



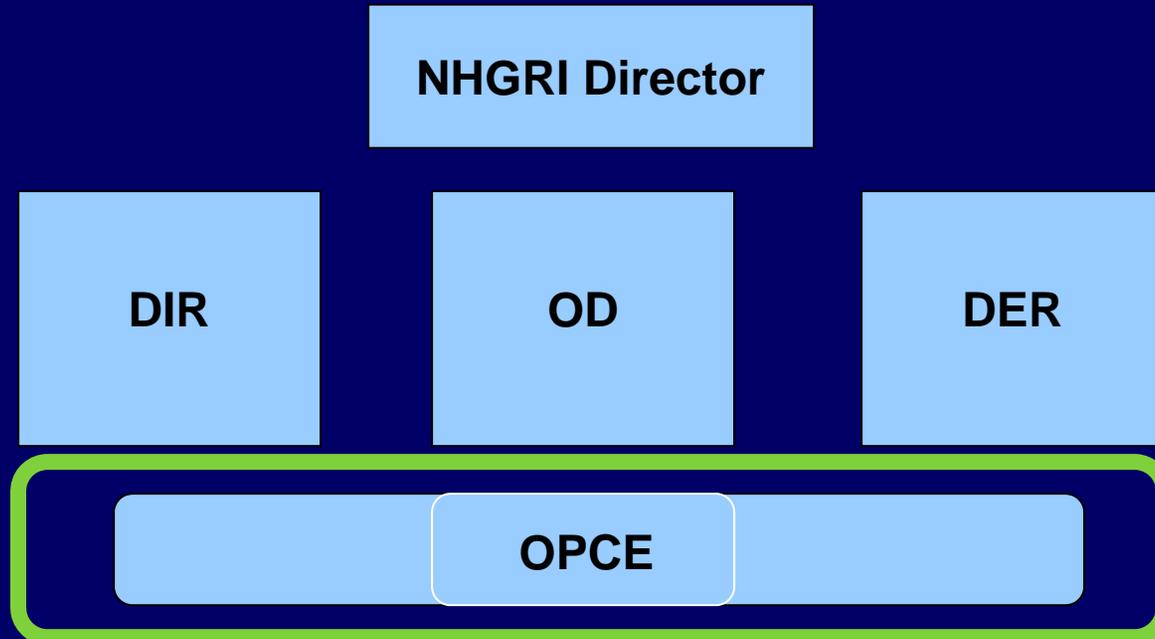
**Update from the Office of Policy,
Communications & Education**

Who, What, and Why ...

Laura Lyman Rodriguez, Ph.D.

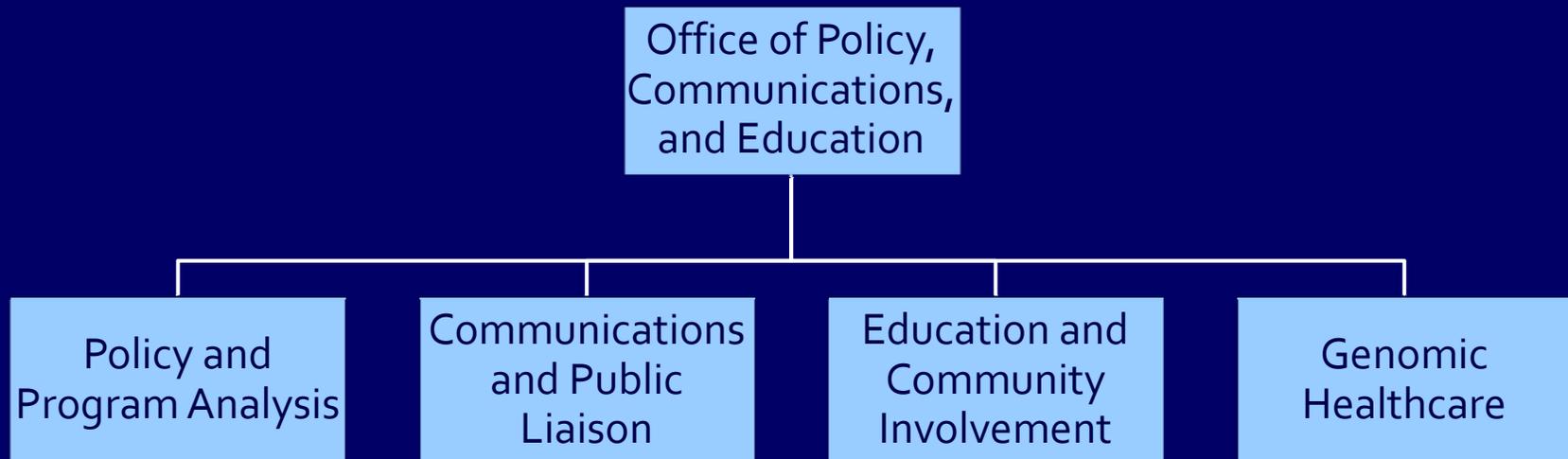
**National Advisory Council for Human Genome Research
September 12, 2011**

