project (KOMP2)

Publications using KOMP2/IMPC Resources




the ONION | POLITICS SPORTS LOCAL ENTERTAINMENT OPINION VIDEO CLICKHOLE


AMERICAN VOICES


## Scientist Find Genetic Basis For Bad Breath

Yesterday 9:42am · SEE MORE OPINION ▾

By studying a range of individuals with persistent cabbage-scented breath, scientists have isolated a gene called *SELENBP1* that generates sulphur-containing molecules and results in bad breath. What do you think?

 “Ugh—Fine, I’ll cut down on the amount of *SELENBP1* I’ve been eating.”  
STEPHEN WEST · URINAL CAKE REPLACER

 “This is a huge win for supporters of eugenics.”  
NICHOLE BIANCHI · FOOT STYLIST

 “It’s good to know it’s my unchangeable genetics, and not some personal failing, that’s made me repellent to people.”  
TIM BANKS · WIND CHIME JINGLER

- >1,400 publications using KOMP2 resources from 2004-2017
- KOMP *SELENBP1*-knockout mouse used to confirm genetic variation that causes extra-oral halitosis

# Genotype-Tissue Expression (GTEx)



nature.com > collection

MENU ▾

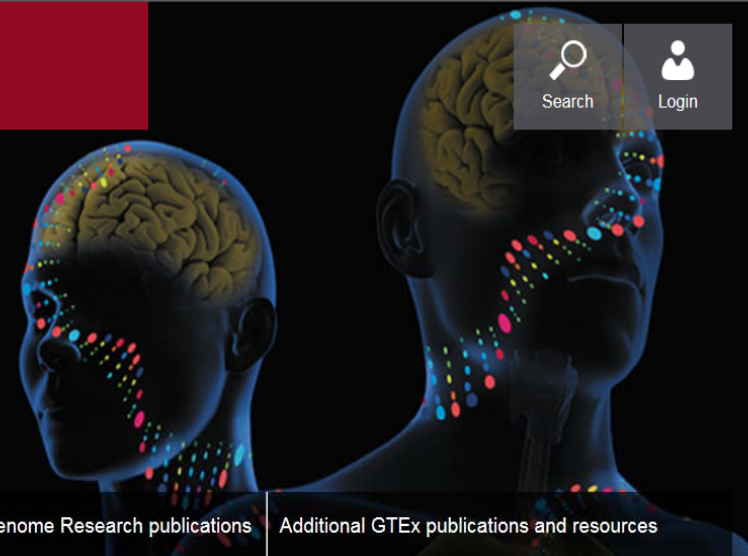
nature.com

Search

Login

Collection

## The Genotype-Tissue Expression project



[Collection home](#)

[News & Commentary](#)

[Research](#)

[Methods publications](#)

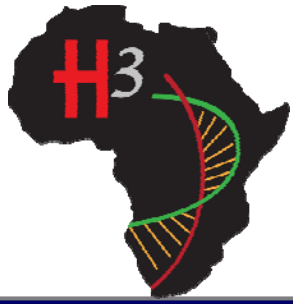
[Genome Research publications](#)

[Additional GTEx publications and resources](#)

### A more personal gene expression catalogue

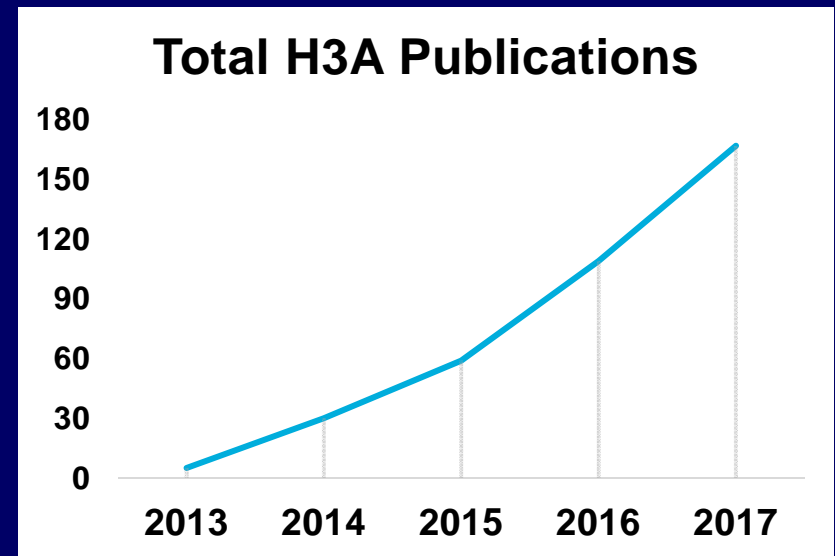
We meet a new frontier in biomedical research with publications from the Genotype-Tissue Expression (GTEx) Consortium, that of cataloguing genetic variation and its influence on gene expression within and between all major tissues in the human body. The GTEx project was proposed in 2008 with the lofty goals of establishing a resource database and associated tissue biobank to study the relationship between genetic variation and gene expression in all major human tissues across 1000 individuals. This nearly decade long



