## POPULATION-BASED CARRIER SCREENING FOR SINGLE GENE DISORDERS: LESSONS LEARNED AND NEW OPPORTUNITIES

February 6-7, 2008 Hilton Washington DC/Rockville Executive Meeting Center Rockville, Maryland

## **Participant List**

### Duane Alexander, M.D.

Director

National Institute of Child Health and Human

Development

National Institutes of Health

Bethesda, MD

## Mara G. Aspinall, M.B.A.

President

Genzyme Corporation

Westborough, MA

## Don Bailey, Ph.D.

Distinguished Fellow

**RTI** International

Research Triangle Park, NC

### Judith Benkendorf, M.S., CGC

Project Manager

American College of Medical Genetics

Bethesda, MD

### Miriam G. Blitzer, Ph.D.

Professor and Head

**Division of Human Genetics** 

Department of Pediatrics

School of Medicine

University of Maryland

Baltimore, MD

#### Michael L. Bloom, Ph.D., M.B.A.

Scientific Review Administrator

National Institute of Arthritis and Musculoskeletal

and Skin Diseases

National Institutes of Health

Bethesda, MD

#### Vence Bonham, J.D.

Senior Advisor to the Director

National Human Genome Research Institute

National Institutes of Health

Bethesda, MD

#### Natasha Bonhomme

Program Manager

Genetic Alliance

Washington, DC

## Joann A. Boughman, Ph.D.

**Executive Vice President** 

American Society of Human Genetics

Bethesda, MD

#### Kristin Brinner, Ph.D.

**AAAS** Fellow

Personalized Health Care Initiative

U.S. Department of Health and Human Services

San Francisco, CA

### Ned Calonge, M.D., M.P.H.

Chief Medical Officer

Colorado Department of Public Health and

Environment

Denver, CO

### Kathleen Calzone, M.S.N.

Senior Nurse Specialist (Research)

Genetics Branch

Center for Cancer Research

National Cancer Institute

National Institutes of Health

Bethesda, MD

### Frederick Chen, M.D., M.P.H.

American Academy of Family Physicians

Seattle, WA

#### Francis S. Collins, M.D., Ph.D.

Director

National Human Genome Research Institute

National Institutes of Health

Bethesda, MD

## Carolyn Constantin, Ph.D., R.N.C.

**Health Scientist** 

Centers for Disease Control and Prevention

Atlanta, GA

## Pam Costa, M.A.

**Acting Director** 

Division of Human Development and Disability Centers for Disease Control and Prevention Atlanta, GA

