

SENATE CONCURRENT RESOLUTION NO. 17

BY SENATOR MILLS

A CONCURRENT RESOLUTION

To direct the Department of Health and Hospitals to evaluate and report to the Senate and House committees on health and welfare the health benefits and costs of adding Krabbe disease to the list of mandatory screenings performed on newborns when it is recommended by the United States Department of Health and Human Services Discretionary Advisory Committee on Heritable Disorders in Newborns and Children, the American College of Medical Genetics, and the Louisiana Newborn Screening Advisory Committee.

WHEREAS, Krabbe disease, also known as globoid cell leukodystrophy, is a degenerative disorder that affects the nervous system; and

WHEREAS, Krabbe disease affects one in one hundred thousand persons in the United States; and

WHEREAS, in most cases, signs and symptoms of Krabbe disease develop in babies before six months of age, and the disease usually results in death by age two; and

WHEREAS, initial signs and symptoms often include feeding difficulties, episodes of unexplained fever, stiff posture, and developmental delay, and as the disease progresses, muscles continue to weaken, affecting the infant's ability to move, chew, swallow, and breathe with affected infants also experiencing vision loss and intellectual disability.

THEREFORE, BE IT RESOLVED that the Legislature of Louisiana does hereby direct the Department of Health and Hospitals to evaluate and report to the House and Senate committees on health and welfare the health benefits and costs of adding Krabbe disease to the current list of mandatory newborn screenings to be performed when it is recommended

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by the United States Department of Health and Human Services Discretionary Advisory Committee on Heritable Disorders in Newborns and Children, the American College of Medical Genetics, and the Louisiana Newborn Screening Advisory Committee.

BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the secretary of the Department of Health and Hospitals.

PRESIDENT OF THE SENATE

SPEAKER OF THE HOUSE OF REPRESENTATIVES