

Introductory Remarks of Senator Christopher Dodd (D-CT) on the Newborn Screening Saves Lives Act of 2007

Mr. President, I am pleased today to join with my colleague Senator Hatch to introduce legislation to protect the most vulnerable members of our society: newborn infants. Many people know the joy of parenthood. These parents know the sense of worry about whether their kids are doing well, are feeling well, and are safe. Nothing is of greater importance than the health and well-being of our children.

Thanks to incredible advances in medical technology, it is now possible to test newborns for more than 50 genetic and metabolic disorders. Many of these disorders, if undetected, would lead to severe disability or death. However, babies that are properly diagnosed and treated can, in many cases, go on to live healthy lives. So newborn screening can literally save lives.

Frighteningly, the disorders that newborn screening tests for can come without warning. For most of these disorders, there is no medical history of the condition in the family and no way to predict the health of a baby based on the health of the parents. Although the disorders that are tested for are quite rare, there is a chance that any one newborn will be affected. In that sense, this is an issue that has a direct impact on the lives of all families.

Fortunately, some screening has become common practice in every state. Each year, over four million infants have blood taken from their heel after birth to detect these disorders that could threaten their life and long-term health. As a result, about one in 4,000 babies is diagnosed with one of these disorders. That means that newborn screening could protect the health or save the life of approximately 1,000 newborns each year. That is 1,000 tragedies that can be averted families that can know the joy of a new infant rather than absolute heartbreak.

In 2004, the American College of Medical Genetics (ACMG) completed a report commissioned by the U.S. Department of Health and Human Services which recommended that every baby born in the U.S. be screened for twenty-nine disorders, including certain metabolic conditions and hearing deficiency. Unfortunately, as of February 2007, only 11 States and the District of Columbia require infants to be screened for all twenty-nine of these recommended disorders. If diagnosed early, all of these conditions can be successfully managed or treated to prevent or mitigate severe and often lifelong health problems.

For every baby saved, another two are estimated to be born with potentially detectable disorders that go undetected because they are not screened. These infants and their families face the prospect of disability or death from a preventable disorder. The survival of a newborn may very well come down to the state in which it is born, because not all states test for every detectable disorder.

The Government Accountability Office, GAO, released a report in 2003 highlighting the need for this legislation. According to the report, most states do not educate parents and

health care providers about the availability of tests beyond what is mandated by a State. States also reported that they do not have the resources to purchase the technology and train the staff needed to expand newborn screening programs. Finally, even when States do detect an abnormal screening result, the majority do not inform parents directly.

The legislation that we are introducing today will give states an additional helping hand toward meeting the advisory's committee's recommendation by providing \$25 million for states to expand and improve their newborn screening programs. In order to access these resources, states will be required to commit to screening for all 29 disorders.

Our legislation will also authorize \$15 million for two types of grants. The first seeks to address the lack of information available to health care professionals and parents about newborn screening. Every parent should have the knowledge necessary to protect their child. The tragedy of a newborn's death is only compounded by the frustration of learning that the death was preventable. This bill authorizes grants to provide education and training to health care professionals, state laboratory personnel, families and consumer advocates.

The second type of grant will support States in providing follow-up care for those children diagnosed by a disorder detected through newborn screening. While these families are the fortunate ones, in many cases they are still faced with the prospect of extended and complex treatment and major lifestyle changes. We need to remember that care does not stop at diagnosis.

To ensure the quality of laboratories involved in newborn screening, so that tests are as accurate as possible and infants receive appropriate care, the legislation authorizes \$5 million for the Centers for Disease Control and Prevention, CDC, to carry out a number of functions such as quality assurance for newborn screening tests, performance evaluation services, and technical assistance and technology transfer to newborn screening labs.

In the event of a public health emergency, such as Hurricane Katrina, newborn screening may seem like a low priority. However, if babies aren't tested and, when necessary, treated within the first few days of life, they may suffer irreparable harm or even death. In the wake of a public health crisis, contingency planning for newborn screening is essential. Our legislation requires the CDC, in consultation with the Health Resources and Services Administration, HRSA, to develop a national contingency plan for newborn screening in the event of a public health emergency within 180 days of enactment of the bill.

Finally, the bill directs the CDC, in consultation with HRSA, to establish a national surveillance program for newborn screening, and authorizes \$15 million for that purpose. Such a program will help us conduct research to better understand these rare disorders, and will hopefully lead us toward more effective treatments and cures.

I urge my colleagues to support this important legislation so that every newborn child will have the best possible opportunity that America can offer to live a long, healthy and happy life. I look forward to working with the Chairman of the Health, Education, Labor and Pensions (HELP) Committee, Senator Kennedy, and Ranking Member Enzi to advance this legislation as early as possible.