SLS 15RS-11 ORIGINAL

2015 Regular Session

SENATE CONCURRENT RESOLUTION NO. 17

BY SENATOR MILLS

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HEALTH/HOSPITALS DEPT. Directs the Department of Health and Hospitals to evaluate and report on the health benefits and costs of adding Krabbe disease to the list of mandatory screenings performed on newborns under certain circumstances.

A CONCURRENT RESOLUTION

2 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 3 Krabbe disease to the list of mandatory screenings performed on newborns when it 4 5 is recommended by the United States Department of Health and Human Services Discretionary Advisory Committee on Heritable Disorders in Newborns and 6 7 Children, the American College of Medical Genetics, and the Louisiana Newborn 8 Screening Advisory Committee. 9 WHEREAS, Krabbe disease, also known as globoid cell leukodystophy, is a 10 degenerative disorder that affects the nervous system; and 11 WHEREAS, Krabbe disease affects one in one hundred thousand persons in the United States; and 12 13 WHEREAS, in most cases, signs and symptoms of Krabbe disease develop in babies 14 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 15 16 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 17 breathe with affected infants also experiencing vision loss and intellectual disability. 18

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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 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.

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SCR 17 Original

The original instrument and the following digest, which constitutes no part of the legislative instrument, were prepared by Christopher D. Adams.

DIGEST 2015 Regular Session

Mills

Requires DHH 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 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.