

BY REPRESENTATIVE DAVIS

1 A CONCURRENT RESOLUTION

2 To urge and request the Louisiana Department of Health to study the costs and benefits

3 associated with the potential inclusion of all conditions listed on the federal

4 Recommended Uniform Screening Panel in the newborn screening panel of this

5 state, and to report findings of the study to the legislative committees on health and

6 welfare.

7 WHEREAS, the Recommended Uniform Screening Panel (RUSP) is the set of

8 conditions that the secretary of the United States Department of Health and Human Services

9 recommends for inclusion in the newborn screening panel of each state; and

10 WHEREAS, disorders listed on the RUSP are selected based on evidence that

11 supports the potential net benefit of screening, the ability of states to screen for the disorders,

12 and the availability of effective treatments; and

13 WHEREAS, though the RUSP establishes a standardized list of disorders that has

14 been vetted by the federal Advisory Committee on Heritable Disorders in Newborns and

15 Children and recommended by the secretary of the federal health and human services

16 agency, states ultimately determine which disorders are included in their respective newborn

17 screening panels; and

18 WHEREAS, according to the Health Resources and Services Administration of the

19 United States Department of Health and Human Services, most states screen for the majority

20 of disorders on the RUSP and some states also screen for additional disorders; and

1 WHEREAS, certain states such as Florida have taken an incremental approach to
2 including all RUSP-listed conditions in their state newborn screening panels by phasing in
3 conditions over time; and

4 WHEREAS, the newborn screening panel of this state is established in R.S.
5 40:1081.2, which lists disorders for which all newborns in Louisiana must be screened and
6 authorizes the Louisiana Department of Health to add conditions to this list by rule; and

7 WHEREAS, as of the date of filing of this Resolution, the RUSP encompasses at
8 least twenty-two diseases and conditions that are not on Louisiana's newborn screening
9 panel; these include Pompe disease, mucopolysaccharidosis type I, X-linked
10 adrenoleukodystrophy, spinal muscular atrophy, isobutyrylglycinuria,
11 2-methylbutyrylglycinuria, medium-chain ketoacyl-CoA thiolase deficiency, 2,4
12 dienoyl-CoA reductase deficiency, carnitine palmitoyltransferase deficiency (types I and II),
13 carnitine acylcarnitine translocase deficiency, argininemia, citrullinemia type II,
14 hypermethioninemia, benign hyperphenylalaninemia, bipterin defect in cofactor
15 biosynthesis, bipterin defect in cofactor regeneration, tyrosinemia (types II and III),
16 galactose epimerase deficiency, galactokinase deficiency, and T-cell related lymphocyte
17 deficiencies; and

18 WHEREAS, the health and well-being of newborns is a vital public health priority
19 of this state.

20 THEREFORE, BE IT RESOLVED that the Legislature of Louisiana does hereby
21 urge and request the Louisiana Department of Health to study the costs and benefits
22 associated with ultimately adding to the state newborn screening panel all conditions listed
23 on the federal Recommended Uniform Screening Panel which are not presently included in
24 the state panel.

25 BE IT FURTHER RESOLVED that in conducting the study called for in this
26 Resolution, the department shall consider cost-effective and practicable options for
27 achieving the goal of screening for all RUSP-listed conditions including, without limitation,
28 a phase-in approach for adding conditions to the state's newborn screening panel such as that
29 taken by Florida and other states.

1 BE IT FURTHER RESOLVED that in conducting the study requested in this
2 Resolution, the department shall engage, collaborate with, and obtain information and
3 perspective from stakeholder groups as deemed necessary or appropriate by the assistant
4 secretary of the office of public health.

5 BE IT FURTHER RESOLVED that the department shall submit a written report of
6 its findings resulting from the study requested in this Resolution to the House Committee
7 on Health and Welfare and the Senate Committee on Health and Welfare on or before
8 December 31, 2019.

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

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)]

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2019 Regular Session

Davis

Urges and requests the La. Department of Health (LDH) to study the costs and benefits associated with ultimately adding to the state newborn screening panel all conditions listed on the federal Recommended Uniform Screening Panel which are not presently included on the state panel.

Requires LDH to submit a written report of findings resulting from the study to the legislative committees on health and welfare on or before December 31, 2019.