

By the Committee on Health Policy; and Senator Book

588-02956-17

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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; requiring the council to determine whether a
9 condition should be included in the state's screening
10 program within a specified period after its addition
11 to the federal panel; 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. Subsection (2) and paragraph (a) of subsection
16 (5) of section 383.14, Florida Statutes, are amended to read:
17 383.14 Screening for metabolic disorders, other hereditary
18 and congenital disorders, and environmental risk factors.—

19 (2) RULES.—

20 (a) After consultation with the Genetics and Newborn
21 Screening Advisory Council, the department shall adopt and
22 enforce rules requiring that every newborn in this state shall:
23 1. Before, ~~prior to~~ becoming 1 week of age, be subjected to
24 a test for phenylketonuria;
25 2. Be tested for any condition included on the federal
26 Recommended Uniform Screening Panel which the council advises
27 the department should be included under the state's screening
28 program. The department shall expand statewide screening of
29 newborns to include screening for such conditions within 18

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30 months after the council renders such advice, if a test approved
31 by the United States Food and Drug Administration or a test
32 offered by an alternative vendor which is compatible with the
33 clinical standards established under part I of chapter 483 is
34 available. If such a test is not available within 18 months
35 after the council makes its recommendation, the department shall
36 implement such screening as soon as a test offered by the United
37 States Food and Drug Administration or by an alternative vendor
38 is available; and

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

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

47 (c) The department shall adopt such additional rules as are
48 found necessary for the administration of this section and s.
49 383.145, including rules providing definitions of terms, rules
50 relating to the methods used and time or times for testing as
51 accepted medical practice indicates, rules relating to charging
52 and collecting fees for the administration of the newborn
53 screening program authorized by this section, rules for
54 processing requests and releasing test and screening results,
55 and rules requiring mandatory reporting of the results of tests
56 and screenings for these conditions to the department.

57 (5) ADVISORY COUNCIL.—There is established a Genetics and
58 Newborn Screening Advisory Council made up of 15 members

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59 appointed by the State Surgeon General. The council shall be
60 composed of two consumer members, three practicing
61 pediatricians, at least one of whom must be a pediatric
62 hematologist, one representative from each of the four medical
63 schools in the state, the State Surgeon General or his or her
64 designee, one representative from the Department of Health
65 representing Children's Medical Services, one representative
66 from the Florida Hospital Association, one individual with
67 experience in newborn screening programs, one individual
68 representing audiologists, and one representative from the
69 Agency for Persons with Disabilities. All appointments shall be
70 for a term of 4 years. The chairperson of the council shall be
71 elected from the membership of the council and shall serve for a
72 period of 2 years. The council shall meet at least semiannually
73 or upon the call of the chairperson. The council may establish
74 ad hoc or temporary technical advisory groups to assist the
75 council with specific topics which come before the council.
76 Council members shall serve without pay. Pursuant to the
77 provisions of s. 112.061, the council members are entitled to be
78 reimbursed for per diem and travel expenses. It is the purpose
79 of the council to advise the department about:

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

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