

May 22, 2013

The Honorable Kathleen Sebelius
Secretary
U.S. Department of Health and Human Services
200 Independence Ave, SW
Washington, DC 20201

Dear Secretary Sebelius,

The undersigned organizations applaud your commitment to improving the health of newborns with the establishment of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (DACHDNC). We sincerely appreciate your swift action to allow this vitally important Advisory Committee to continue its work.

Since the establishment of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children in 2003, we have made great progress advancing the application of technologies, policies, guidelines, and standards for effectively reducing morbidity and mortality in newborns. Over the years, the Committee has developed systematic evidence-based and peer-reviewed recommendations for adding conditions to the Recommended Uniform Screening Panel (RUSP), which now serves as the model for state newborn screening programs. Continuation of this critical Committee will ensure newborns with heritable disorders are identified and continue to receive the highest quality of care. Further, it will allow the consideration of conditions currently under review, including the nomination of Pompe Disease to the RUSP, which was voted on by the Committee earlier this month.

As we mark the 50th anniversary of newborn screening, please know that we are committed to reauthorizing P.L. 110-204, the Newborn Screening Saves Lives Act, and working with you on behalf of families across the nation to ensure that infants continue to receive comprehensive and effective screenings. Thank you again for your leadership in promoting the health of all newborns and families.

Sincerely,

American Academy of Pediatrics
American Association for Clinical Chemistry
American College of Medical Genetics and Genomics
American Congress of Obstetricians and Gynecologists
American Heart Association
Association of Maternal & Child Health Programs
Association of Public Health Laboratories
Association of State and Territorial Health Officials
Fabry Support & Information Group
FOD Family Support Group

Genetic Alliance
Hunter's Hope
Immune Deficiency Foundation
Jeffrey Modell Foundation
Lymphedema Advocacy Group
Madison County Community Health Centers, Inc.
March of Dimes
Mended Little Hearts
Muscular Dystrophy Association
National Adrenal Diseases Foundation
National Association of County and City Health Officials
National Association of Neonatal Nurse Practitioners
National Association of Neonatal Nurses
National Organization for Rare Disorders
National Tay-Sachs and Allied Diseases Association
National Urea Cycle Disorders Foundation
Newborn Coalition
Newborn Foundation
Organic Acidemia Association in the letter
Organization
Purine Research Society
Save Babies Through Screening Foundation
SCID, Angels for Life Foundation
Shire
Society for Inherited Metabolic Disorders
Spastic Paraplegia Foundation
The Legacy of Angels Foundation
The Stop ALD Foundation
Trisomy 18 Foundation
Tuberous Sclerosis Alliance
Voices for America's Children
ZERO TO THREE

cc: Mary Wakefield PhD, RN, Administrator, Health Resources and Services Administration
Michael Lu, MD, MS, MPH, Associate Administrator, Maternal and Child Health Bureau