NHGRI and OPCE

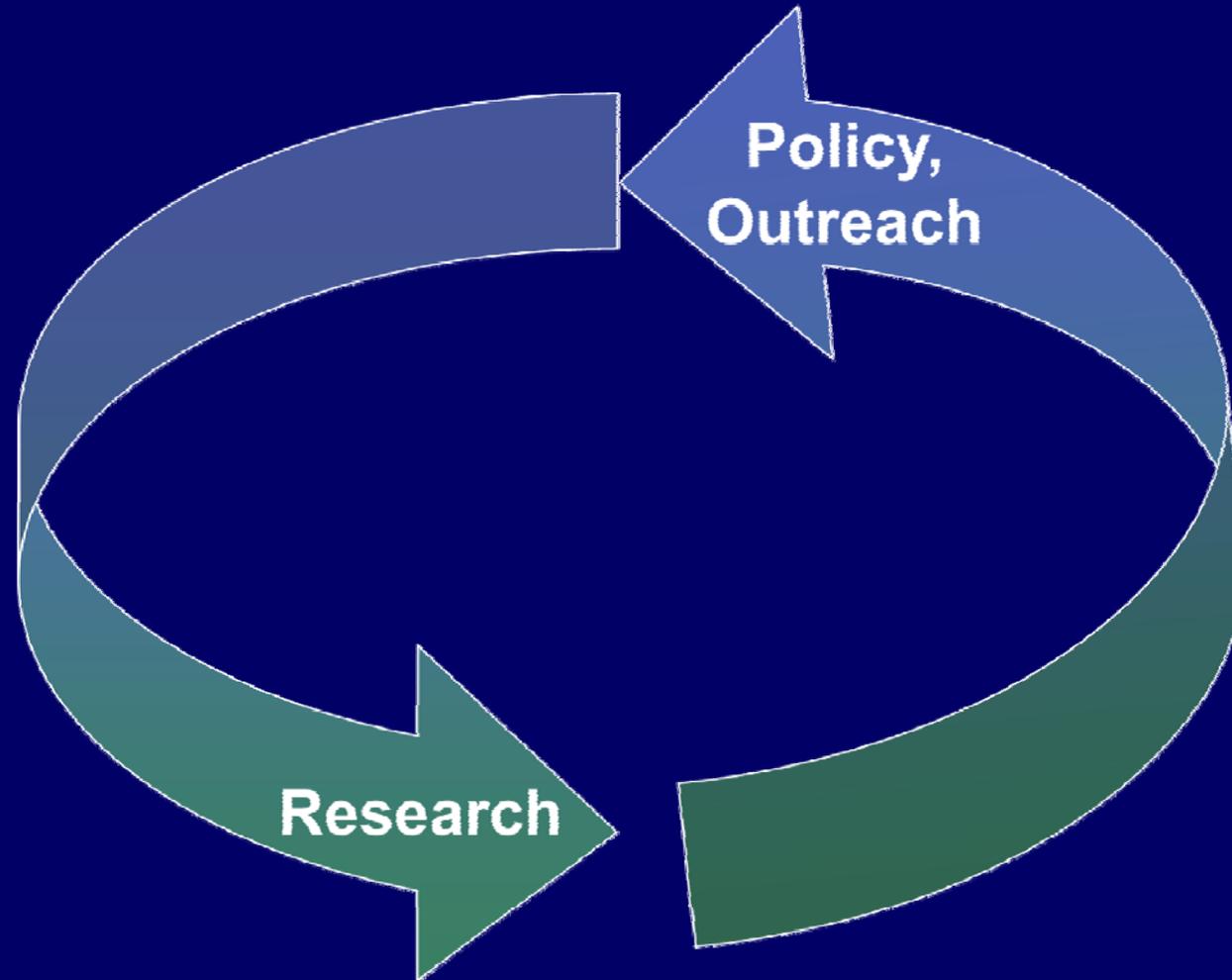


OPCE Overview

Mission: To promote the integration and utilization of genomic knowledge to advance human health and society.



Aim: Iterative Dialog and Process



Who We Are

Immediate Office



Laura Rodriguez



Rosann Wise



Alice Bailey



Nicole Moore

Policy and Program Analysis Branch (PPAB)



Derek Scholes
Branch Chief



Jonathan Giflin



Sanja Basaric



Tracey Crawford

Genomic Healthcare Branch (GHB)



Greg Feero



Jean Jenkins

Education and Community Involvement Branch (ECIB)



Vence Bonham
Branch Chief



Carla Easter



Jeffrey Witherly



Linda Turner

Communications and Public Liaison Branch (CPLB)



Larry Thompson
Branch Chief



Jeannine Mjoseph
Deputy Chief



Ray MacDougall



Geoff Spencer



Omar McCrimmon



Maggie Bartlett



Jane Ades



Judy Wyatt



David Smith



Alan Klemm



Mukul Nerukar



Mabel Bialecki



Alvaro Encinas

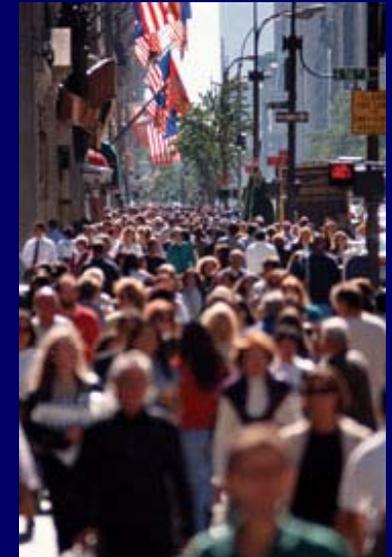
What We Do: OPCE Function(s)



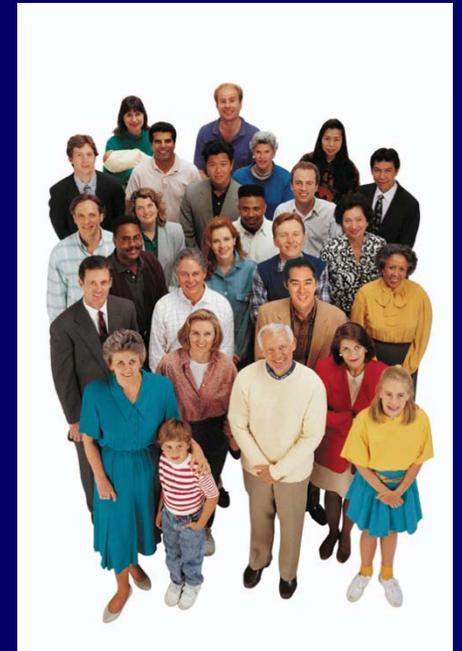
Who are OPCE's Audiences?



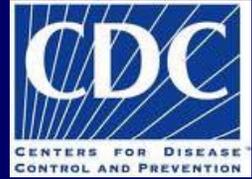
The New York Times
ON THE WEB



Audiences = Potential Partners



Plus ... Fellow Parts of the Administration



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Office of Biotechnology Activities

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Home | Recombinant DNA | **Genetics, Health, Society** | Dual Use Research | Clinical Research Policy

Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS)

Policy and Program Analysis



Derek Scholes



Jonathan Gitlin



Sanja Basaric



Tracey Crawford



FY2012 Appropriations Update

*FY2012 President's
Request:*

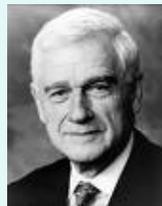
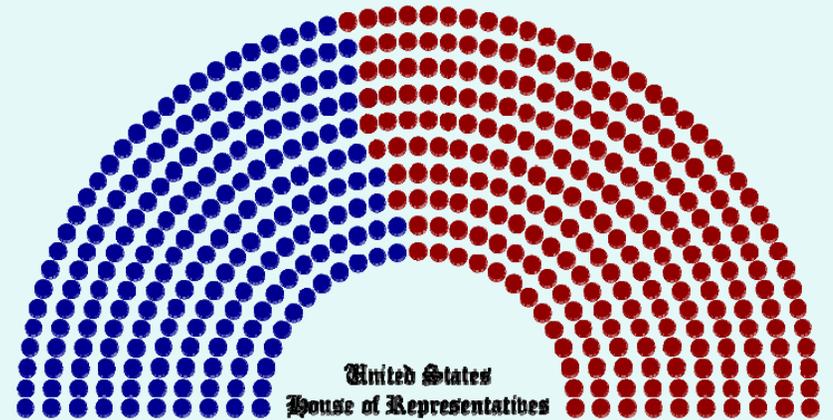
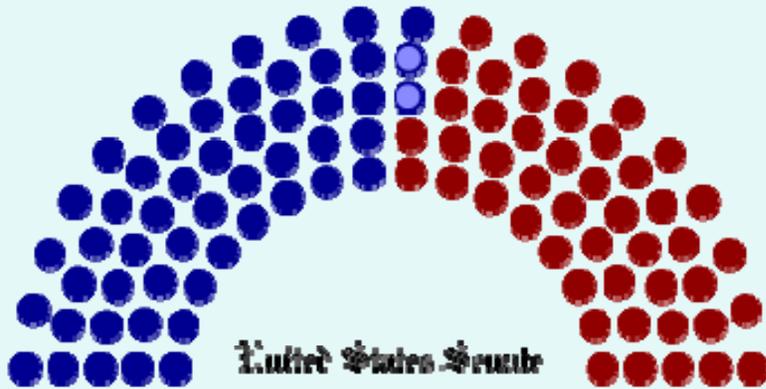
NIH - \$32 B (+2.4%)

