



## **AGENDA**

### **National Genetic Policy Summit**

Genetics & Public Policy Center  
Johns Hopkins University  
September 21-22, 2006  
The Fairmont Hotel, Washington, DC  
2401 M Street, NW  
Washington, DC 20037

#### **Wednesday, September 20, 2006**

8:00 pm – 10:00 pm     **Reception**, Dumbarton Suite

#### **Thursday, September 21, 2006**

8:00 am - 9:00 am     **Registration**, Executive Forum Foyer

**Breakfast**, Culpeper Room

9:00 am - 9:10 am     **Welcome**, Executive Forum

Jim O'Hara  
Director, Policy Initiatives and Health and Human Services Programs  
The Pew Charitable Trusts

9:10 am - 9:30 am     **Summit Overview and Goals**

Kathy Hudson, Ph.D.  
Director, Genetics and Public Policy Center

9:30 am - 10:00 am     **Plenary**

Janet Woodcock, M.D.  
Deputy Commissioner for Operations  
Food and Drug Administration

10:00 am - 10:30 am     **Remarks**

The Honorable Barack Obama  
U.S. Senator from Illinois

10:30 am - 10:45 am     **Break**

10:45 am - 12:15 pm     **Genetic Testing 2006: Focus on Quality**

Industry leaders discuss the market forces driving genetic testing and the scientific, economic, and regulatory challenges facing the industry. Data from a 2006 survey of U.S. genetic testing laboratories regarding laboratory practices and laboratory director perspectives are presented.

Moderator:     Mary Pendergast, J.D., LL.M.  
Pendergast Consulting

*The Commercialization of Genetic Testing: An Insider's Perspective*

Brad Popovich, Ph.D.  
President and CEO, Sirius Genomics

*Kits vs. Homebrews: Two Paths to the Same Place?*

Greg Hines  
President and CEO, Tm Bioscience

*Survey Says...*

Kathy Hudson, Ph.D.  
Director, Genetics and Public Policy Center

12:15 pm - 1:15 pm **Lunch**, The Colonnade

1:15 pm - 2:45 pm **Genes in Practice**, Executive Forum

The consumers of advances in genetic testing – providers, payors, and consumers – address the genetic health care delivery system and the opportunities and challenges posed by the acceleration of genetic tests in the current regulatory landscape.

Moderator: Sharon Terry, M.A.  
President and CEO, Genetic Alliance

*The Genetic Odyssey: Consumers' Experiences and Expectations*

Patricia Furlong  
Jana Monaco  
Rebecca Fisher

*What Do Clinicians Need to Know and When Do They Need to Know It?*

Ned Calonge, M.D., MPH  
Chief Medical Officer and State Epidemiologist  
Colorado Department of Public Health and Environment  
Associate Professor  
University of Colorado Health Sciences Center

*Paying the Bill*

Joanne Armstrong, M.D., MPH  
Senior Medical Director, Aetna

2:45 pm - 3:15 pm **Break**

3:15 pm - 4:45 pm **Genetic Testing of Embryos**

Experts in the growing field of preimplantation genetic diagnosis (also known as PGD or the genetic testing of embryos) will discuss the current state of the technology and issues likely to arise in the future. The Genetics and Public Policy Center will report results from its survey of U.S. IVF clinics about PGD.

Moderator: Joe Leigh Simpson, M.D.  
Baylor College of Medicine

*PGD: What It Is and Where It's Headed*  
Mark Hughes, M.D., Ph.D.  
Director, Genesis Genetics

*Ethics, Morality, and PGD*  
Eric Cohen  
Fellow and Director, Bioethics & American Democracy Program  
Ethics and Public Policy Center

*Survey Says...*  
Susannah Baruch, J.D.  
Director, Reproductive Genetics  
Genetics and Public Policy Center

6:00 pm - 7:00 pm      **Reception**, Garden Courtyard

7:00 pm - 9:30 pm      **Dinner**, The Colonnade

### **Friday, September 22, 2006**

7:30 am - 8:30 am      **Breakfast**, Culpeper Room

8:30 am - 10:00 am      **Plenary**, Executive Forum  
Francis Collins, M.D., Ph.D.  
Director, National Human Genome Research Institute

Steve Phurrough, M.D. MPA  
Director, Coverage and Analysis Group  
Centers for Medicare and Medicaid Services

10:00 am - 10:15 am      **Break**

10:15 am - 11:30 am      **Direct-to-Consumer Genetic Testing: Empowerment or Endangerment?**

This panel will examine “direct-to-consumer” genetic testing, discuss the potential risks and benefits of this mode of delivering genetic testing, and describe the regulatory landscape.

Moderator: Rick Borchelt  
Communications Director  
Genetics and Public Policy Center

Gail Javitt, J.D., MPH  
Law and Policy Director  
Genetics and Public Policy Center

Robert Nussbaum, M.D.  
Professor of Medicine and Chief of Medical Genetics  
University of California, San Francisco

Howard Coleman  
CEO, Genelex Corporation

Peter Lurie, M.D., MPH  
Deputy Director, Public Citizen's Health Research Group

11:30 am - 1:00 pm

**Where do we go from here?**

Facilitated discussion of specific policy issues and solutions.

Facilitator: Jonathan Ortman  
President, Public Forum Institute

1:00 pm - 2:00 pm

**Lunch**, The Colonnade

2:00 pm

**Adjourn**