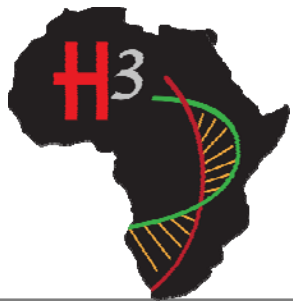


# Human Heredity and Health in Africa (H3Africa)

- 10<sup>th</sup> Annual Meeting of the African Society of Human Genetics in November 2017 (Egypt)



- 11<sup>th</sup> Consortium Meeting in March 2018 (Uganda)



# Human Heredity and Health in Africa (H3Africa)

## Stage II Awards (Fall 2017)

Funded Initiative	Funding ICs	Participating African Countries
Coordinating Center	Common Fund, FIC, NCI, NEI, NHGRI, NICHD, NIDCD, NIDDK, NIEHS, NHLBI, NIMH, NINDS, OAR, ORWH	South Africa, Morocco, Zimbabwe, Botswana, Egypt, Nigeria, Sudan, Senegal, Tunisia, Ghana, Malawi, United Republic of Tanzania, Uganda, Mauritius, Mali, Kenya, Cameroon, Swaziland, Gambia, Sierra Leone, Rwanda, Democratic Republic of the Congo
Bioinformatics Network		
Bioinformatics Training Program		
Collaborative Centers		
Research Projects		
ELSI Collaborative Center		
ELSI Projects		

# Undiagnosed Diseases Network (UDN)



## UDN Applications and Acceptances



Applications Received



Applications Under Review



Applications Accepted



Participants Evaluated



Participants Diagnosed

Follow us on social media for real-time research updates.  
[udnconnect](#) and [@UDNconnect](#)





# Human BioMolecular Atlas Program (HuBMAP)



- New Common Fund Program
- RFA-RM-17-025: Transformative Technology Development
- RFA-RM-17-027: Tissue Mapping Centers
- **COMING SOON** – HuBMAP Integration, Visualization and Engagement (or HIVE)

# Somatic Cell Genome Editing



- **Develop quality tools to perform effective and safe genome editing in human patients**
- **Program elements: delivery systems, novel editors, improved assays for safety and efficacy, and a dissemination center**
- **Funding announcements published in January 2018**