NHGRI - \$525 M (+1.7%)

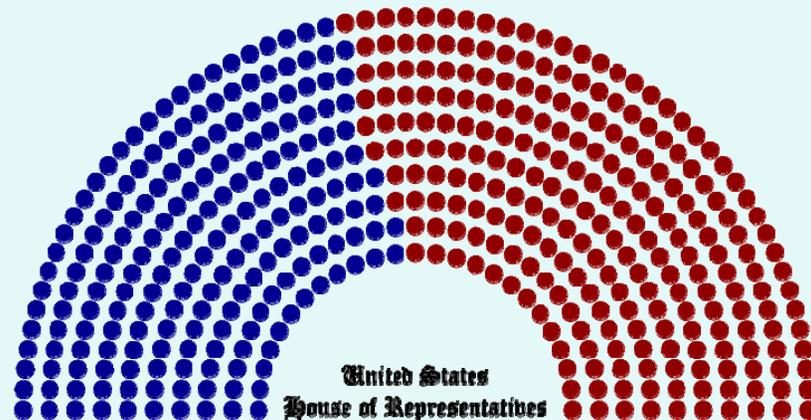
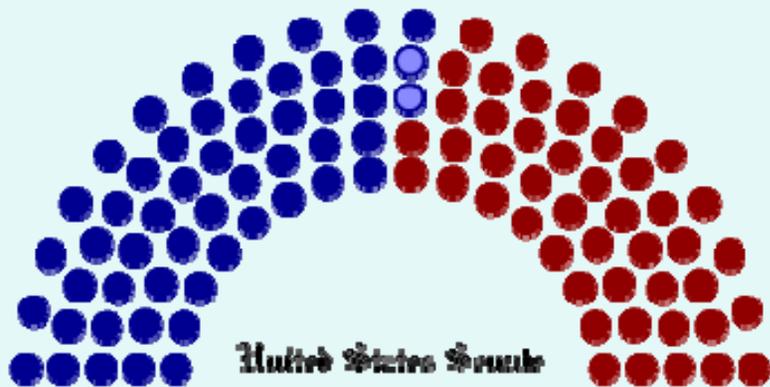


- **House: Passed 6 of 12, 3 out of committee, and 3 (including Labor/HHS) pending**
- **Senate: Passed 1 of 12, 3 out of committee, and 8 pending**
- **Continuing Resolution likely**

Understanding through Relationships



Building Relationships



Appropriations



Appropriations



Authorizing



Authorizing

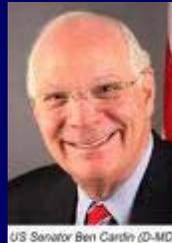


Others with a Special Interest

Maryland Delegation



**Barbara
Mikulski (D)**



**Ben
Cardin (D)**



**Chris
Van Hollen (D)**

Members with Expressed Interest



**Louise Slaughter
NY (D)**



**Anna Eshoo
CA (D)**



**Xavier Becerra
CA (D)**



**Richard Burr
NC (R)**



**Brian Bilbray
CA (R)**



**Michael Burgess
TX (R)**

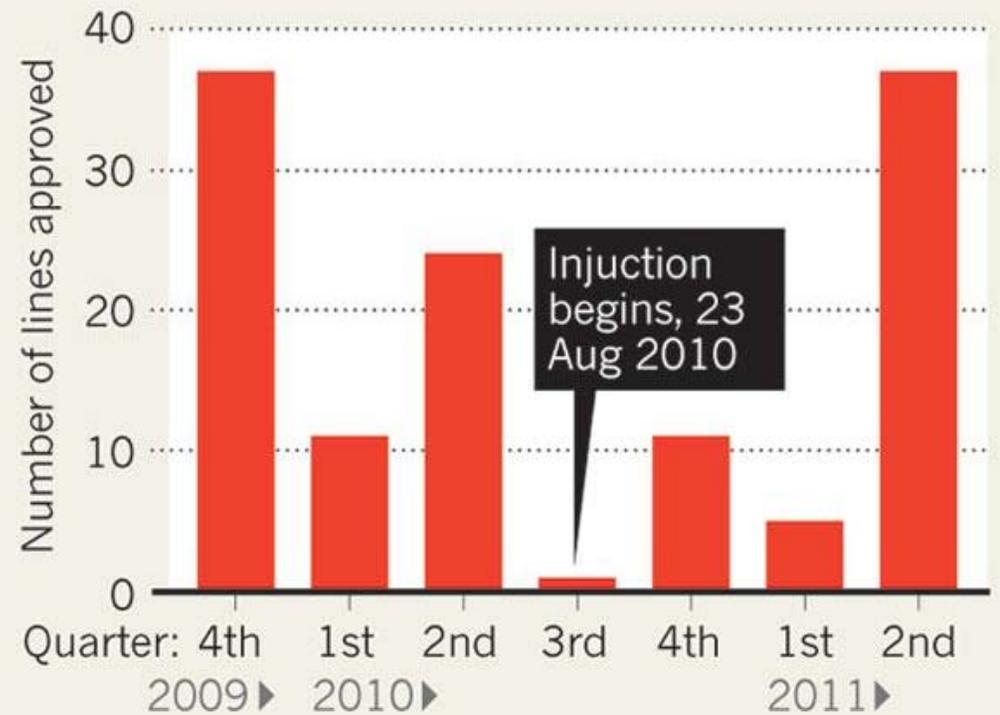
Courts give NIH hESC funding the all-clear



Judge Royce Lamberth

BOUNCING BACK

The NIH has approved 42 stem-cell lines this year, ending a lull that followed the 2010 injunction.



