

May 13, 2014

The Honorable John Boehner
Speaker
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Nancy Pelosi
Democratic Leader
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Eric Cantor
Majority Leader
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Steny Hoyer
Democratic Whip
U.S. House of Representatives
Washington, D.C. 20515

Dear Speaker Boehner, Leader Pelosi, Leader Cantor, and Whip Hoyer:

The undersigned organizations urge you to swiftly schedule a vote on H.R. 1281, the Newborn Screening Saves Lives Reauthorization Act, which was reported favorably by the Energy and Commerce Committee on April 3, 2014. This bipartisan legislation will help ensure that infants continue to receive comprehensive, effective and lifesaving screenings for genetic and endocrine conditions soon after birth. Your leadership on this important legislation will significantly impact the lives of families nationwide.

For the past half-century, virtually every one of the more than 4 million infants born in the United States each year has undergone newborn screening. Newborn screening is a well-established and proven state public health program that identifies newborns with certain genetic, metabolic, hormonal and functional conditions. Initially, affected newborns appear healthy, but can deteriorate quickly and without warning. Approximately 1 in every 300 newborns in the U.S. has a condition that can be detected through screening. With the early detection afforded by newborn screening, affected infants receive prompt treatment, which prevents permanent disability, developmental delay and even death. No child should suffer or die when there is a means to identify and treat these conditions.

Since Congress passed the original Newborn Screening Saves Lives Act (P.L. 110-204) in 2008, there has been significant progress made to establish national newborn screening guidelines and to facilitate comprehensive newborn screening in every state. Prior to passage of P.L. 110-204, the number and quality of newborn screens varied greatly from state to state. In 2002, some states were screening for only four conditions, while others were screening for up to 36. Today, 44 states and the District of Columbia require screening for at least 29 of the 31 treatable core conditions on the Recommended Uniform Screening Panel. This widespread expansion and standardization of newborn screening has led to life-saving treatments and interventions for at least 12,500 newborns diagnosed with genetic and endocrine conditions each year.

The Newborn Screening Saves Lives Reauthorization Act will continue the systematic evidence-based and peer-reviewed process of determining the federal Recommended Uniform Screening Panel, which now serves as the model for state newborn screening programs. If enacted, it would also extend federal programs that provide assistance to states to improve and expand their newborn screening programs; support parent and provider education; and ensure laboratory quality and surveillance for newborn screening programs.

Thank you for your enduring commitment to improving children's health. We look forward to working with you on behalf of families across the nation to advance this important legislation as quickly as possible.

Sincerely,

American Academy of Pediatrics
American Association for Clinical Chemistry
American College of Nurse-Midwives
American Congress of Obstetricians and Gynecologists
American Heart Association
American Public Health Association
Association of Maternal & Child Health Programs
Association of Public Health Laboratories
Association of State and Territorial Health Officials
Everylife Foundation for Rare Diseases
Fabry Support & Information Group
FOD Family Support Group
Friedreich's Ataxia Research Alliance
Families of SMA
Genetic Alliance
Genomera
Hunter's Hope
Immune Deficiency Foundation
Jeffrey Modell Foundation
Lymphedema Advocacy Group
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 Nurses
National Association of Nurse Practitioners
National Organization for Rare Disorders
National Tay-Sachs & Allied Diseases Association
National Urea Cycle Disorders Foundation
Organic Acidemia Association
Save Babies through Screening Foundation
Tuberous Sclerosis Alliance

cc: The Honorable Fred Upton
The Honorable Henry Waxman