APPENDIX: WORKSHOP PARTICIPANTS

The following is a list of workshop participants. Being listed as a participant does not imply that

the individuals or the organization that they represent endorses all aspects of this report.

Carolyn Anderson, PNP, MSPH, Minnesota Department of Health

Susan A. Berry, MD, Follow-up and Treatment Subcommittee, Department of Pediatrics,

University of Minnesota

Coleen Boyle, PhD, MS, Follow-up and Treatment Subcommittee Chair, Secretary of Health and

Human Services Advisory Committee on Heritable Disorders in Newborns and Children,

Division of Birth Defects and Developmental Disabilities, National Center on Birth Defects and

Developmental Disabilities, Centers for Disease Control and Prevention

Amy Brower, PhD, National Coordinating Center for the Regional Genetics and Newborn

Screening Collaborative

Christine S. Brown, MS, National PKU Alliance

Ann Marie Comeau, PhD, New England Regional Newborn Screening Program

W. Carl Cooley, MD, Crotched Mountain Foundation, Center for Medical Home Improvement,

Department of Pediatrics, Dartmouth Medical School

Sara Copeland, MD, Genetic Services Branch, Maternal and Child Health Bureau, Health

Resources and Services Administration

Lisa Feuchtbaum, DrPH, MPH, California Department of Public Health

Debra Freedenberg, MD, PhD, Texas Department of State Health Services

Tim A. Geleske, MD, American Academy of Pediatrics, Secretary of Health and Human

Services Advisory Committee on Heritable Disorders in Newborns and Children

Alaina Harris, MSW, MPH, Genetic Services Branch, Maternal and Child Health Bureau, Health

Resources and Services Administration

Katharine B. Harris, MBA, New York State Department of Health

Kathryn Hassell, MD, University of Colorado Health Sciences Center

Alan R. Hinman, MD, MPH, Public Health Informatics Institute

Cynthia F. Hinton, PhD, MS, MPH, Division of Birth Defects and Developmental Disabilities,

National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control

and Prevention

Amy Hoffman, MPH, Newborn Screening Translational Research Network

R. Rodney Howell, MD, Secretary of Health and Human Services Advisory Committee on

Heritable Disorders in Newborns and Children Chair, Department of Pediatrics, Leonard M.

Miller School of Medicine, University of Miami

Celia I. Kaye, MD, PhD, Department of Pediatrics, University of Colorado at Denver School of

Medicine

Alex R. Kemper, MD, MPH, MS, Follow-up and Treatment Subcommittee, Department of

Pediatrics and Duke Clinical Research Institute, Duke University

Mary Kay Kenney, PhD, Maternal and Child Health Bureau, Health Resources and Services

Administration

Christopher A. Kus, MD, MPH, Association of State & Territorial Health Officials, Follow-up

and Treatment Subcommittee, Secretary of Health and Human Services Advisory Committee on

Heritable Disorders in Newborns and Children, New York State Department of Health

Jennifer Lail, MD, Chapel Hill Pediatrics and Adolescents, Chapel Hill, NC

Jill Levy-Fisch, Follow-up and Treatment Subcommittee, Save Babies Through Screening

Foundation

Michele Lloyd-Puryear, Secretary of Health and Human Services Advisory Committee on

Heritable Disorders in Newborns and Children Executive Secretary, Genetic Services Branch,

Maternal and Child Health Bureau, Health Resources and Services Administration

Fred Lorey, PhD, California Department of Public Health

Julie Luedtke, BS, Nebraska State Health Department

Marie Mann, MD, MPH, Genetic Services Branch, Maternal and Child Health Bureau, Health

Resources and Services Administration

Kwaku Ohene-Frempong, MD, Children’s Hospital of Philadephia, Secretary of Health and

Human Services Advisory Committee on Heritable Disorders in Newborns and Children

Alison Reynolds, MBA, National PKU Alliance

Jill F. Shuger, ScM, Genetic Services Branch, Maternal and Child Health Bureau, Health

Resources and Services Administration

Rani Singh, PhD, Department of Human Genetics, Emory University School of Medicine

Phyllis J. Sloyer, RN, PhD, Association of Maternal and Child Health Programs, Florida

Department of Health

Kimberly Symonds, BA, Follow-up and Treatment Subcommittee, Wilson’s Disease Association

Brad Therrell, PhD, National Newborn Screening and Genetics Resource Center

Janet Thomas, MD, The Children’s Hospital, Denver, CO

Vickie Thomson, PhD, Colorado Department of Health and Environment

Tracy L. Trotter, MD, San Ramon Valley Primary Care Group, San Ramon, CA, Secretary of

Health and Human Services Advisory Committee on Heritable Disorders in Newborns and

Children

Jacque Waggoner, Hunter’s Hope Foundation

Mike Watson, PhD, American College of Medical Genetics

Sheila Weiss, MS, Washington State Department of Health

Andrea M. Williams, BA, Education and Training Subcommittee, Children’s Sickle Cell

Foundation, Inc.

Alan E. Zuckerman, MD, Department of Pediatrics, Georgetown University School of Medicine