

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; requiring the council to
 10 determine whether a condition should be included in
 11 the state's screening program within a specified
 12 period after its addition to the federal panel;
 13 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. The department shall expand statewide screening of
31 | newborns to include screening for such conditions within 18
32 | months after the council renders such advice, if a test approved
33 | by the United States Food and Drug Administration or a test
34 | offered by an alternative vendor which is compatible with the
35 | clinical standards established under part I of chapter 483 is
36 | available. If such a test is not available within 18 months
37 | after the council makes its recommendation, the department shall
38 | implement such screening as soon as a test offered by the United
39 | States Food and Drug Administration or by an alternative vendor
40 | is approved; and,

41 | 3. At the appropriate age, be tested for such other
42 | metabolic diseases and hereditary or congenital disorders as the
43 | department may deem necessary from time to time.

44 | (b) After consultation with the Office of Early Learning,
45 | the department shall ~~also~~ adopt and enforce rules requiring
46 | every newborn in this state to be screened for environmental
47 | risk factors that place children and their families at risk for
48 | increased morbidity, mortality, and other negative outcomes.

49 | (c) The department shall adopt such additional rules as
50 | are found necessary for the administration of this section and

51 s. 383.145, including rules providing definitions of terms,
52 rules relating to the methods used and time or times for testing
53 as accepted medical practice indicates, rules relating to
54 charging and collecting fees for the administration of the
55 newborn screening program authorized by this section, rules for
56 processing requests and releasing test and screening results,
57 and rules requiring mandatory reporting of the results of tests
58 and screenings for these conditions to the department.

59 (5) ADVISORY COUNCIL.—There is established a Genetics and
60 Newborn Screening Advisory Council made up of 15 members
61 appointed by the State Surgeon General. The council shall be
62 composed of two consumer members, three practicing
63 pediatricians, at least one of whom must be a pediatric
64 hematologist, one representative from each of the four medical
65 schools in the state, the State Surgeon General or his or her
66 designee, one representative from the Department of Health
67 representing Children's Medical Services, one representative
68 from the Florida Hospital Association, one individual with
69 experience in newborn screening programs, one individual
70 representing audiologists, and one representative from the
71 Agency for Persons with Disabilities. All appointments shall be
72 for a term of 4 years. The chairperson of the council shall be
73 elected from the membership of the council and shall serve for a
74 period of 2 years. The council shall meet at least semiannually
75 or upon the call of the chairperson. The council may establish

76 | ad hoc or temporary technical advisory groups to assist the
77 | council with specific topics which come before the council.
78 | Council members shall serve without pay. Pursuant to the
79 | provisions of s. 112.061, the council members are entitled to be
80 | reimbursed for per diem and travel expenses. It is the purpose
81 | of the council to advise the department about:

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

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

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