

1 A bill to be entitled
 2 An act relating to newborn screenings; amending s.
 3 383.14, F.S.; requiring the Department of Health, upon
 4 the advice of the Genetics and Newborn Screening
 5 Advisory Council, to expand within a specified period
 6 the statewide screening of newborns to include any
 7 condition on the federal Recommended Uniform Screening
 8 Panel, contingent upon the availability of certain
 9 approved screening tests and an appropriation;
 10 requiring the council to determine whether a condition
 11 should be included in the state's screening program
 12 within a specified period after its addition to the
 13 federal panel; providing an effective date.

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

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 17 Section 1. Subsection (2) and paragraph (a) of subsection
 18 (5) of section 383.14, Florida Statutes, are amended to read:

19 383.14 Screening for metabolic disorders, other hereditary
 20 and congenital disorders, and environmental risk factors.—

21 (2) RULES.—

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

25 1. ~~Before, prior to~~ becoming 1 week of age, be subjected

26 | to a test for phenylketonuria;

27 | 2. Be tested for any condition included on the federal
28 | Recommended Uniform Screening Panel which the council advises
29 | the department should be included under the state's screening
30 | program. After the council recommends a condition be included,
31 | the department shall submit a legislative budget request to seek
32 | an appropriation to add testing of the condition to the newborn
33 | screening program. The department shall expand statewide
34 | screening of newborns to include screening for such conditions
35 | within 18 months after the council renders such advice, if a
36 | test approved by the United States Food and Drug Administration
37 | or a test offered by an alternative vendor which is compatible
38 | with the clinical standards established under part I of chapter
39 | 483 is available. If such a test is not available within 18
40 | months after the council makes its recommendation, the
41 | department shall implement such screening as soon as a test
42 | offered by the United States Food and Drug Administration or by
43 | an alternative vendor is approved; and,

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 from time to time.

47 | (b) After consultation with the Office of Early Learning,
48 | the department shall ~~also~~ adopt and enforce rules requiring
49 | every newborn in this state to be screened for environmental
50 | risk factors that place children and their families at risk for

51 increased morbidity, mortality, and other negative outcomes.

52 (c) The department shall adopt such additional rules as
53 are found necessary for the administration of this section and
54 s. 383.145, including rules providing definitions of terms,
55 rules relating to the methods used and time or times for testing
56 as accepted medical practice indicates, rules relating to
57 charging and collecting fees for the administration of the
58 newborn screening program authorized by this section, rules for
59 processing requests and releasing test and screening results,
60 and rules requiring mandatory reporting of the results of tests
61 and screenings for these conditions to the department.

62 (5) ADVISORY COUNCIL.—There is established a Genetics and
63 Newborn Screening Advisory Council made up of 15 members
64 appointed by the State Surgeon General. The council shall be
65 composed of two consumer members, three practicing
66 pediatricians, at least one of whom must be a pediatric
67 hematologist, one representative from each of the four medical
68 schools in the state, the State Surgeon General or his or her
69 designee, one representative from the Department of Health
70 representing Children's Medical Services, one representative
71 from the Florida Hospital Association, one individual with
72 experience in newborn screening programs, one individual
73 representing audiologists, and one representative from the
74 Agency for Persons with Disabilities. All appointments shall be
75 for a term of 4 years. The chairperson of the council shall be

76 | elected from the membership of the council and shall serve for a
77 | period of 2 years. The council shall meet at least semiannually
78 | or upon the call of the chairperson. The council may establish
79 | ad hoc or temporary technical advisory groups to assist the
80 | council with specific topics which come before the council.
81 | Council members shall serve without pay. Pursuant to the
82 | provisions of s. 112.061, the council members are entitled to be
83 | reimbursed for per diem and travel expenses. It is the purpose
84 | of the council to advise the department about:

85 | (a) Conditions for which testing should be included under
86 | the screening program and the genetics program. Within 1 year
87 | after a condition is added to the federal Recommended Uniform
88 | Screening Panel, the council shall consider whether the
89 | condition should be included under the state's screening
90 | program.

91 | Section 2. This act shall take effect July 1, 2017.
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