# NIH Data Commons Pilot Phase

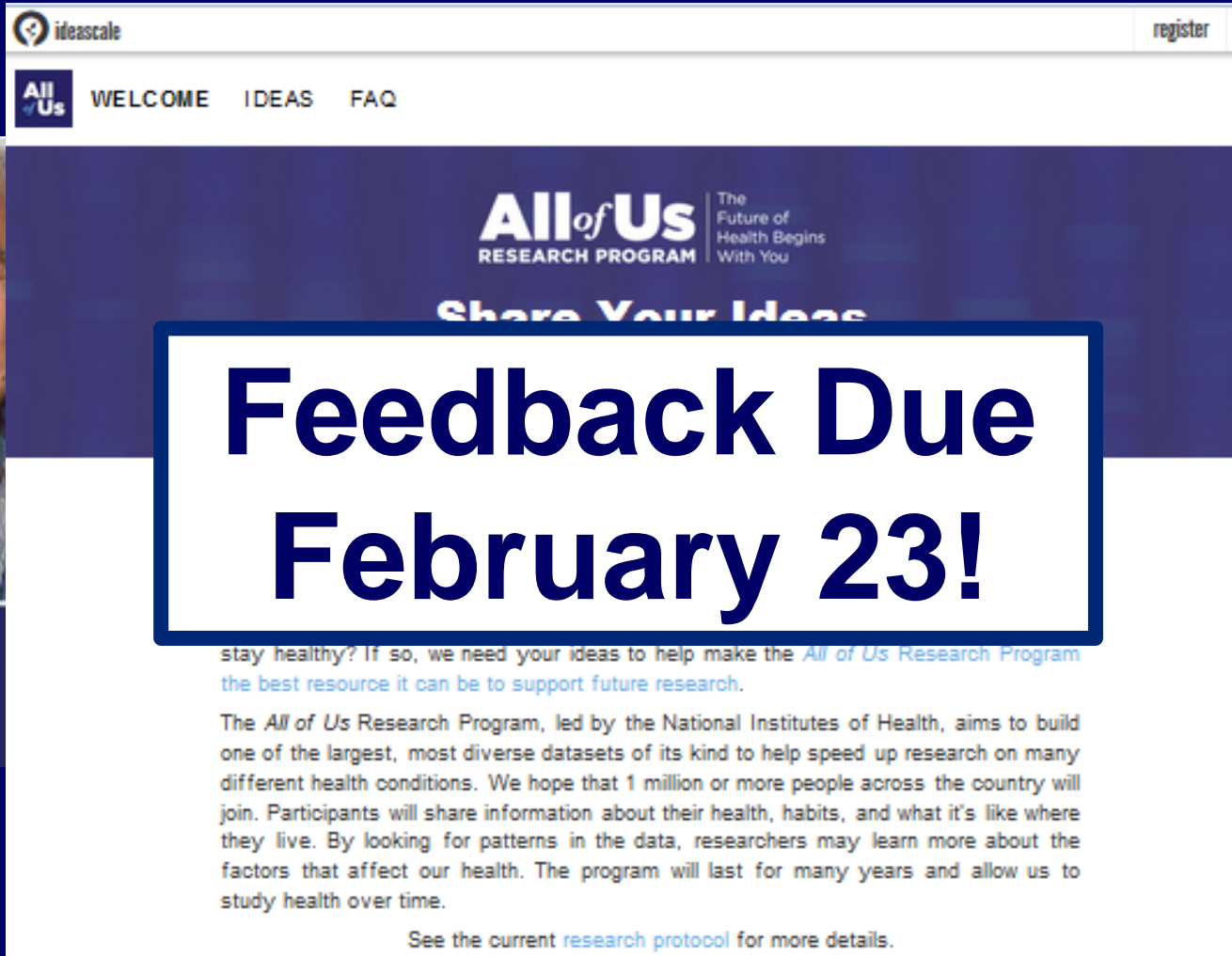
## Data Commons Pilot Phase OT Awardees

Stanley Ahalt, RENC1	Isaac Kohane, Harvard
Titus Brown, UC Davis	Avi Ma'ayan, Mt. Sinai
Merce Crosas, Harvard	Lucila Ohno-Machado, UCSD
Brandi Davis-Dusenbery, SevenBridges	Benedict Paten, UCSC; Robert Grossman, UChicago; Anthony Philippakis, Broad Institute
Ian Foster, UChicago	Owen White, UMD

## Datasets:



- **Pilot Phase Kickoff Meeting: December 2017**
- **Establishment of an NIH cloud 'marketplace'**



ideascale register

**All of Us** WELCOME IDEAS FAQ

**All of Us** | The Future of Health Begins With You  
RESEARCH PROGRAM

Share Your Ideas

# Feedback Due February 23!

stay healthy? If so, we need your ideas to help make the *All of Us* Research Program the best resource it can be to support future research.

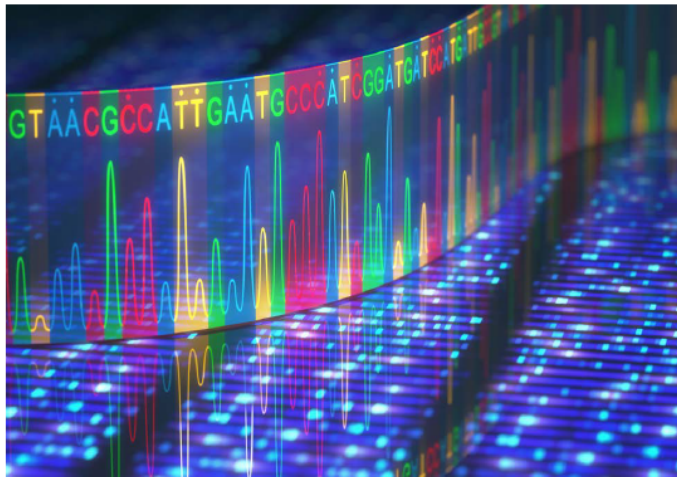
The *All of Us* Research Program, led by the National Institutes of Health, aims to build one of the largest, most diverse datasets of its kind to help speed up research on many different health conditions. We hope that 1 million or more people across the country will join. Participants will share information about their health, habits, and what it's like where they live. By looking for patterns in the data, researchers may learn more about the factors that affect our health. The program will last for many years and allow us to study health over time.

