



Board on Health Sciences Policy

*Roundtable on Translating Genomic-Based Research for Health*

## **Assessing the Economics of Genomic Medicine: A Workshop**

**July 17, 2012**

**National Academy of Sciences Building  
2101 Constitution Ave., N.W.  
Washington, DC 20037**

---

### **Workshop Objective:**

- To advance discussions around the clinical implementation of genetic and genomic technologies by examining costs associated with the development and use of genetic and genomic information in the care of individual patients.

---

**7:45 A.M. Working Breakfast**

**8:30 A.M. Welcoming remarks**

Wylie Burke, *Roundtable Co-Chair, Meeting Moderator*  
Professor and Chair  
Department of Bioethics and Humanities  
University of Washington

**8:35 A.M. Charge to workshop speakers and participants**

W. Gregory Feero, *Workshop Chair*  
Special Advisor to the Director  
National Human Genome Research Institute

---

### **SESSION I: ECONOMICS AND GENOMICS**

---

**Moderators:** W. Gregory Feero  
Special Advisor to the Director  
National Human Genome  
Research Institute

Wylie Burke  
Professor and Chair  
Department of Bioethics and  
Humanities  
University of Washington

8:40 A.M. **Genomics, Population Health, and Technology**

James P. Evans  
Bryson Distinguished Professor of Genetics & Medicine  
University of North Carolina at Chapel Hill

9:10 A.M. **Discussion**

9:25 A.M. **Intersection of Genomics and Health Economics**

David L. Veenstra  
Professor, Pharmaceutical Outcomes Research and Policy  
Program  
University of Washington

9:55 A.M. **Discussion**

**10:10 A.M. Break**

---

## **SESSION II: PRECONCEPTION CARE AND SEQUENCING**

---

**Moderators:** Robert L. Nussbaum  
Chief, Division of Medical  
Genetics; Dept. of Medicine and  
Institute of Human Genetics  
UCSF, School of Medicine

Wylie Burke  
Professor and Chair  
Department of Bioethics and  
Humanities  
University of Washington

10:25 A.M. **Case presentation:** In 2012 a 35 year old well Ashkenazi female smoker presents for a preconception visit. Under the current standard care model, targeted carrier status testing is offered. In terms of high effect size variations that would be detected by traditional genetic testing she is found to be a carrier for Tay Sachs. Additionally, if testing were extended in this scenario beyond what might be considered to be current standard of care, she would be found to harbor a prothrombin gene mutation, as well as variations in CYP2C9 and VKORC indicating that she is likely to be highly sensitive to warfarin anticoagulation. She is also homozygous for APOE4, but does not have familial hypercholesterolemia. She can be expected to have lower risk variants and variants of unknown significance in accordance with expected population frequencies for the conditions under consideration.

10:30 A.M. **Stakeholder Presentations (10 minutes each)**

### **Clinician**

Siobhan M. Dolan  
Associate Professor of Clinical Obstetrics & Gynecology  
and Women's Health  
Albert Einstein College of Medicine

### **Futurist**

Arthur L. Beaudet  
Henry and Emma Meyer Professor and Chair  
Department of Molecular and Human Genetics  
Baylor College of Medicine

### **Patient**

Michelle Gilats  
Genetic Counselor  
Chicago Center for Jewish Genetic Disorders

11:00 A.M. **Discussion with speakers and participants**

11:20 A.M. **Economics Panel Discussion**

#### **Moderator:**

David L. Veenstra  
Professor, Pharmaceutical Outcomes Research and  
Policy Program  
University of Washington

#### **Panelists:**

Paul R. Billings  
Chief Medical Officer  
Life Technologies

Scott Grosse  
Research Economist and Associate Director for Health  
Services Research and Evaluation  
Division of Blood Disorders, National Center on Birth  
Defects and Developmental Disabilities  
Centers for Disease Control and Prevention

Scott Ramsey  
Full Member in the Cancer Prevention Program  
Division of Public Health Science  
Fred Hutchinson Cancer Research Center

**12:20 P.M. LUNCH**

---

**SESSION III: UNPROVOKED DVT/PULMONARY EMBOLISM**

---

**Moderators:** Frederick Chen  
Chief of Family Medicine,  
Harborview Medical Center;  
Associate Professor  
Department of Family Medicine  
University of Washington

Wylie Burke  
Professor and Chair  
Department of Bioethics and  
Humanities  
University of Washington

1:05 P.M. **Case presentation:** The individual presents at 40 years of age with progressive left lower extremity swelling and pain. Evaluation reveals an unprovoked deep vein thrombosis in her left lower extremity. She will be managed as an outpatient with low molecular weight heparin and warfarin. Targeted testing includes CYP2C9 and VKORC gene analysis.

1:10 P.M. **Stakeholder Presentations (10 minutes each)**

**Clinician**

Michael F. Murray  
Clinical Chief, Genetics Division  
Department of Medicine  
Brigham and Women's Hospital

**Futurist**

Euan A. Ashley  
Director, Center for Inherited Cardiovascular Disease  
Stanford University School of Medicine

**Patient**

John West  
CEO  
Personalis, Inc.

