

2016 Regular Session

HOUSE BILL NO. 283

BY REPRESENTATIVES EMERSON AND DUSTIN MILLER

CHILDREN/NEWBORNS: Requires screening of newborns for Krabbe disease

1 AN ACT

2 To amend and reenact R.S. 40:1081.2(A)(1) and to enact R.S. 40:1081.11, relative to
3 newborn screening; to require all newborns to be screened for Krabbe disease; to
4 make technical changes; to require information on Krabbe disease to be posted on
5 the Department of Health and Hospitals' website; and to provide for related matters.

6 Be it enacted by the Legislature of Louisiana:

7 Section 1. R.S. 40:1081.2(A)(1) is hereby amended and reenacted and R.S.
8 40:1081.11 is hereby enacted to read as follows:

9 §1081.2. Tests

10 A.(1) The physician attending a newborn child, or the person attending a
11 newborn child who was not attended by a physician, shall cause the child to be
12 subjected to tests for phenylketonuria, congenital hypothyroidism, sickle cell
13 diseases, biotinidase deficiency, congenital adrenal hyperplasia, carnitine uptake
14 defect, long-chain 3-hydroxyacyl-CoA dehydrogenase deficiency, medium-chain
15 acyl-CoA dehydrogenase deficiency, trifunctional protein deficiency, very long-
16 chain acyl-CoA dehydrogenase deficiency, glutaric acidemia type I, 3-hydroxy-3-
17 methylglutaryl-CoA lyase deficiency, isovaleric acidemia, 3-methylcrotonyl-CoA
18 carboxylase deficiency, methylmalonic acidemia (CBL A,B), beta ketothiolase,
19 methylmalonic acidemia (MUT), propionic acidemia, multiple carboxylase
20 deficiency, argininosuccinate acidemia, citrullinemia type I, homocystinuria, maple
21 syrup urine disease, tyrosinemia type I, cystic fibrosis, Krabbe disease, and other

1 genetic conditions that have been approved by the Department of Health and
2 Hospitals; however, no such tests shall be given to any child whose parents object
3 thereto. ~~Effective July 1, 2007, cystic fibrosis shall be included in the tests that the~~
4 ~~newborn child shall be subject to by the physician attending the newborn child or the~~
5 ~~person attending the newborn child who was not attended by a physician.~~

6 * * *

7 §1081.11. Krabbe disease; public information

8 A. The Department of Health and Hospitals shall develop and maintain
9 information regarding Krabbe disease on its website.

10 B. The information provided by the department pursuant to this Section shall
11 include, at a minimum, all of the following:

12 (1) An explanation of Krabbe disease symptoms, diagnosis, and treatment
13 options.

14 (2) Information on relevant state agency and nonprofit resources, parent
15 support groups, and available Medicaid waiver services.

16 Section 2. This Act shall be known and may be cited as "The Anniston Bazar Act".

17 Section 3. R.S. 40:1081.2(A)(1) as enacted by this Act shall be effective subject to
18 appropriation by the legislature.

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)]

HB 283 Engrossed

2016 Regular Session

Emerson

Abstract: Requires all newborns to be screened for Krabbe disease.

Present law requires the physician attending a newborn child, or the person attending a newborn child who was not attended by a physician, to have the child tested for all of the following:

- (1) Phenylketonuria.
- (2) Congenital hypothyroidism.
- (3) Sickle cell diseases.
- (4) Biotinidase deficiency.
- (5) Congenital adrenal hyperplasia.
- (6) Carnitine uptake defect.
- (7) Long-chain 3-hydroxyacyl-CoA dehydrogenase deficiency.

- (8) Medium-chain acyl-CoA dehydrogenase deficiency.
- (9) Trifunctional protein deficiency.
- (10) Very long-chain acyl-CoA dehydrogenase deficiency.
- (11) Glutaric acidemia type I.
- (12) 3-hydroxy-3-methylglutaryl-CoA lyase deficiency.
- (13) Isovaleric acidemia.
- (14) 3-methylcrotonyl-CoA carboxylase deficiency.
- (15) Methylmalonic acidemia (CBL A,B).
- (16) Beta ketothiolase.
- (17) Methylmalonic acidemia (MUT).
- (18) Propionic acidemia.
- (19) Multiple carboxylase deficiency.
- (20) Argininosuccinate acidemia.
- (21) Citrullinemia type I.
- (22) Homocystinuria.
- (23) Maple syrup urine disease.
- (24) Tyrosinemia type I.
- (25) Other genetic conditions that have been approved by the Dept. of Health and Hospitals.

Proposed law retains present law and adds Krabbe disease to the list of required screenings.

Present law further provides that no such tests shall be given to any child whose parents object.

Proposed law retains present law.

Present law requires the physician attending a newborn child to have the child subjected to tests for cystic fibrosis effective July 1, 2007.

Proposed law retains present law but makes a technical change by relocating the requirement through adding cystic fibrosis to the list of required tests and deleting the current language.

Proposed law requires the Dept. of Health and Hospitals to develop and maintain the following information regarding Krabbe disease on its website:

- (1) An explanation of Krabbe disease symptoms, diagnosis, and treatment options.
- (2) Information on relevant state agency and nonprofit resources, parent support groups, and available Medicaid waiver services.

(Amends R.S. 40:1081.2(A)(1); Adds R.S. 40:1081.11)

Summary of Amendments Adopted by House

The Committee Amendments Proposed by House Committee on Health and Welfare to the original bill:

1. Make technical changes.
2. Make proposed law relative to adding Krabbe disease to the screening panel for newborns subject to appropriation by the legislature.
3. Require DHH to post information regarding Krabbe disease on its website.
4. Designate the Act as "The Anniston Bazar Act".