

1 A bill to be entitled
2 An act relating to newborn screenings; providing a
3 short title; amending s. 383.14, F.S.; revising
4 rulemaking procedures; requiring, beginning on a
5 specified date, that newborns to be screened for
6 biliary atresia; requiring the Department of Health to
7 consult with the Genetics and Newborn Screening
8 Advisory Council before adopting certain rules;
9 requiring the department, by a specified date, to
10 implement a certain education campaign relating to
11 biliary atresia; providing an effective date.

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

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

16 **Section 2. Paragraph (a) of subsection (2) of section**
17 **383.14, Florida Statutes, is amended and paragraph (c) is added**
18 **to that subsection and paragraph (i) is added to subsection (3)**
19 **of that section, to read:**

20 383.14 Screening for metabolic disorders, other hereditary
21 and congenital disorders, and environmental risk factors.—

22 (2) RULES.—

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

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

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

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

47 4. Beginning January 1, 2027, be screened for biliary
48 atresia; and

49 5.4. Subject to legislative appropriation, beginning
50 January 1, 2027, be screened for Duchenne muscular dystrophy.

51 (c) The department shall consult with the Genetics and
52 Newborn Screening Advisory Council before adopting rules
53 regarding screening methods, follow-up procedures, and the
54 inclusion of additional conditions in the screening program.

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

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

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

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

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68 All provisions of this subsection must be coordinated with the
69 provisions and plans established under this chapter, chapter
70 411, and Pub. L. No. 99-457.

71 **Section 3.** This act shall take effect July 1, 2026.