

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.
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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
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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
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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
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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

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July 18, 2012

**National Academy of Sciences Building
2101 Constitution Ave., N.W.
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7:45 A.M. Working Breakfast

8:30 A.M. Welcoming remarks

W. Gregory Feero, *Workshop Chair*
Special Advisor to the Director
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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
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Life Technologies

Scott Grosse
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Division of Blood Disorders, National Center on Birth
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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