

By Senator Bracy Davis

15-00087A-26

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

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

19 Section 2. Paragraph (a) of subsection (2) of section
20 383.14, Florida Statutes, is amended, paragraph (c) is added to
21 that subsection, and paragraph (i) is added to subsection (3) of
22 that section, to read:

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

(2) RULES.—

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

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

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

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

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

54 5.4. Subject to legislative appropriation, beginning
55 January 1, 2027, be screened for Duchenne muscular dystrophy.

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

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59 inclusion of additional conditions in the screening program.

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

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

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

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

72
73 All provisions of this subsection must be coordinated with the
74 provisions and plans established under this chapter, chapter
75 411, and Pub. L. No. 99-457.

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

78 395.3043 Mandatory newborn screening for biliary atresia.—A
79 hospital that provides birthing services shall screen newborns
80 for biliary atresia as required in s. 383.14(2)(a)4.

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