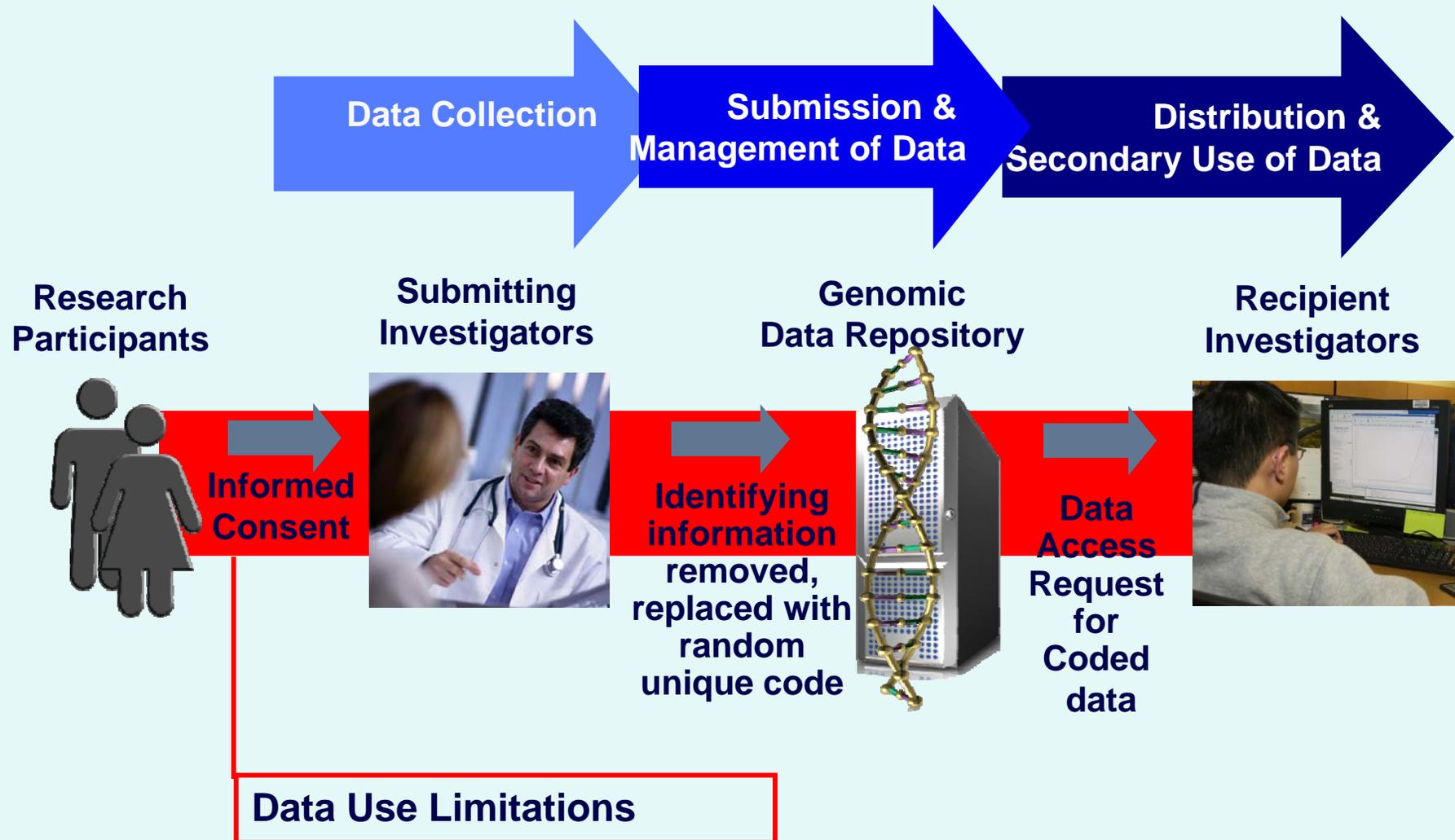
Appeals Court Rules on Myriad Gene Patents



Neal Katyal, ex-Acting Solicitor General

- Isolated DNA is patent-eligible
- cDNA is patent-eligible
- Methods claim to associate genotype to phenotype invalid as written

Genomic Data Sharing Policies



Updating the Common Rule

- Genetic samples considered inherently identifiable – risk classified as “informational”
- Data security protections, calibrated to level of identifiability
- Written consent required for all uses of existing research samples (short forms, broad consent OK; only applies prospectively)

Advanced Notice of Proposed Rule Making (ANPRM)

[Read more](#) about the July 22, 2011 ANPRM for changes under consideration to the Common Rule.

These changes, the most extensive since the Department of Health, Education, and Welfare published proposed rules for the protection of human subjects involved in research on [August 14, 1979](#), are **available for public comment until September 26, 2011**.



Genomic Healthcare



Greg Feero



Jean Jenkins

- Mission to improve the ability of all providers to apply advances in genomics & improve outcomes in patient care.
- Small but nimble: have made enormous use of partnerships and broad information dissemination



NEJM Genomic Medicine Series

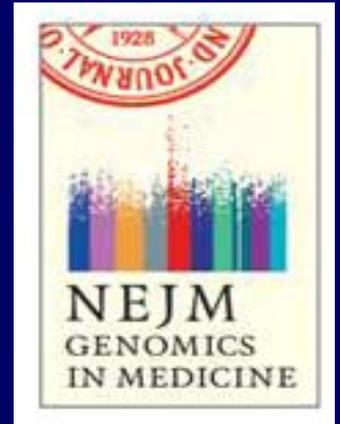
REVIEW ARTICLE

GENOMIC MEDICINE

W. Gregory Feero, M.D., Ph.D., and Alan E. Guttmacher, M.D., *Editors*

Genomics and the Eye

Val C. Sheffield, M.D., Ph.D., and Edwin M. Stone, M.D., Ph.D.



REVIEW ARTICLE

GENOMIC MEDICINE

W. Gregory Feero, M.D., Ph.D., and Alan E. Guttmacher, M.D., *Editors*

Microbial Genomics and Infectious Diseases

David A. Relman, M.D.

Building Resources



GENETICS/GENOMICS COMPETENCY CENTER
FOR EDUCATION

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Competencies &
Guidelines

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What you can do on this site:

- 1. Search for genetics/genomics resources to use in your classroom**
Find websites, download PDFs, locate courses-enhance your class content with genetic/genomic resources for [Nurses](#), [Physician Assistants](#), and [Genetic Counselors](#).
- 2. Review the Competency Guidelines and Curriculum Map**
Need to match your classroom genomics teaching to competencies? View the guidelines and the curriculum map to find the right resources to download.
- 3. Share resources, activities, and assessments to be included on this site**
Do you have activities, resources or assessments you would like to share? Submit websites,

The **Genetics/Genomics Competency Center for Education** provides links to curricular materials and resources for educators of Genetic Counselors, Nurses,



Upcoming Meeting: Pharmacist Education in the Era of Genomic Medicine

- November 30 – December 1, 2011
- 14 professional organizations invited



JAMA 2011 Medical Education Issue

COMMENTARY

9/7/2011

JAMA®

The Journal of the American Medical Association

Genomics Education for Health Care Professionals in the 21st Century

W. Gregory Feero, MD, PhD

Eric D. Green, MD, PhD

RECENT GENOMIC DISCOVERIES HAVE BROUGHT ABOUT far-reaching advances in understanding the molecular basis of human health and disease. The vision for the future of genomics research developed by the National Human Genome Research Institute suggests more discoveries are likely to occur over the next few decades.¹ These insights have helped reveal remarkable and unexpected complexities of human biology; how-

90% lacked confidence in their clinician's ability to understand and use genomic information.⁷

Past efforts to enhance the genomics literacy of health care professionals have often taken the form of a push of information from the genomics community to other professional groups. The underlying assumption of these efforts has been that spontaneous interest in additional genomics education would follow. The push approach has met with reasonable success in the nursing and physician assistant communities. For example, the nursing profession has internally developed genomics education competencies, which have now been broadly adopted across 50 organizations.⁸

