CARESFoundation
research, education and support for CAH

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Statement of Position on Newborn Screening

CARES Foundation supports universal, comprehensive, mandated newborn screening for every baby including testing for Congenital Adrenal Hyperplasia (CAH) and long-term follow-up for those determined to be affected. Newborn screening saves babies from death, mental retardation and severe disability by allowing for early intervention and timely treatment for certain devastating genetic diseases. Every baby deserves a healthy start at life.

Background Information

- Newborn biochemical screening is simple and inexpensive. It involves no more than collecting a drop of blood from the heel of a newborn at birth on filter paper, allowing it to dry, and then sending it to a laboratory for testing.
- The tests are conducted for all newborns and completed before the infant leaves the hospital.
- Approximately one in 800 babies will be born each year with a genetic disease that can be detected in newborn screening. With approximately 4.2 million babies born in the Untied States each year, **every day 14 babies are at risk of severe mental retardation/disability or dying unnecessarily from a disease that can be screened for at birth as part of a comprehensive screening panel allowing life-saving early intervention.**
- In the United States, more than 2/3 of infants are tested for more than 20 conditions at birth; however, both screening and follow-up are largely inconsistent across the nation.
- Medical care costs (not to mention physical and emotional costs) for a child left undiagnosed for one of the core 29 conditions recommended for testing can easily run to a $1 million over the lifetime of the child. If detected early, however, treatment often is simple and inexpensive.
- **Our nation cannot afford not to screen. Moreover, we have a moral obligation to do so.**

Newborn Screening for CAH in the United States

- Based on a genetic frequency of one in 10,000 to 15,000, 280 to 420 babies are born each year in the United States with CAH. If not detected at birth, these infants will go into adrenal crisis and risk death within a couple of weeks of birth. If detected through newborn screening, however, these children merely need simple and inexpensive medications to live a normal life.
- The cost to screen for CAH is approximately $2 per infant. The cost to treat a child with CAH who was not diagnosed at birth and subsequently suffered adrenal crisis, trauma and possible disability, can run to hundreds of thousands of dollars or more over the child's lifetime.

Recommendation

CARES Foundation fully supports the immediate passage of the Newborn Screening Saves Lives Act (S.1858/H.R.3825) to make mandated, comprehensive screening and long-term follow-up for those determined to be affected universally available in the United States.

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