#### Jennifer Couch, Ph.D.

Program Director

National Cancer Institute

National Institutes of Health

Bethesda, MD

#### Robert J. Desnick, M.D., Ph.D.

Professor and Chairman

Department of Genetics and Genomic Sciences

Mount Sinai School of Medicine

New York University

New York, NY

#### James R. Eckman, M.D., FFACMG

Professor

Department of Hematology and Oncology

School of Medicine

**Emory University** 

Atlanta, GA

#### Louis J. Elsas II, M.D., FFACMG

Professor, Pediatrics and Biochemistry

Emeritus Director, The Dr. John T. Macdonald

Foundation

Center for Medical Genetics

Leonard Miller School of Medicine

University of Miami

Miami, FL

## Greg Evans, Ph.D.

**Program Director** 

**Blood Diseases Branch** 

National Heart, Lung, and Blood Institute

National Institutes of Health

Bethesda, MD

## Andy Faucett, M.S.

Instructor

Department of Human Genetics

School of Medicine

**Emory University** 

Atlanta, GA

#### Greg Feero, M.D., Ph.D.

Chief, Genomic Healthcare Branch

National Human Genome Research Institute

National Institutes of Health

Bethesda, MD

### Phyllis Frosst, Ph.D.

Senior Science Policy Analyst

Policy and Program Analysis Branch

National Human Genome Research Institute

National Institutes of Health

Bethesda, MD

## William A. Gahl, M.D., Ph.D.

Clinical Director

National Human Genome Research Institute

National Institutes of Health

Bethesda, MD

### Maria Y. Giovanni, Ph.D.

Assistant Director for Microbial Genomics and

Advanced Technologies

National Institute of Allergy and Infectious Diseases

National Institutes of Health

Bethesda, MD

## Mark D. Grant, M.D., M.P.H.

Senior Scientist

**Technology Evaluation Center** 

Blue Cross Blue Shield Association

Chicago, IL

#### Carol L. Greene, M.D.

School of Medicine

University of Maryland

Baltimore, MD

#### Anthony Gregg, M.D.

Associate Professor

School of Medicine

University of South Carolina

Columbia, SC

## Rachel Grob, Ph.D., M.A.

Associate Dean of Graduate Studies

Director, Child Development Institute

Sarah Lawrence College

Bronxville, NY

#### Scott Grosse, Ph.D.

Health Economist

Centers for Disease Control and Prevention

Atlanta, GA

### Amelie K. Gubitz, Ph.D.

National Institute of Neurological Disorders and

Stroke

National Institutes of Health

Bethesda, MD

### Alan E. Guttmacher, M.D.

**Deputy Director** 

National Human Genome Research Institute

National Institutes of Health

Bethesda, MD

#### Katrina Gwinn, M.D.

**Program Director** 

National Institute of Neurological Disorders and

Stroke

National Institutes of Health

Bethesda, MD

## James Hanson, M.D.

Director

Center for Developmental Biology and Perinatal

Medicine

National Institute of Child Health and Human

Development

National Institutes of Health

Rockville, MD

### Curtis Harris, M.D.

Chief

Laboratory of Human Carcinogenesis

National Cancer Institute

National Institutes of Health

Bethesda, MD

### Emily L. Harris, Ph.D., M.P.H.

**Epidemiologist** 

National Human Genome Research Institute

National Institutes of Health

Rockville, MD

### Suzanne Hart, Ph.D.

Associate Investigator

Office of the Clinical Director

National Human Genome Research Institute

National Institutes of Health

Bethesda, MD

# Kathryn L. Hassell, M.D.

Director

Colorado Sickle Cell Center

University of Colorado Health Sciences Center

Bethesda, MD

### **Chris Heine**

Claire Altman Heine Foundation, Inc.

Santa Monica, CA

#### Deborah Heine, J.D.

**Executive Director** 

Claire Altman Heine Foundation, Inc.

Santa Monica, CA

#### Eric P. Hoffman, Ph.D.

Director

Research Center for Genetic Medicine

Clark Professor of Pediatrics

Children's National Medical Center

School of Medicine

George Washington University

Washington, DC

## Karen J. Hofman, M.D.

Director

Division of International Science Policy, Planning

and Evaluation

Fogarty International Center

National Institutes of Health

Bethesda, MD

### M.K. Holohan, J.D.

Senior Health Policy Analyst

Policy and Program Analysis Branch

National Human Genome Research Institute

National Institutes of Health

Bethesda, MD

#### R. Rodney Howell, M.D.

Special Assistant to the Director

National Institute of Child Health and Human

Development

National Institutes of Health

Bethesda, MD

## Kathy Hudson, Ph.D.

Director

Genetics and Public Policy Center

Johns Hopkins University

Washington, DC

### Jean Jenkins, Ph.D., R.N., FAAN

Senior Clinical Advisor

Office of the Director

National Human Genome Research Institute

National Institutes of Health

Bethesda, MD

### Carol H. Kasten, M.D.

Geneticist

Medical Officer

National Cancer Institute

National Institutes of Health

Bethesda, MD

### Martin Kharrazi, Ph.D.

Research Scientist Supervisor Genetic Disease Screening Program California Department of Public Health Richmond, CA