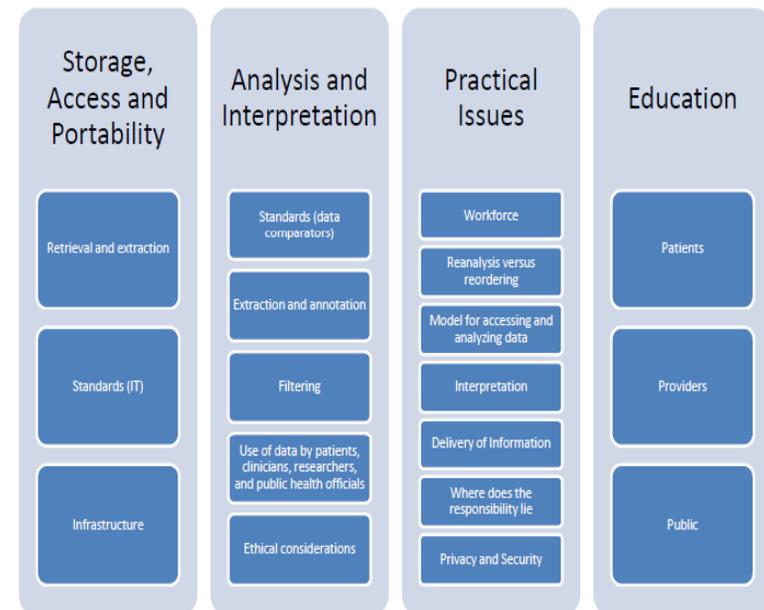
IOM Genomics Roundtable

Integrating Large-Scale Genomic Information into Clinical Practice: A Workshop July 19-20, 2011

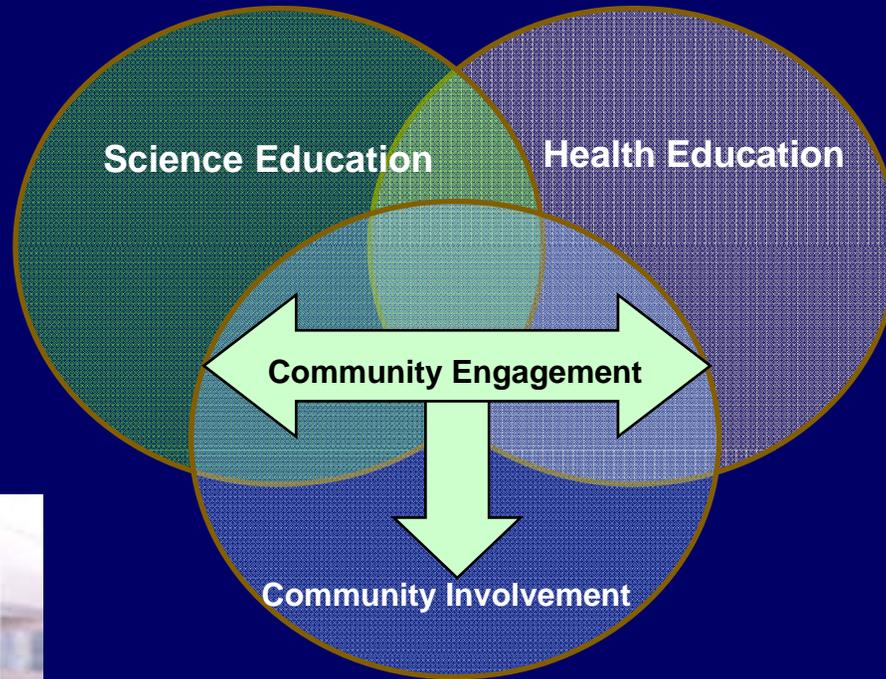
5 Sessions:

- Workforce
- Analysis
- Interpretation
- Delivery of Information
- Ethical, legal and social issues

Standing room only!!!



Education & Community Involvement



Linda
Turner



Jeffrey
Witherly



Carla
Easter



Vence Bonham



Genomic Opportunities for Studying Sickle Cell Disease: December 8-9, 2011

- Sponsored by several NIH Institutes (NHGRI, NHLBI, NICHD, NIDDK, NIMHD, NINDS)
- External Co-Chairs:
 - Michael DeBaun**, M.D., M.P.H.
Vanderbilt University
School of Medicine
 - Richard Gibbs**, Ph.D.
Baylor College of Medicine
 - Julie Makani**, Ph.D.
Muhimbili University



Working with Communities



卫生署长的
家族史方案

Brigham and Women's Hospital Family History Project



INITIATIVE DU CHIRURGIEN GÉNÉRAL
SUR L'HISTOIRE DE LA FAMILLE

Pour Créer Un Portrait de Santé de Famille En Ligne
Visitez:

www.hhs.gov/familyhistory/

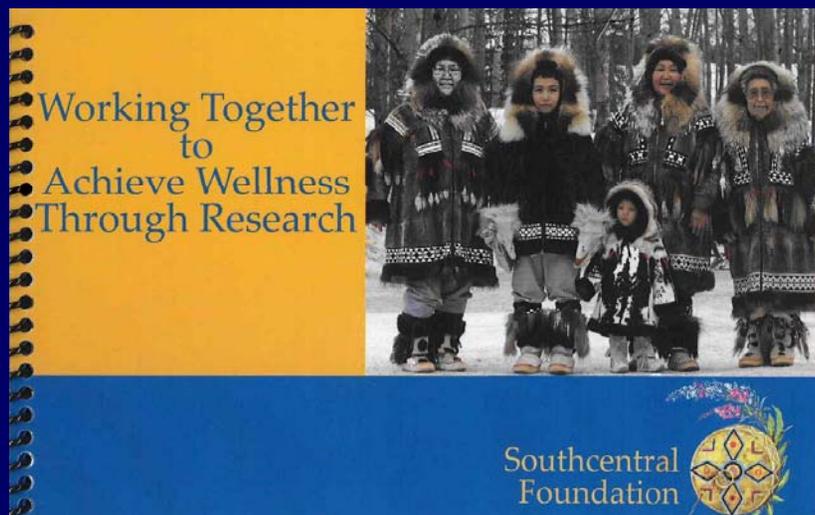


INICJATYWA NACZELNEGO LEKARZA/
STANÓW ZJEDNOCZONYCH W SPRAWIE
HISTORII ZDROWIA RODZINY

Brigham and Women's Hospital Family History Project



LA HERENCIA GENETICA:
EL HISTORIAL DE SALUD FAMILIAR



Southcentral
Foundation



NCAI

National Congress of American Indians

Education Outreach

DNA DAY APRIL 15 '11

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Chatroom Webcasts Ambassadors Teaching Tools News About Feedback



The navigation menu consists of seven items: 'Chatroom' with a photo of two people at a computer; 'Webcasts' with a photo of a person holding a camera; 'Ambassadors' with a group photo; 'Teaching Tools' with a DNA base pair graphic (A, T, C, G); 'News' with a laptop displaying a website; 'About' with a DNA double helix; and 'Feedback' with an '@' symbol icon. A colorful DNA double helix graphic runs through the center of the menu items.

Interactive Videos
Find Career Videos

Tour or Interview
 Category:

Find fulfilling & rewarding
genomic careers
with this interactive tool



The graphic features a screenshot of the 'genomiccareers' website interface. The website shows a 'Find View Ask' section with a video player and a 'Robotics Engineer' job listing. Below the screenshot is a dark blue banner with the URL 'www.genome.gov/GenomicCareers/' and a right-pointing arrow. At the bottom right, there is a photo of four diverse people (two men and two women) standing together, with a faint DNA double helix in the background.

