

SENATE CONCURRENT RESOLUTION NO. 3

BY SENATORS MILLS, HEWITT, PERRY AND GARY SMITH

A CONCURRENT RESOLUTION

To urge and request the Department of Health and Hospitals to submit a report by October 1, 2016, on the health benefits and healthcare costs associated with adding Adrenoleukodystrophy (ALD) to the newborn screening panel and to add ALD to the newborn screening panel no later than August 1, 2017.

WHEREAS, ALD is a lysosomal storage disorder caused by mutations in the ABCD1 gene located on the X chromosome; and

WHEREAS, the overall incidence of ALD in the United States is estimated at 6 per 100,000 births regardless of sex; and

WHEREAS, the most serious form of ALD appears in children between 2.5 and 10 years of age and is associated with rapid neurological decline and death or disability within three years after onset; and

WHEREAS, screening for ALD in a newborn child is not included in newborn screening panels in most states, including Louisiana; and

WHEREAS, the United States Department of Health and Human Services Secretary's Advisory Committee on Heritable Disorders in Newborns recommended to the secretary that ALD be added to the newborn screening panel in September 2015; and

WHEREAS, on February 16, 2016, the secretary of the United States Department of Health and Human Services accepted the recommendation to add ALD to the Recommended Uniform Screening Panel; and

WHEREAS, while the secretary's acceptance did not make this a mandatory screening for the states, it does acknowledge the value and importance to families and newborns of conducting this screening; and

WHEREAS, R.S. 40:1081.2(A)(1) specifically identifies several tests to be conducted on Louisiana newborns and provides the Department of Health and Hospitals with the option to add other genetic conditions at their discretion; and

WHEREAS, R.S. 40:1081.2(A)(1) does not provide deadlines for the Department of Health and Hospitals to add such conditions within their discretion; and

WHEREAS, now that the United States Department of Health and Human Services Secretary's Advisory Committee on Heritable Disorders in Newborns and Children has recommended adding ALD and that recommendation has been approved by the secretary of HHS, it is appropriate for DHH to take proactive steps to protect Louisiana newborns.

THEREFORE, BE IT RESOLVED by the Legislature of Louisiana that the Department of Health and Hospitals submit a report by October 1, 2016, on the health benefits and healthcare costs associated with adding ALD to the newborn screening panel. The healthcare costs reported on shall include costs to the state lab operated through the Office of Public Health and shall also include a financial analysis that details the costs incurred by healthcare facilities and providers associated with testing for ALD in the newborn screening panel and how those costs would be reimbursed by Medicaid and, to the extent determinable, by commercial insurance.

BE IT FURTHER RESOLVED that the Department of Health and Hospitals should add ALD to the newborn screening panel no later than August 1, 2017, under the authority provided in R.S. 40:1081.2(A)(1).

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

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PRESIDENT OF THE SENATE

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SPEAKER OF THE HOUSE OF REPRESENTATIVES