#### Sarah Knerr

Post-Baccalaureate Intramural Research Training

National Human Genome Research Institute

National Institutes of Health

Bethesda, MD

## Penny Kyler, M.A., OTR

Public Health Analyst

Maternal and Child Health Bureau

Genetic Services Branch

Health Resources and Services Administration

Rockville, MD

### Marie Y. Mann, M.D., M.P.H.

Maternal and Child Health Bureau

Health Resources and Services Administration

Rockville, MD

## Kimberly A. McAllister, Ph.D.

Program Administrator

National Institute of Environmental Health Sciences

National Institutes of Health

Research Triangle Park, NC

## Joseph D. McInerney, M.A., M.S.

**Executive Director** 

National Coalition for Health Professional Education

in Genetics

Lutherville, MD

#### Catherine McKeon, Ph.D.

Senior Advisor for Genetic Research

National Institute of Diabetes and Digestive and

Kidney Diseases

National Institutes of Health

Bethesda, MD

## Bob McNellis, M.P.H., PA

Director

Science and Education

American Academy of Physician Assistants

Alexandria, VA

### Cynthia Moore, M.D., Ph.D.

Associate Director for Science

Division of Birth Defects and Developmental

Disabilities

National Center on Birth Defects and Developmental

Disabilities

Centers for Disease Control and Prevention

Atlanta, GA

#### Thomas J. Musci, M.D.

University of California, San Francisco

San Francisco Perinatal Associates

San Francisco, CA

## Lawrence M. Nelson, M.D.

Investigator

Intramural Research Program on Reproductive and

Adult Endocrinology

National Institute of Child Health and Human

Development

National Institutes of Health

Bethesda, MD

#### Janet Ohene-Frempong, M.S.

President

J.O. Frempong and Associates

Elkins Park, PA

## Jelili Ojodu, M.P.H.

Senior Manager for Newborn Screening and

Genetics

Association of Public Health Laboratories

Silver Spring, MD

## Richard Olney, M.D., M.P.H.

Team Leader, Pediatric Genetics

National Center on Birth Defects and Developmental Disabilities

Centers for Disease Control and Prevention

Atlanta, GA

## Kenneth A. Pass, Ph.D.

Chief

Laboratory of Molecular Screening Technologies

Wadsworth Center

New York State Department of Health

Albany, NY

## Stephen Pauker, M.D.

Professor of Medicine Tufts-New England Medical Center Tufts University Boston, MA

### Susan P. Pauker, M.D., FACMG

Associate Professor Harvard Medical School Chief Genetics Department Harvard Vanguard Medical Associates Boston, MA

## Stephen Pemberton, Ph.D.

Assistant Professor
Federated Department of History
Rutgers University
New Jersey Institute of Technology and Rutgers
University
Newark, NJ

## **Spencer Perlman**

Vice President, Government Affairs Claire Altman Heine Foundation, Inc. Washington Strategic Consulting Washington, DC

#### Karen Peterson, Ph.D.

Senior Advisor to the Director National Institute of Biomedical Imaging and Bioengineering National Institutes of Health Bethesda, MD

## V.M. Pratt, Ph.D.

Chief Director Molecular Genetics Nichols Institute Quest Diagnostics Chantilly, VA

#### Thomas W. Prior, Ph.D.

Professor Ohio State University Columbus, OH

## Cynthia A. Prows, M.S.N.

Clinical Nurse Specialist
Genetics
Patient Services
Division of Human Genetics
Cincinnati Children's Hospital Medical Center
Cincinnati, OH

## Michele Puryear, M.D., Ph.D.

Chief

Genetic Services Branch Maternal and Child Health Bureau Health Resources and Services Administration Rockville, MD

### Michael A. Rackover, PA-C, M.S.

Program Director and Associate Professor Physician Assistant Program Philadelphia University Philadelphia, PA

## Gurvaneet S. Randhawa, M.D., M.P.H.

Center for Outcomes and Evidence Agency for Healthcare Research and Quality Rockville, MD