Spanish Language Talking Glossary

[Inicio Glosario](#) | [Versión de texto](#)

[English Version](#)

Glosario *hablado de* **Términos Genéticos**

Buscar en el Glosario

A B C D E F G H I J K L M
N O P Q R S T U V W X Y Z

- Cáncer
- Cáncer de Prostata
- Carcinógeno
- Cariotipo
- Cariotipo Espectral (SKY)
- Cartografía genética
- Célula
- Célula madre
- Células somáticas
- Centimorgan
- Centríolo
- Centrómero
- Centrosoma
- Ciclo Celular
- Citogenética
- Citogenetista
- Citoplasma
- Citosina
- Clonación
- Clonación posicional
- Código genético
- Codominancia
- Codón
- Codón de parada
- Columna vertebral de fosfato
- Congénito
- Consejo genético
- Cóntigo (Contig)
- Cromátida
- Cromatina
- Cromosoma
- Cromosoma artificial bacteriano
- Cromosoma artificial de levadura
- Cromosoma sexual
- Cromosoma X
- Cromosoma Y

Haga clic aquí

Ponga a prueba SU CONOCIMIENTO génico

[Enviar este término a un amigo](#) [Cómo citar este término en los manuscritos de investigación](#)

Cromosoma

[Pronunciación](#)

Escuchar
Dr. Eric D. Green define Cromosoma

« » ||

Un cromosoma es un paquete ordenado de ADN que se encuentra en el núcleo de la célula. Los diferentes organismos tienen diferentes números de cromosomas. Los humanos tenemos 23 pares de cromosomas - 22 pares autosómicos, y un par de cromosomas sexuales, X e Y. Cada progenitor contribuye con un cromosoma de su par de autosomas y uno del par sexual, de manera que la descendencia obtenga la mitad de sus cromosomas de su madre y la mitad de su padre.

Perfil **Figura - Ilustración** **Animación 3-D**

Dr. Eric D. Green

Director Científico del Instituto Nacional para la Investigación del Genoma Humano (NHGRI); Jefe e Investigador Principal de la División de Tecnología del Genoma, Jefe de la Sección de Secuenciación y Mapeo Físico (NISC) y Director de la Sección Intramuros del NIH

La investigación del Dr. Green se centra en tres áreas principales: En primer lugar, la secuenciación y la comparación de regiones específicas del ADN de una gran variedad de especies con la finalidad de desentrañar la complejidad de la función del genoma; en segundo lugar, el desarrollo de herramientas de investigación y tecnologías innovadoras para la realización de análisis del genoma; y en tercer lugar, la identificación y caracterización de los genes asociados con enfermedades humanas. En sus múltiples funciones como director científico del NHGRI, jefe de la División de Tecnología del Genoma, y director del Centro de Secuenciación (NISC) Intramural del NIH, Dr. Green tiene interés fundamental en mapear, secuenciar e interpretar los genomas de los vertebrados.

Genetics Glossary App

The screenshot shows the App Store page for the 'Talking Glossary of Genetics' app. The page is viewed on a Mac browser window with the address bar showing 'witherlys@aol.com'. The app's icon is a DNA double helix. The title is 'Talking Glossary of Genetics' and the developer is the National Human Genome Research Institute. The description states that the app features more than 250 common genetic terms pronounced and explained by leading scientists. The 'What's New in Version 1.0.3' section lists 'Bug Fixes'. The 'iPhone Screenshots' section shows three screenshots of the app's interface. The first screenshot is the app's main screen, featuring a DNA double helix background and a search bar. The second screenshot shows a detailed 3D diagram of a cell with labels for various organelles: Nucleus, Nucleolus, Ribosomes, Rough Endoplasmic Reticulum, Smooth Endoplasmic Reticulum, and Microtubule. The third screenshot shows a 3D model of a cell with a blue nucleus and other internal structures. The app's interface includes a search bar, a 'Search' button, and a bottom navigation bar with icons for 'Terms', 'Quiz', 'Email', and 'About'. The app is categorized as 'Education' and is available for free.

App Store > Education > National Human Genome Research Institute

Talking Glossary of Genetics

Description

The Talking Glossary of Genetic Terms features more than 250 common genetic terms pronounced and explained in an easy-to-understand way by leading scientists and professionals at the National Human Genome Research Institute (NHGRI)....

[National Human Genome Research Institute Web Site >](#) [Talking Glossary of Genetics Support >](#)

What's New in Version 1.0.3

Bug Fixes

iPhone Screenshots

The National Human Genome Research Institute's
Talking Glossary of Genetic Terms

Terms Quiz Email About

Nucleus
Nucleolus
Ribosomes
Rough Endoplasmic Reticulum
Smooth Endoplasmic Reticulum
Microtubule

Expert Definition Illustration Animation

2011 NHGRI Summer Workshop in Genomics



- 2011 Genomics Short Course held July 24-29
- 33 participants from the US, Puerto Rico and the US Virgin Islands

Genetics Instruction Lacking Current Concepts in Most States

CBE—Life Sciences Education
Vol. 10, 318–327, Fall 2011

Article

A Comprehensive Analysis of High School Genetics Standards: Are States Keeping Pace with Modern Genetics?

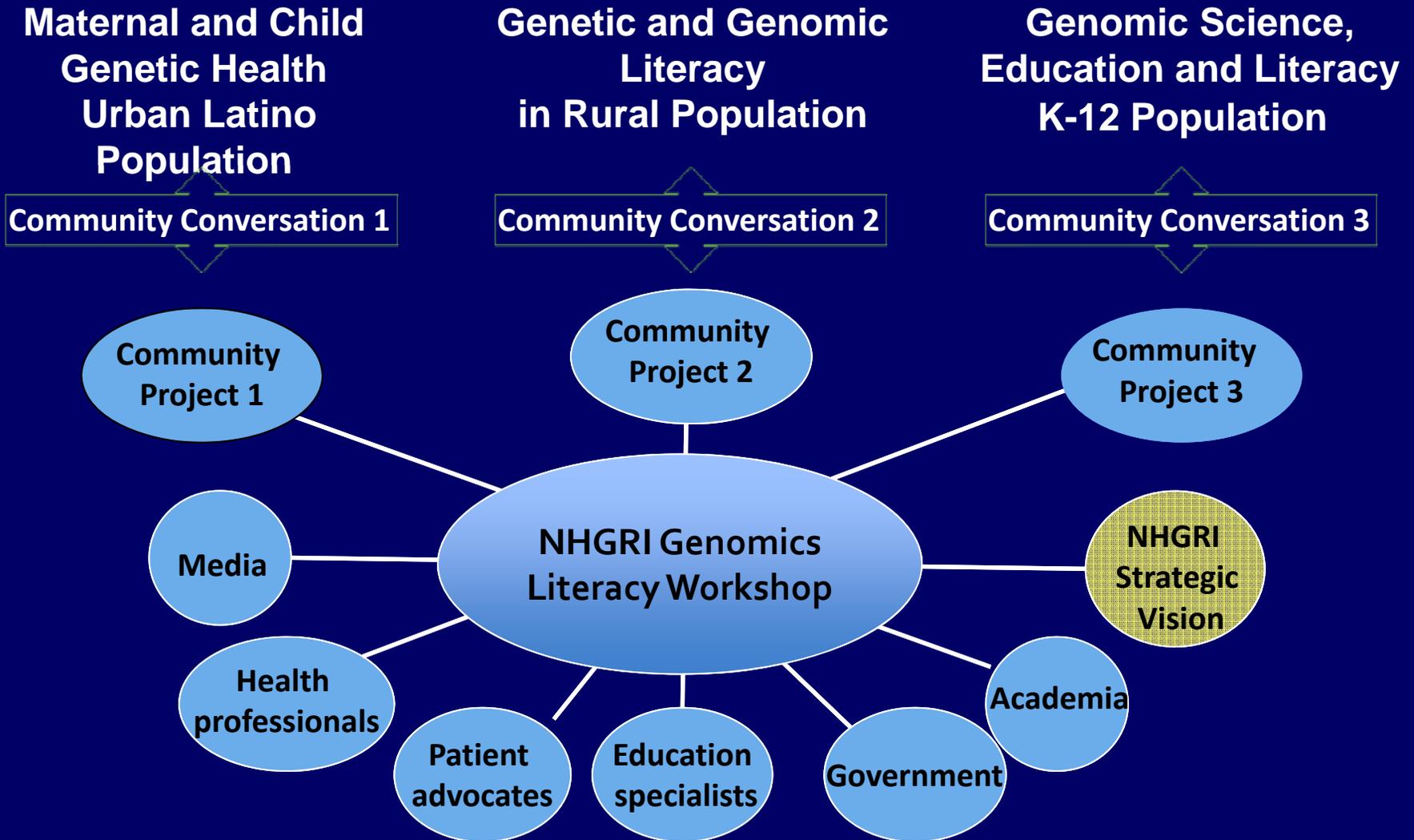
M.J. Dougherty,* C. Pleasants,[†] L. Solow,[‡] A. Wong,* and H. Zhang*

