

The Human Genome: A Decade of Discovery, Creating a Healthy Future

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**NHGRI Science Writers' Workshop
June 7, 2010**

Questions for this panel...

What do people want to know?

How will people use what they know?

What are the [policy] responsibilities?

How do we move forward responsibly...

... with research?

... with “protections”?

Putting the Pieces Together

- **Science**

- Research aims and objectives
- Emerging and evolving findings
- Differing perspectives and agendas
- Perpetual motion

- **Policies and Procedures**

- Applicable laws and regulations
- Guiding principles
- Community expectations ??

- **Program Implementation**

- Policy and ethics
- Transparency
- Shared responsibilities



Policy Issues

- What level of de-identification provides “adequate” privacy or confidentiality protection to participants without damaging the science?
- How do we respect the wishes of the individual participants and sustain the public’s trust?
 - What is the standard for informed consent?
- Should individual results from “basic” studies be returned? If so, how and in what form?
- How to provide responsible stewardship of the research?

The Jiffy Lube of Genome Decoding

09.20.2008

A new company promises to map your DNA while-U-wait—for only a few hundred bucks.

by Boonsri Dickinson

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Born to Run? Little Ones Get Test for Sports Gene



Kevin Moloney for The New York Times

DNA collected by swabbing the inside of a cheek can be used to determine whether a child is likely to excel at a particular sport.

By **JULIET MACUR**

Published: November 29, 2008

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New Scientist

How my genome was hacked

By Peter Aldhous and Michael Reilly

3/28/2009, Vol. 201 Issue 2701, p6-9,
Special Report



If our reporter's DNA is vulnerable, then so is yours. *New Scientist* investigates an alarming new threat to genetic privacy

INTIMATE secrets hidden in your DNA could be stolen without you even realising. By taking a glass from which you have drunk, a "genome hacker" could obtain a comprehensive scan of your genome, revealing DNA variants that help determine your susceptibility to a wide range of diseases, from a common form of blindness to Alzheimer's disease.

But.....

■ Back to the people ...

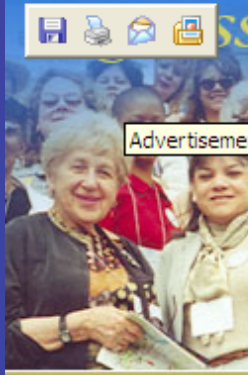
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.... patient

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Spotlight

Who said it? When did they say it? How did they know?



Use the new "Trust it or Trash it?" tool to judge the quality of materials about genetic conditions (such as booklets, websites, and handouts). Also, use it to help create new materials. Click [here](#) to learn how to think about and evaluate the

Genetic Alliance 2009 Annual Conference: *Discovering Openness in Health Systems*



Join us in transforming the way we understand health!
Friday, July 17th – Sunday, July 19th
Bethesda North Marriott Hotel and Conference Center
In the Washington, DC Metropolitan Area

[Conference Program](#)

Also in July: [Genetics Day on the Hill](#), July 16 · [Gene Screen](#), July 16

Network

Gene Screen



Join us on Thursday, July 16, immediately following [Genetics Day on the Hill](#), for Genetic Alliance's *Gene Screen: A Night of Film on Health and Genetics*.

Policy

Sign On to Consensus Principles for Health Reform!

Join over 100 organizations, coalitions, and companies in a collective voice to inform the health reform process. Download the consensus principles [here](#), and sign on in support by emailing your organization name to healthreform@geneticalliance.org. The deadline to sign on is Monday, July 13.

The consensus principles are the result

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Chief Executive of GSI Health, Inc.

Program Manager, Healthcare IT Standards Panel

* Founding Chief Technology Officer for Private Access, Inc.

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Your Privacy is Our Priority

Control Access to Your Records

Putting the Pieces Together

- **Science**

- Potential Benefit
- Potential Harm
- Hope vs. Hype

- **Policies and Procedures**

- Informed consent
- Informed by research
- Public trends/individual choice

- **Program Implementation**

- Responsive governance
- Transparency
- Shared responsibilities