#### Kyu Rhee, M.D., M.P.P.

Director

Office of Innovation and Program Coordination National Center on Minority Health and Health Disparities National Institutes of Health Bethesda, MD

### Piero Rinaldo, M.D., Ph.D.

Vice Chair

Academic Affairs and Intramural Practice Department of Laboratory Medicine and Pathology Mayo Clinic Rochester, MN

### Laura Lyman Rodriguez, Ph.D.

Senior Advisor to the Director for Research Policy Office of the Director National Human Genome Research Institute National Institutes of Health Bethesda, MD

### Elisa Ross

President Genetic Disease Foundation Scarsdale, NY

## Winnie Rossi, M.A.

Deputy Director Geriatrics and Clinical Gerontology Program National Institute on Aging National Institutes of Health Bethesda, MD

#### Derek Scholes, Ph.D.

Government Relations Manager American Heart Association Washington, DC

## Pauline Sieverding, J.D., Ph.D.

Scientific Program Manager Health Services Genomics Office of Research and Development U.S. Department of Veterans Affairs Washington, DC

## **Geoff Spencer**

Public Affairs Specialist National Human Genome Research Institute National Institutes of Health Bethesda, MD

## Giovanna M. Spinella, M.D.

Program Consultant Office of Rare Diseases Office of the Director National Institutes of Health Bethesda, MD

#### Danilo A. Tagle, Ph.D., M.S.

Program Director, Neurogenetics National Institute of Neurological Disorders and Stroke National Institutes of Health Bethesda, MD

## Sharon F. Terry, M.A.

President and Chief Executive Officer Genetic Alliance Washington, DC

### Bradford Therrell, Ph.D.

Director

National Newborn Screening and Genetics Resource

University of Texas Health Science Center at San Antonio Austin, TX

## Elizabeth J. Thomson, D.N.Sc., CGC, FAAN

Program Director, ELSI Research Program National Human Genome Research Institute National Institutes of Health Bethesda, MD

## Susan Tinley, Ph.D., R.N.

President International Society of Nurses in Genetics School of Nursing

Creighton University

Omaha, NE

## Alan Trachtenberg, M.D., M.P.H.

Acting Research Director Headquarters Indian Health Service Rockville, MD

# Angela Trepanier, M.S.

President
National Society of Genetic Counselors
Assistant Professor
Center for Molecular Medicine and Genetics
Wayne State University
Detroit, MI

## Santa Tumminia, Ph.D.

Special Assistant to the Director National Eye Institute National Institutes of Health Bethesda, MD

### Clesson Turner, M.D.

Genetics Fellow National Human Genome Research Institute National Institutes of Health Bethesda, MD

## Susan Vasquez

Special Assistant to the Deputy Director National Human Genome Research Institute National Institutes of Health Bethesda, MD

#### Keith Wailoo, Ph.D.

Martin Luther King, Jr. Professor Institute for Health, Health Care Policy, and Aging Research Department of History Rutgers University New Brunswick, NJ

## Bracie Watson, Ph.D.

Program Director National Institute on Deafness and Other Communication Disorders National Institutes of Health Bethesda, MD

## Michael S. Watson, Ph.D., M.S.

Executive Director American College of Medical Genetics Rockville, MD

## Daniel Wattendorf, M.D.

Deputy Director Medical Innovations Office of the Air Force Surgeon General Alexandria, VA

### Meredith Weaver, Sc.M.

Genetic Counselor American College of Medical Genetics Bethesda, MD

### Ellen Werner, Ph.D.

Program Director National Heart, Lung, and Blood Institute National Institutes of Health Bethesda, MD

## Janet K. Williams, Ph.D., R.N., FAAN

Kelting Professor of Nursing University of Iowa Iowa City, IA

## Ran Zhang, Ph.D.

National Institute of Neurological Disorders and Stroke National Institutes of Health Bethesda, MD