

By Senator Bracy Davis

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A bill to be entitled
An act relating to newborn screenings; providing a
short title; amending s. 383.14, F.S.; revising
rulemaking procedures; requiring that newborns,
beginning on a specified date, be screened for biliary
atresia; requiring the Department of Health to consult
with the Genetics and Newborn Screening Advisory
Council before adopting certain rules; requiring the
department, by a specified date, to implement a
certain education campaign relating to biliary
atresia; creating s. 395.3043, F.S.; requiring
hospitals that provide birthing services to screen for
biliary atresia in a specified manner; providing an
effective date.

Be It Enacted by the Legislature of the State of Florida:

Section 1. This act may be cited as "Mattie's Law."

Section 2. Paragraph (a) of subsection (2) of section
383.14, Florida Statutes, is amended, paragraph (c) is added to
that subsection, and paragraph (i) is added to subsection (3) of
that section, to read:

383.14 Screening for metabolic disorders, other hereditary
and congenital disorders, and environmental risk factors.—

(2) RULES.—

(a) ~~After consultation with the Genetics and Newborn
Screening Advisory Council,~~ The department shall adopt and
enforce rules requiring that every newborn in this state must
~~shall~~:

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1. Before becoming 1 week of age, have a blood specimen collected for newborn screenings;

2. Be tested for any condition included on the federal Recommended Uniform Screening Panel which the council advises the department should be included under the state's screening program. After the council recommends that a condition be included, the department shall submit a legislative budget request to seek an appropriation to add testing of the condition to the newborn screening program. The department shall expand statewide screening of newborns to include screening for such conditions within 18 months after the council renders such advice, if a test approved by the United States Food and Drug Administration or a test offered by an alternative vendor is available. If such a test is not available within 18 months after the council makes its recommendation, the department must ~~shall~~ implement such screening as soon as a test offered by the United States Food and Drug Administration or by an alternative vendor is available;

3. At the appropriate age, be tested for such other metabolic diseases and hereditary or congenital disorders as the department may deem necessary; ~~and~~

4. Beginning January 1, 2027, be screened for biliary atresia by testing the newborn's direct bilirubin levels using the blood specimen collected for newborn screenings; and

5.4- Subject to legislative appropriation, beginning January 1, 2027, be screened for Duchenne muscular dystrophy.

(c) The department shall consult with the Genetics and Newborn Screening Advisory Council before adopting rules regarding screening methods, follow-up procedures, and the

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inclusion of additional conditions in the screening program.

(3) DEPARTMENT OF HEALTH; POWERS AND DUTIES.—The department shall administer and provide certain services to implement the provisions of this section and shall:

(i) By October 1, 2026, implement a statewide public health education campaign to increase public awareness and understanding of biliary atresia and its associated risks. The campaign shall, at a minimum:

1. Educate new and expecting parents on the symptoms of biliary atresia and the importance of early diagnosis.

2. Provide guidance to health care providers licensed under chapters 458, 459, and 464 on strategies for identifying biliary atresia in infants and the risks of delayed treatment.

All provisions of this subsection must be coordinated with the provisions and plans established under this chapter, chapter 411, and Pub. L. No. 99-457.

Section 3. Section 395.3043, Florida Statutes, is created to read:

395.3043 Mandatory newborn screening for biliary atresia.—A hospital that provides birthing services shall screen newborns for biliary atresia as required in s. 383.14(2)(a)4.

Section 4. This act shall take effect July 1, 2026.