# Regular Session, 2014

# HOUSE CONCURRENT RESOLUTION NO. 81

### BY REPRESENTATIVE PEARSON

# CHILDREN/NEWBORNS: Authorizes and directs the Department of Health and Hospitals to amend the administrative rule relative to the mandatory screenings to be performed for a newborn child

1	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

2

4

5

9

11

12

13

14

15

have not recommended screening newborn children for adrenoleukodystrophy; and 3 WHEREAS, the Department of Health and Hospitals promulgates LAC 48:V.6303, the administrative rule that contains the current list of mandatory screenings performed on newborns. 6 THEREFORE, BE IT RESOLVED by the Legislature of Louisiana that the 7 Department of Health and Hospitals shall add adrenoleukodystrophy to the current list of 8 mandatory newborn screenings to be performed when it is recommended by the United States Department of Health and Human Services Secretary's Advisory Committee on 10 Heritable Disorders in Newborns and Children, the American College of Medical Genetics, and the Louisiana Newborn Screening Advisory Committee. BE IT FURTHER RESOLVED that if the United States Department of Health and Human Services Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, the American College of Medical Genetics, and the Louisiana Newborn Screening Advisory Committee do recommend that adrenoleukodystrophy be added to the list of

College of Medical Genetics, and the Louisiana Newborn Screening Advisory Committee

16 mandatory screenings performed on newborns, the secretary of the Department of Health

17 and Hospitals is hereby authorized and directed to amend LAC 48:V.6303 to add

- 18 adrenoleukodystrophy to the list of mandatory screenings performed on newborns.
- 19 BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the
- 20 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 amend LAC 48:V.6303 to add adrenoleukodystrophy to the mandatory screenings to be performed on a newborn child.