

February 22, 2008

The Honorable John Dingell
Chairman
Energy and Commerce Committee
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Joe Barton
Ranking Member
Energy and Commerce Committee
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairman Dingell and Ranking Member Barton:

The undersigned organizations are writing to urge you to schedule an opportunity for the Energy and Commerce Committee to review and vote on the “Newborn Screening Saves Lives Act” S. 1858/H.R. 3825 with the goal of enabling the House to consider the bill as soon as possible. This bipartisan bill will reauthorize Title XXVI of the Children’s Health Act and also authorizes funding to expand and improve current newborn screening programs.

Newborn screening is a public health activity used for the early identification of infants affected by certain genetic, metabolic, hormonal and/or functional conditions. Screening detects disorders in newborns that, if left untreated, can cause disability, intellectual disabilities, serious illness and even death. The American College of Medical Genetics recommends that, at a minimum, every baby be screened for a core set of 29 treatable disorders regardless of the state in which he or she is born.

Parents are often unaware that the number and quality of newborn screens varies from state to state and while newborns are regularly screened and treated for debilitating conditions in some states, in others, screening may not be required and conditions may go undiagnosed and untreated. If diagnosed early, these conditions can be successfully managed, thereby avoiding serious long term complications or even death. Yet, only 16 states and the District of Columbia currently require infants to be screened for all 29 recommended disorders. This means that an estimated 1,000 of the 5,000 babies born every year in the United States with one of the 29 conditions potentially go unscreened.

The “Newborn Screening Saves Lives Act” authorizes a modest amount of funding to help states expand and improve their newborn screening programs, provide much needed educational materials to families and improve follow-up care and treatment of newborns who screen positive for a treatable condition.

On December 13, 2007, the Senate unanimously approved S. 1858 the Newborn Screening Saves Lives Act. The House companion bill, H.R. 3825, was introduced by Representatives Roybal-Allard (D-CA), Michael Simpson (R-ID), Henry Waxman (D-CA) and Tom Reynolds (R-NY) on October 16, 2007.

We respectfully urge you to report the Senate passed version of the “Newborn Screening Saves Lives Act,” which is a carefully crafted, bipartisan bill that garnered unanimous

support in the Senate. 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.

Sincerely,

American Academy of Family Physicians

American Academy of Neurology Professional Association

American Academy of Pediatrics

American Association on Intellectual and Developmental Disabilities

Association of Maternal and Child Health Programs

Association of Public Health Laboratories

BioMarin Pharmaceutical Inc.

Congenital Adrenal Hyperplasia Research, Education and Support (CARES) Foundation

Easter Seals

Hunter's Hope Foundation

March of Dimes Foundation

National Organization for Rare Disorders

Organic Academia Association

Save Babies Through Screening Foundation

Shire

Solvay Pharmaceuticals Inc.

The Arc of the United States

United Cerebral Palsy