1:40 P.M. **Discussion with speakers and participants**

2:00 P.M. **Economics Panel Discussion**

## Moderator:

David L. Veenstra  
Professor, Pharmaceutical Outcomes Research and  
Policy Program  
University of Washington

## Panelists:

Paul R. Billings  
Chief Medical Officer  
Life Technologies

Scott Grosse  
Research Economist and Associate Director for Health  
Services Research and Evaluation  
Division of Blood Disorders, National Center on Birth  
Defects and Developmental Disabilities  
Centers for Disease Control and Prevention

Scott Ramsey  
Full Member in the Cancer Prevention Program  
Division of Public Health Science  
Fred Hutchinson Cancer Research Center

**3:00 P.M.      BREAK**

## SESSION IV: CANCER CARE AND SEQUENCING

## Moderators:

Timothy J. Ley  
Professor of Medicine  
and Genetics  
Division of Oncology  
Washington University  
School of Medicine

Wylie Burke  
Professor and Chair  
Department of Bioethics and  
Humanities  
University of Washington

3:15 P.M. **Case Presentation:** The individual presents at age 50 with cough, dyspnea, and chest discomfort. Evaluation reveals a lung mass; bronchoscopy and biopsy reveals a non-small cell lung cancer. Her tumor is found to have variations that allow the use of targeted therapy and with treatment the patient goes into remission.

3:20 P.M. **Stakeholder Presentations (10 minutes each)**

**Clinician**

Kenneth Offit  
Chief, Clinical Genetics Service  
Department of Human Genetics  
Memorial Sloan-Kettering Cancer Center

**Futurist**

Stephen Eck  
Vice President, Global Head of Medical Oncology  
Astellas Pharma Global Development

**Patient**

Richard Heimler  
Lung Cancer Survivor and Advocate

3:50 P.M. **Discussion with speakers and participants**

4:10 P.M. **Economics Panel Discussion**

**Moderator:**

David L. Veenstra  
Professor, Pharmaceutical Outcomes Research and  
Policy Program  
University of Washington

**Panelists:**

Paul R. Billings  
Chief Medical Officer  
Life Technologies

Scott Grosse  
Research Economist and Associate Director for Health  
Services Research and Evaluation  
Division of Blood Disorders, National Center on Birth  
Defects and Developmental Disabilities  
Centers for Disease Control and Prevention

Scott Ramsey  
Full Member in the Cancer Prevention Program  
Division of Public Health Science  
Fred Hutchinson Cancer Research Center

**5:10 P.M. Wrap-up Day 1**

W. Gregory Feero, *Workshop Chair*  
Special Advisor to the Director  
National Human Genome Research Institute

**5:20 P.M. Adjourn Day 1**

**Workshop will recommence at 8:30 A.M. on July 18, 2012**

# **Assessing the Economics of Genomic Medicine: A Workshop**

**July 18, 2012**

**National Academy of Sciences Building  
2101 Constitution Ave., N.W.  
Washington, DC 20037**

---

## **Workshop Objective:**

- To advance discussions around the clinical implementation of genetic and genomic technologies by examining costs associated with the development and use of genetic and genomic information in the care of individual patients.

---

**7:45 A.M. Working Breakfast**

**8:30 A.M. Welcoming remarks**

W. Gregory Feero, *Workshop Chair*  
Special Advisor to the Director  
National Human Genome Research Institute

---

## **SESSION V: RESEARCH ECONOMICS**

---

**8:35 A.M. Overview of major themes and research questions from Day 1**

**9:00 A.M. Stakeholder Perspectives on research questions (5 minutes each)**

**Moderator:** Wylie Burke  
Professor and Chair  
Department of Bioethics and Humanities  
University of Washington

### **Clinician**

James P. Evans  
Bryson Distinguished Professor of Genetics & Medicine  
University of North Carolina at Chapel Hill

## **Researcher**

Katrina Armstrong  
Professor of Medicine  
Associate Director, Abramson Cancer Center  
Division Chief, Division of General Internal Medicine,  
Department of Medicine  
University of Pennsylvania School of Medicine

## **Industry**

Thomas J. White  
Chief Scientific Officer (retired)  
Celera Corporation  
Regent's Lecturer  
University of California, Berkeley

## **Patient**

Mary Lou Smith  
Co-founder  
Research Advocacy Network

## **Public Health**

Ned Calonge  
President and Chief Executive Officer  
The Colorado Trust

## **Hospital system**

Herbert Pardes  
Professor of Psychiatry and Former CEO  
NewYork-Presbyterian Hospital

**10:00 A.M. Audience perspectives**

**10:30 A.M. BREAK**

**10:45 A.M. Economics Panel Discussion**

**Moderator:**

David L. Veenstra  
Professor, Pharmaceutical Outcomes Research and  
Policy Program  
University of Washington

**Panelists:**

Paul R. Billings  
Chief Medical Officer  
Life Technologies

Scott Grosse  
Research Economist and Associate Director for Health  
Services Research and Evaluation  
Division of Blood Disorders, National Center on Birth  
Defects and Developmental Disabilities  
Centers for Disease Control and Prevention

Scott Ramsey  
Full Member in the Cancer Prevention Program  
Division of Public Health Science  
Fred Hutchinson Cancer Research Center

---

**SESSION VI: WRAP-UP**

---

**11:45 A.M. Concluding Remarks**

W. Gregory Feero, *Workshop Chair*  
Special Advisor to the Director  
National Human Genome Research Institute

**12:00 P.M. WORKSHOP ADJOURNS**