See the current [research protocol](#) for more details.



**All of Us**  
RESEARCH PROGRAM

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Considerations Toward a Comprehensive  
Genomics Strategy

The Genomics Working Group Report to the *All of Us* Research Program  
Advisory Panel

December 5, 2017

- **Genomics Working Group Report**
- **Considerations:**
  - Genome-wide genotyping
  - Exome sequencing
  - Whole-genome sequencing
- **Potential pilot of 50,000 participants**

# Director's Report Outline

- I. General NHGRI Updates
- II. General NIH Updates
- III. General Genomics Updates
- IV. NHGRI Extramural Research Program
- V. NIH Common Fund/Trans-NIH
- VI. NHGRI Division of Policy,  
Communications, and Education
- VII. NHGRI Intramural Research Program

# 2017 ASHG Meeting Policy Luncheon: FDA Oversight of Genomics Research



- Discussed FDA's Investigational Device Exemption (IDE) regulation for genomics studies

# Genomic Literacy, Education, and Engagement (GLEE) Initiative

Engaging Stakeholders to Promote Genomic Literacy

NIH SCIED 2017





# National DNA Day

## '15 for 15' Celebration



- 15 topics shared each day via social/digital media
- Partner engagement
- NHGRI-hosted events

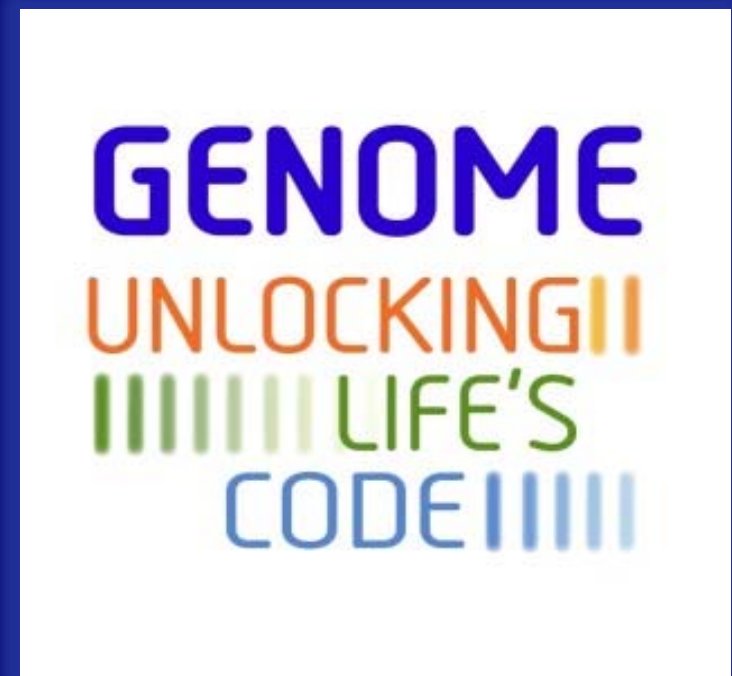
# ***Genome: Unlocking Life's Code* Exhibition**