*American Society of Human Genetics, Bethesda, MD 20814; [†]Hampden-Sydney College, Hampden-Sydney, VA 23943; [‡]Wesleyan University, Middletown, CT 06459

- **7 states determined to have ‘adequate’ standards**
- **Most states have adequate coverage of between only 3 and 10 of 19 core genetic concepts**



Genomic Literacy Workshop



“What Does It Mean to be Genomically Literate?”

Communications & Public Liaison



Larry Thompson



Jeannine Mjoseth



Ray MacDougall



Geoff Spencer



Omar McCrimmon



Maggie Bartlett



Jane Ades



Alvaro Encinas



Judy Wyatt



David Smith



Alan Klemm



Mukul Nerukar



Mabel Bialecki



The Washington Post



Provides the Public Face of the Institute

The image shows a screenshot of the NIH News website on the genome.gov domain. The page features the NIH News logo, navigation links (Home, About, For You), and social media icons (Facebook, Twitter, YouTube). Several news articles are displayed, each with a red border highlighting its content. The articles include:

- eMERGE network m... NIH-supported projec...** (partially visible)
- NHGRI funds developme... NIH-supported work to bo...** (partially visible)
- International genome consortium discovers new genes that control blood pressure**
NIH institutes participate in global study that finds new genetic risk factors for cardiovascular disease
Bethesda, Md., Sun., Sept. 11, 2011 — In one of the largest genomics studies ever, an international research consortium that includes the National Institutes of Health has identified 29 genetic variations across 28 regions of the human genome that influence blood pressure. This unprecedented effort brought together more than 230 researchers across six continents and scanned the genomes of over 200,000 people. The results appear in the Sept. 11 edition of *Nature*.
"It is fitting that a global research group came together to provide new insight into a condition that affects over 1 billion people worldwide," said Susan B. Shurin, M.D., acting director of the NIH's National, Heart, Lung, and Blood Institute (NHLBI), which was part of the international consortium behind the study. "This is one of the most important studies of the genetics of blood pressure to date and a significant step toward finding better therapies for it."
- Leaping Lizards Genome** (partially visible)

Additional elements on the page include a search bar, a "View All" link, and a section titled "On Other Sites:" with a link to a *Nature* article: [Genetic variants in novel pathways influence blood pressure and cardiovascular disease risk](#) (Sept. 11, 2011). At the bottom, there are links for "information" and "Genome Advance".

NHGRI Genome Advance of the Month

Protecting the food supply and human health with genomics

May 2011

Keywords: [what's this?](#) 

> [genome sequencing](#)

Transforming clinical care with whole genome sequencing

June 2011

Keywords: [what's this?](#) 

> [large scale genome](#)

Proteus: Discovering the tiniest disease-causing flaws — and improving sequencing technologies

By **Jonathan Gitlin, Ph.D.**
Science Policy Analyst



Proteus, a sea-god from Greek mythology, could change his shape to improve his fortunes. People suffering the syndrome that bears his name are not so lucky and the cause of their plight has been as mysterious as the disease can be debilitating. It's a strange genetic disorder that's never inherited; each individual appears to have a new mutation. Moreover, the genetic defect is only found in some of the patient's cells while other tissues are genetically normal and healthy, a condition geneticists call a mosaicism.

NHGRI's Genome Advance of the Month selection, however, provides the answer — and it's a shocker: Proteus syndrome is caused by a spontaneous change in a single base pair among the three billion base pairs in the human genome that occurs in a single cell of a developing embryo. The severity of the disease — which varies dramatically between sufferers — depends on when during embryonic development the mutation occurs and in which cell.

Expanding Capacity to Market & Disseminate NHGRI News



01:48 / 13:16 480p

Optimizing Our Use of Today's Tools

The image shows a screenshot of a YouTube channel page for GenomeTV. At the top, the YouTube logo is on the left, and search, browse, movies, and upload buttons are in the center. On the right, there are links for 'Create Account' and 'Sign In'. Below this is a red banner for the National Human Genome Research Institute, with the genome.gov logo and the text 'National Institutes of Health'. A 'Visit genome.gov' link is on the right. The channel name 'GenomeTV' and 'GenomeTV's Channel' are on the left, with a 'Subscribe' button. Navigation tabs for 'All', 'Uploads', and 'Playlists' are in the center. On the right, there are icons for a video player and a menu. The main video player shows a telebriefing with three men at a table. The title is 'Proteus Syndrome Telebriefing' and the date is 'July 27, 2011'. Below the video player are buttons for 'Info', 'Favorite', 'Share', and 'Flag'. The video description is titled 'Proteus Syndrome Telebriefing (HD)' and includes the text: 'From: GenomeTV | Jul 27, 2011 | 853 views' and 'July 27, 2011 - NHGRI scientists have found the gene mutation that causes Proteus syndrome, a rare disorder that causes tissue and bone to grow out of proportion to the body. The study describing the AKT1 gene mutation was published in the online edition of The New England Journal of Medicine. For more information go to: <http://www.genome.gov/proteus>. ... (more info)'. Below the description is a link: 'View comments, related videos, and more'. On the right side, there is a 'Featured' section with a list of videos: '1 month ago more info', 'May 2011 NACHGR Open Session 1 month ago more info', 'A Decade with the Human Genome 1 month ago more info', '1000 Genomes Tutorial 1 month ago more info', 'The Human Genome: A Decade 1 month ago more info', 'Current Topics in Genome Analysis 1 month ago more info', and 'NIH Intramural Sequencing Center 1 month ago more info'.

Building a Social Media Presence

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Government & Community · Bethesda, Maryland · Edit Info

Wall

Share: Status Photo Link Video Question

Write something...

567 like this

Write a comment...

