

June 11, 2007

The Honorable Edward Kennedy
Chairman
Health, Education, Labor and
Pensions Committee
U.S. Senate
Washington, D.C. 20510

The Honorable Michael Enzi
Ranking Member
Health, Education, Labor and
Pensions Committee
U.S. Senate
Washington, D.C. 20510

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 Kennedy, Ranking Member Enzi, Chairman Dingell and Ranking Member Barton:

The undersigned organizations are writing to urge you to mark up S. 634/H.R. 1634 the “Newborn Screening Saves Lives Act” 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. Currently, only 13 states and the District of Columbia require infants to be screened for all 29 of the recommended disorders. Also, an estimated 1,000 of the 5,000 babies born every year in the United States with one of the 29 core conditions potentially go unscreened through newborn screening. If diagnosed early these conditions can be successfully managed.

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

We are eager to see this measure enacted into law and therefore respectfully request that a mark-up of S.634/H.R. 1634 be scheduled as soon as possible.

Sincerely,

Association of Maternal and Child Health Programs
American Academy of Family Physicians
American Academy of Pediatrics
Association of Public Health Laboratories
Biomarin
Genetic Alliance
Hunter's Hope Foundation
March of Dimes Foundation
National Association of Children's Hospitals
National Association of County and City Health Officials
National MPS Society
National Organization for Rare Disorders
Save Babies Through Screening Foundation
Shire
The Arc of the United States
United Cerebral Palsy

Individuals

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Lucile Packard Children's Hospital
Stanford University Medical Center

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Director, Biochemical Genetics Program
Lucile Packard Children's Hospital
Stanford University Medical Center

CC: Senator Dodd
Senator Hatch
Representative Roybal-Allard
Representative Simpson