



November 5, 2014

Senator Mike Lee  
316 Hart Senate Office Building  
Washington, DC 20510

Dear Senator Lee:

The American Association for Clinical Chemistry (AACC) urges you to permit final passage of H.R.1281, the Newborn Screening Saves Lives Reauthorization Act, which would preserve recent advances in state newborn screening programs. Since the enactment of the initial law in 2008, the number of states testing for 29 of the 31 treatable core newborn conditions has increased four-fold. Your support is critical to continuing this vital and highly successful federal-state partnership.

Each year, more than 4 million newborns are tested for health conditions that, if left undetected and untreated, could result in death or serious long-term mental and/or physical limitations. The Health Resources and Services Administration estimates that one of every 500-700 newborns has a condition that can be detected through screening.<sup>1</sup> As a result of early testing, more than 12,500 babies in the United States receive life-saving treatments and interventions each year.

If reauthorized, this bipartisan bill will continue to assist state newborn screening programs, such as the Utah Department of Health Newborn Screening program, meet the needs of your constituents. The Utah program currently tests for 38 conditions, including severe combined immunodeficiency (SCID), which is a severe immune deficiency disease that, if left untreated, could prevent an infant from fending off dangerous infections and result in death.

Just recently the Utah screening program reported the first diagnosis of a SCID case since the screening measure was implemented in 2013.<sup>2</sup> The six-week old baby, Calla Hauenstein, is shortly scheduled to receive a bone marrow transplant that will likely save her life. We need your help to make sure that other newborns are promptly tested, diagnosed and treated. One way to achieve this is the reauthorize H.R.1281 this year.

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<sup>1</sup> <http://www.babysfirsttest.org/newborn-screening/screening-facts>

<sup>2</sup> <http://udohnews.blogspot.com/2014/10/new-newborn-screening-test-ids-rare.html>

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Enactment of the Newborn Screening Saves Lives Reauthorization Act will assist Utah and other states identify and treat new conditions, confirm the accuracy of the screening tests, and ensure that children testing positive for a condition receive proper care. This bill also seeks to reduce the time between collecting the specimen, performing the test, and initiating medical intervention when warranted. AACC urges you to allow your colleagues to bring this bill to the Senate floor for final passage. Thank you for your help on this important matter

By way of background, AACC is the principal scientific association of professional laboratorians--including MDs, PhDs and medical technologists. AACC's members develop and use chemical concepts, procedures, techniques and instrumentation in health-related investigations and practice in hospitals, independent laboratories and the diagnostics industry worldwide. The AACC provides international leadership in advancing the practice and profession of clinical laboratory science and medicine and its applications to health care. If you have any questions, please call me at (336) 716-2639, or Vince Stine, PhD, Director, Government Affairs, at (202) 835-8721.

Sincerely,

 

Steven H. Wong, Ph.D., DABCC (TC), FACB  
President, AACC

P.S. Enclosed is AACC's position statement on newborn screening, which will provide additional information on this issue.