

2016 Regular Session

SENATE CONCURRENT RESOLUTION NO. 3

BY SENATORS MILLS, PERRY AND GARY SMITH

HEALTH/HOSPITALS DEPT. Directs the Department of Health and Hospitals to submit a report by May 1, 2016, and to add Adrenoleukodystrophy (ALD) to the newborn screening panel no later than January 1, 2017.

A CONCURRENT RESOLUTION

To authorize and direct the Department of Health and Hospitals to submit a report by May 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 January 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

1 Health and Human Services accepted the recommendation to add ALD to the Recommended  
2 Uniform Screening Panel; and

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

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

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

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

15 THEREFORE, BE IT RESOLVED by the Legislature of Louisiana that the  
16 Department of Health and Hospitals shall submit a report by May 1, 2016, on the health  
17 benefits and healthcare costs associated with adding ALD to the newborn screening panel.

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

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

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The original instrument and the following digest, which constitutes no part  
of the legislative instrument, were prepared by Christine Arbo Peck.

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DIGEST

SCR 3 Original

2016 Regular Session

Mills

Provides a directive to the Department of Health and Hospitals to submit a report by May 1, 2016, on the health benefits and healthcare costs associated with adding ALD to the newborn screening panel.

Provides that DHH shall add ALD to the newborn screening panel no later than January 1, 2017.