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 Award
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
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 Center
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