1 like this

was here

Gregor Mendel

Rare Metabolic Disorder Awareness (GA 1)

American Cancer Society

National Organization for

Genome.gov | National Human Genome Research Institute (NHGRI)
NHGRI announces outstanding scientific leaders to key leadership roles: James Mullikin to direct intramural sequencing center; Mark Guyer named institute deputy director. <http://goo.ly/6uf>

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EDIT

About

The National Human Genome Research Institute (NHGRI) working towards a f...
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people like this.

Write a comment...

Dominic P. Eslava
pls how can i download lizard dna sequence? And what sequencing technology they use?
Like · Comment · Monday at 5:43am

Genome.gov | National Human Genome Research Institute (NHGRI) Hi Dominic, For a full description of methods, including sample collection, sequencing, assembly, anchoring, mass spectrometry and all sequence analysis, go to the Supplementary Information section of the paper at <http://www.nature.com/nature/journal/vaop/ncurrent/full/nature10390.html>.

The genome of the green anole lizard and a comparative analysis with birds and mammals : Nature ..
www.nature.com
The evolution of the amniotic egg was one of the great evolutionary innovations ...
See More

Monday at 9:43am · Like · Remove Preview

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National DNA Day

Government Organization · Bethesda, Maryland · Edit Info

Wall

Share: Status Photo Link Video Question

Write something...

4,050 like this

Write a comment...

4,050 like this

Write a comment...

National DNA Day
A new study by the American Society of Human Genetics reveals that 43 of 50 states fail to keep pace with modern genetics in their high school science curricula. For more information, go to: <http://goo.ly/6u9>

Wall Photos

More

2024 Impressions · 0.30% Feedback

Like · Comment · Share · Yesterday at 11:21am

5 people like this.

View all 4 comments

Kristen Cloud I live in Kansas...and a lot of schools try. it's about 50/50, I think. in one of my intro biology classes a few years ago, the professor asked how many of us were taught evolution/genetics in HS, and probably half the class raised their hand. I will say that a lot of students left the room though during high school when we learned about it. /sigh. "is a genetics major"
17 hours ago · Like

Raising Epilepsy Awareness: Just a Brain Storm on an Otherwise Sunny Day They should all be dark green, we need a revamp for public education- we rank 26th out of well educated countries as far as how smart our children rank, and spend 5x more than any other country. something is wrong with that.
14 hours ago · Like

Write a comment...

National DNA Day
Emory University in Atlanta, will offer a Master's in genetic counseling next

ASHG - American Society of Human Genetics

ACMG - American College of Medical Genetics

Genome.gov | National Human Genome

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Reaching Our Audiences Where They Are

genome_gov
@genome_gov (Bethesda, MD)
If you're looking for the official source of information about the National Human Genome Research Institute, please visit our homepage at www.genome.gov
<http://www.genome.gov>

643 Tweets 300 Following 451 Followers 25 Listed

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DNA Day
@DNAday Bethesda MD
The National Human Genome Research Institute (NHGRI) created this Twitter account to raise awareness of National DNA Day, celebrated each year on April 25th.
<http://www.genome.gov/10506367>

223 Tweets 17 Following 2,029 Followers 104 Listed

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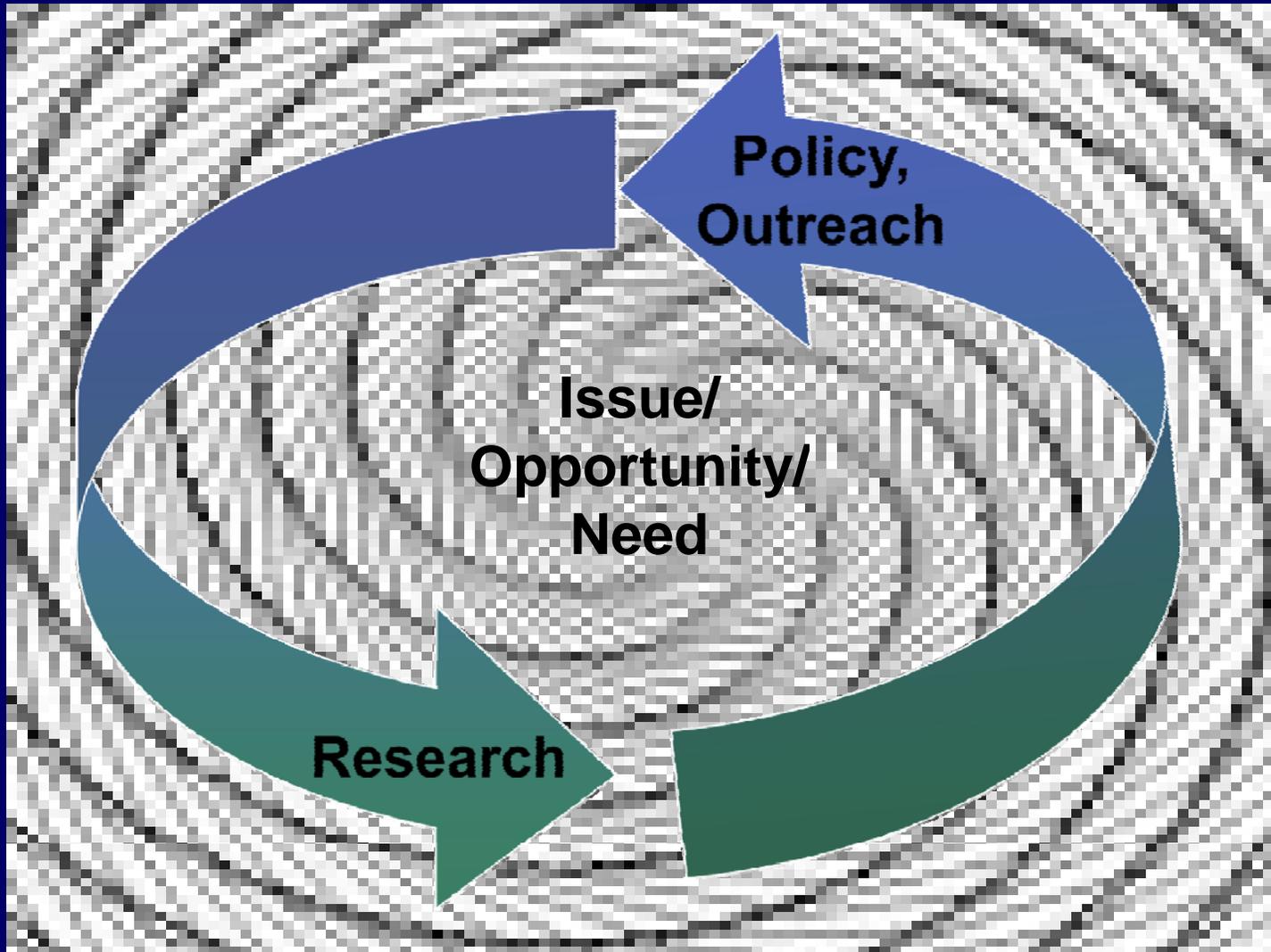
About @genome_gov

643	300	451	25
Tweets	Following	Followers	Listed

About @DNAday

223	17	2,029	104
Tweets	Following	Followers	Listed

Goal: Iterative Dialog and Process



Thank You !!

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