HLS 14RS-2243 REENGROSSED

Regular Session, 2014

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HOUSE CONCURRENT RESOLUTION NO. 81

BY REPRESENTATIVE PEARSON

CHILDREN/NEWBORNS: Directs the Dept. of Health and Hospitals to submit a report to the House Health and Welfare Committee evaluating the health benefits and healthcare costs of adding adrenoleukodystrophy to the mandatory screenings to be performed on a newborn child

A CONCURRENT RESOLUTION

2	To authorize and direct the Department of Health and Hospitals to amend LAC 48:V.6303
3	to add adrenoleukodystrophy to the list of mandatory screenings performed on
4	newborns when it is recommended by the United States Department of Health and
5	Human Services Secretary's Advisory Committee on Heritable Disorders in
6	Newborns and Children, the American College of Medical Genetics, and the
7	Louisiana Newborn Screening Advisory Committee.
8	WHEREAS, adrenoleukodystrophy is a genetically determined neurological disorder
9	that affects one in every seventeen thousand nine hundred boys worldwide; and
10	WHEREAS, the presentation of symptoms occurs somewhere between the ages of
11	four and ten; and
12	WHEREAS, adrenoleukodystrophy affects the brain with demyelination, damage to
13	the myelin sheath, an insulating membrane that surrounds nerve cells in the brain; and
14	WHEREAS, adrenoleukodystrophy does not have any specific treatment regimen and
15	the prognosis is poor; and
16	WHEREAS, the childhood form is a progressive disease that declines with age; and
17	WHEREAS, screening for adrenoleukodystrophy in a newborn child is relatively new
18	and, at this time, the United States Department of Health and Human Services Secretary's
19	Advisory Committee on Heritable Disorders in Newborns and Children, the American

- 1 College of Medical Genetics, and the Louisiana Newborn Screening Advisory Committee
- 2 have not recommended screening newborn children for adrenoleukodystrophy.
- THEREFORE, BE IT RESOLVED by the Legislature of Louisiana that the
- 4 Department of Health and Hospitals shall submit a report to the House Health and Welfare
- 5 Committee evaluating the health benefits and health care cost of adding
- 6 adrenoleukodystrophy to the current list of mandatory newborn screenings to be performed
- 7 when it is recommended by the United States Department of Health and Human Services
- 8 Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, the
- 9 American College of Medical Genetics, and the Louisiana Newborn Screening Advisory
- 10 Committee.
- BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the
- secretary of the Department of Health and Hospitals.

## DIGEST

The digest printed below was prepared by House Legislative Services. It constitutes no part of the legislative instrument. The keyword, one-liner, abstract, and digest do not constitute part of the law or proof or indicia of legislative intent. [R.S. 1:13(B) and 24:177(E)]

Pearson HCR No. 81

Directs the Dept. of Health and Hospitals to submit a report to the House Health and Welfare Committee evaluating the health benefits and healthcare cost of adding adrenoleukodystrophy to the mandatory screenings to be performed on a newborn child.

## Summary of Amendments Adopted by House

## House Floor Amendments to the engrossed concurrent resolution.

- 1. Changed the requirement that the Dept. of Health and Hospitals amend LAC 48:V.6303 to add adrenoleukodystrophy to the mandatory screenings to be performed on a newborn child to a requirement that DHH submit a report to the House Health and Welfare Committee evaluating the health benefits and health care cost of adding adrenoleukodystrophy.
- 2. Deleted reference to LAC 48:V.6303.