## **Travel Schedule**

**2018**

**January 28-April 24**  
**Rochester Museum and**  
**Science Centre**  
**Rochester, NY**

**June 23-September 15**  
**Mayo Clinic**  
**Rochester, MN**



# Tribal Colleges Consortium on Genomics Training (TCCGT)

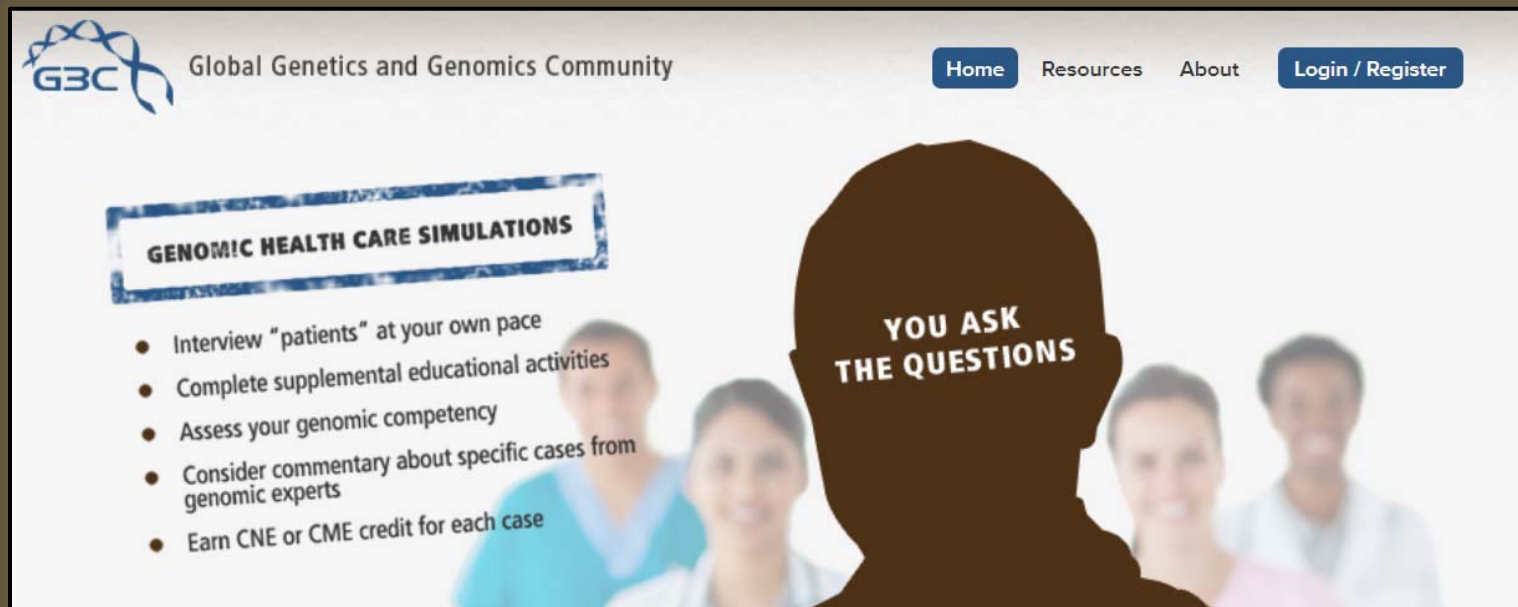


T C C G T



Tribal Colleges Consortium  
on Genomics Training

# Global Genetics and Genomics Community Case Study



The screenshot shows the website for the Global Genetics and Genomics Community. The header includes the GBC logo, the site name, and navigation links for Home, Resources, About, and Login/Register. The main content area features a section titled 'GENOMIC HEALTH CARE SIMULATIONS' with a list of bullet points and a silhouette of a person's head with the text 'YOU ASK THE QUESTIONS' inside it. The background of the page shows a group of diverse healthcare professionals.

**GENOMIC HEALTH CARE SIMULATIONS**

- Interview "patients" at your own pace
- Complete supplemental educational activities
- Assess your genomic competency
- Consider commentary about specific cases from genomic experts
- Earn CNE or CME credit for each case

**YOU ASK THE QUESTIONS**

- **New case study: Familial Hypercholesterolemia**
- **'Expert Commentary' provided by Robert Shamburek (NHLBI)**

# National Family Health History Day



# Inter-Society Coordinating Committee for Practitioner Education (ISCC)

## 7<sup>th</sup> In-Person Meeting



# Director's Report Outline

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Communications, and Education
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# Society for the Indian Academy of Medical Genetics S. S. Agarwal Oration Honor



**Les Biesecker, M.D.**





# **New Editor in Chief, *American Journal of Medical Genetics***




**Max Muenke, M.D.**



# NHGRI Intramural Research Highlights

**PNAS**  
Proceedings of the National Academy of Sciences of the United States of America

Multimodal mapping of the brain's functional connectivity and the adult outcome of attention deficit hyperactivity disorder



**Science**

Loci associated with skin pigmentation identified in African populations

**AJMG** AMERICAN JOURNAL OF **medical genetics** PART A

Noonan syndrome in diverse populations





To receive *The Genomics Landscape*,  
go to [list.nih.gov](http://list.nih.gov)

Search for **NHGRILANDSCAPE**

Past issues can be accessed at:  
[genome.gov/27541196](http://genome.gov/27541196)



National Human Genome Research Institute  
*Advancing human health through genomics research*

**Thanks!**



**Special Thanks!**



# NATIONAL HUMAN GENOME RESEARCH INSTITUTE



*Advancing human health  
through genomics research*