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Heritable Disorders in Newborns

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HHS Establishes New Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children

HHS Secretary Tommy G. Thompson today appointed 15 members to a new Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children. Heritable disorders are passed from parents to children; many such disorders are treatable if detected early.

The committee will make recommendations to the Secretary on grants and projects to help states and local public health agencies improve screening, counseling and health care services to newborns and children who have or are at risk for heritable disorders. Committee members will also advise the Secretary on policies and priorities to help agencies provide these services.

Established in 2003 to review screening practices for genetic diseases, the committee – including medical doctors, geneticists and a parent/health care consultant – will consider the most appropriate application of universal newborn screening tests, technologies and guidelines. Title XXVI of the Children's Health Act of 2000 established a program to support states in providing screening to reduce death and disease related to heritable disorders in newborns and children.

Voting members include:

R. Rodney Howell, M.D., Ph.D., chairman, Department of Pediatrics, University of Miami School of Medicine and chief of pediatrics, Jackson Children's Hospital, Miami (chair);

William J. Becker, D.O., M.P.H., medical director, Ohio Department of Health, Southeast Ohio Regional Medical Center/University Hospital East, Columbus;

Amy Brower, Ph.D., director, Medical Informatics and Genetics, Third Wave Technologies, Madison, Wis.;

Peter B. Coggins, Ph.D., senior vice-president, PerkinElmer, Inc., president, PerkinElmer Life and Analytical Sciences, Boston;

Gregory A. Hawkins, Ph.D., assistant professor of internal medicine and director, DNA Sequencing Laboratory, Center for Human Genomics, Wake Forest University Baptist Medical Center, Winston-Salem, N.C.;

Piero Rinaldo, M.D., Ph.D., director, Biochemical Genetics Laboratory, Mayo Clinic, Rochester, Minn.; and

Derek Robertson, M.B.A., J.D., parent and health care consultant, Hemophilia Alliance, Inc., Germantown, Md.

Non-voting organizational liaisons are listed as follows:

James W. Collins, Jr., M.D., M.P.H., Advisory Committee on Infant Mortality, associate professor of pediatrics, Northwestern University Medical School and medical director, Neonatal Intensive Care Unit, Children's Memorial Hospital, Chicago;

Reed Vaughn Tuckson, M.D., Advisory Committee on Genetics, senior vice-president for Health and Society, Consumer Health and Medical Care Advancement, United Health Group, Minnetonka, Minn.;

E. Stephen Edwards, M.D., president, American Academy of Pediatrics, also representing other professional

organizations, Elk Grove Village, Ill.; and

Jennifer L. Howse, Ph.D., representing members of the public, president, March of Dimes Foundation, White Plains, N.Y.

Participating HHS agencies and their representatives include:

Health Resources and Services Administration (HRSA), Peter C. van Dyck, M.D., M.P.H.;

Agency for Healthcare Research and Quality, Denise Dougherty, Ph.D.;

Centers for Disease Control and Prevention, Coleen Boyle, Ph.D.; and

National Institutes of Health, Duane Alexander, M.D.

HRSA provides staff support to the committee through its Maternal and Child Health Bureau, directed by Dr. van Dyck.