

2023 Regular Session

HOUSE BILL NO. 200

BY REPRESENTATIVE LAFLEUR

Prefiled pursuant to Article III, Section 2(A)(4)(b)(i) of the Constitution of Louisiana.

CHILDREN/NEWBORNS: Provides relative to newborn screening for certain genetic conditions

1 AN ACT

2 To amend and reenact R.S. 40:1081.2(A)(1) and (5) and (B), relative to the state's newborn
3 screening panel; to require the laboratory established by the Louisiana Department
4 of Health to provide certain tests; to require the provision of a genetic conditions list;
5 to establish guidelines for the genetic conditions list; to provide for an effective date;
6 and to provide for related matters.

7 Be it enacted by the Legislature of Louisiana:

8 Section 1. R.S. 40:1081.2(A)(1) and (5) and (B) are hereby amended and reenacted
9 to read as follows:

10 §1081.2. Tests

11 A.(1) The physician attending a newborn child, or the person attending a
12 newborn child who was not attended by a physician, shall, except as may be
13 otherwise provided in this Section, cause the child to be subjected to tests for
14 ~~phenylketonuria, congenital hypothyroidism, sickle cell diseases, biotinidase~~
15 ~~deficiency, congenital adrenal hyperplasia, carnitine uptake defect, long-chain 3-~~
16 ~~hydroxyacyl-CoA dehydrogenase deficiency, medium-chain acyl-CoA~~
17 ~~dehydrogenase deficiency, trifunctional protein deficiency, very long-chain acyl-~~
18 ~~CoA dehydrogenase deficiency, glutaric acidemia type I, 3-hydroxy-3-~~
19 ~~methylglutaryl-CoA lyase deficiency, isovaleric acidemia, 3-methylcrotonyl-CoA~~
20 ~~carboxylase deficiency, methylmalonic acidemia (CBL A,B), beta ketothiolase,~~

1 ~~methylnmalonic acidemia (MUT), propionic acidemia, multiple carboxylase~~
2 ~~deficiency, argininosuccinate acidemia, citrullinemia type I, homocystinuria, maple~~
3 ~~syrup urine disease, tyrosinemia type I, mucopolysaccharidosis type I (MPS I),~~
4 ~~glycogen storage disorder type II (Pompe), and other all genetic conditions that have~~
5 ~~been approved listed in the rule promulgated by the Louisiana Department of Health~~
6 ~~pursuant to Subsection B of this Section; however, no such tests shall be given to any~~
7 ~~child whose parents or guardians object thereto. ~~Effective July 1, 2007,~~ cystic~~
8 ~~fibrosis shall be included in the tests that the newborn child shall be subject to by the~~
9 ~~physician attending the newborn child or the person attending the newborn child who~~
10 ~~was not attended by a physician.~~

11 * * *

12 (5) ~~The~~ laboratory established by the Louisiana Department of Health
13 pursuant to R.S. 40:1081.1(B) shall provide testing for each condition listed in the
14 rule promulgated by the Louisiana Department of Health pursuant to Subsection B
15 of this Section; however, such ~~The tests testing required in Paragraph (A)(1) and the~~
16 ~~services and facilities required by Paragraphs (A)(3) and (4) of this Section shall be~~
17 ~~subject to available funding for the laboratory tests, follow-up, and treatment.~~

18 B.(1) Pursuant to the rule adopted in accordance with the Administrative
19 ~~Procedure Act,~~ The ~~the~~ Louisiana Department of Health shall set forth a list of, after
20 ~~consultation with medical geneticists from each of the state's medical schools and by~~
21 ~~rule adopted in accordance with the Administrative Procedure Act,~~ add to the genetic
22 ~~conditions for which a newborn shall be tested for in Subsection A of this Section;~~
23 ~~however, no approved test for any genetic condition added shall be given to any~~
24 ~~child whose parents or guardians object thereto.~~

25 (2) No condition shall be added to the list unless it is recommended for
26 inclusion by the Genetic Diseases Program Advisory Committee, referred to in this
27 Subsection as the committee, created within the Louisiana Department of Health
28 pursuant to the Louisiana Administrative Code, LAC 48:V.6901, and the state health
29 officer.

1 (3) The list shall be reviewed by the committee at least annually to determine
 2 whether additional conditions, including conditions added to the United States
 3 Department of Health and Human Services' Recommended Uniform Screening Panel
 4 (RUSP), should be recommended to the state health officer and the Louisiana
 5 Department of Health for inclusion therein.

6 (4)(a) If the Louisiana Department of Health does not, within three years
 7 from the date that a condition added to the RUSP is recommended for adoption by
 8 the committee and the state health officer, adopt such condition by rule, then the
 9 Louisiana Department of Health shall provide to the committee a report on the status
 10 and reasons for the non-adoption every six months thereafter.

11 (b) After adding a genetic condition to the list by rulemaking, the Louisiana
 12 Department of Health shall request a legislative appropriation for any funding
 13 necessary for conducting the test and providing the services required in accordance
 14 with Subsection A of this Section.

15 Section 2. This Act shall become effective upon signature by the governor or, if not
 16 signed by the governor, upon expiration of the time for bills to become law without signature
 17 by the governor, as provided by Article III, Section 18 of the Constitution of Louisiana. If
 18 vetoed by the governor and subsequently approved by the legislature, this Act shall become
 19 effective on the day following such approval.

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 200 Engrossed

2023 Regular Session

LaFleur

Abstract: Removes the conditions listed in the state's newborn screening panel and requires the La. Dept. of Health (LDH) to provide a list of genetic conditions in administrative rule for which a newborn child should be tested.

Present law provides that a physician or person attending to the care of a newborn child shall cause the child to be subjected to a list of genetic conditions provided for in present law that has been approved by LDH.

Proposed law removes the list provided in present law and instead requires LDH to provide a list of genetic conditions in administrative rule for which a newborn child should be tested.

Present law allows the parent of a newborn child to object to testing their child for any genetic condition listed in present law.

Proposed law extends present law to allow the guardian of a newborn child to object to testing his child for any genetic condition listed in the rule promulgated by LDH in accordance with proposed law.

Present law provides that the tests required in present law shall be subject to funding for laboratory test, follow-up, and treatment.

Proposed law requires the laboratory established by LDH, in accordance with present law, to provide testing for each condition listed in the rule promulgated by LDH in accordance with proposed law. Proposed law further provides that the testing, services, and facilities required in proposed law shall be subject to available funding.

Present law requires LDH to add to the genetic conditions tested in present law after consultation with medical geneticists from each of the state's medical schools and in accordance with rules adopted in present law.

Proposed law removes the consultation requirement and instead requires LDH, in accordance with present law, to set forth a list of the genetic conditions for which a newborn child shall be tested.

Proposed law provides that no condition shall be added to the list unless it is recommended for inclusion by the Genetic Diseases Program Advisory Committee and the state health officer.

Proposed law provides that the list shall be reviewed by the committee at least annually to determine whether additional conditions should be recommended to the state health officer and LDH for inclusion.

Proposed law provides that if LDH does not, within three years from the date that a condition added to the Recommended Uniform Screening Panel is recommended for adoption by the committee and the state health officer, adopt such condition by rule, LDH shall provide to the committee a report on the status and reasons for the non-adoption every six months thereafter.

Proposed law further provides that, after adding a genetic condition to the list by rulemaking, LDH shall request a legislative appropriation for any funding necessary for conducting the test and providing the services required in accordance with proposed law.

Effective upon signature of governor or lapse of time for gubernatorial action.

(Amends R.S. 40:1081.2(A)(1) and (5) and (B))