

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

Robert D. Steiner, MD  
Professor  
Pediatrics and Molecular and Medical Genetics Vice Chair for Research, Department of  
Pediatrics Deputy Director: Oregon Clinical and Translational Research Institute  
(OCTRI, CTSA grant) Doernbecher Children's Hospital Oregon Health & Science

John P Johnson, MD  
Director, Medical Genetics  
Shodair Hospital  
Helena, MT

Vicki T. Sweet, RN, NP  
Coordinator, Newborn Screening Follow-up  
Lucile Packard Children's Hospital  
Stanford University Medical Center

Gregory M. Enns, MD  
Director, Biochemical Genetics Program  
Lucile Packard Children's Hospital  
Stanford University Medical Center

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