

By the Committees on Appropriations; and Health Policy; and
Senator Book

576-03777-17

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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; requiring the department to
12 submit a legislative budget request to fund additional
13 testing; providing an effective date.

14
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 to
26 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

576-03777-17

20171124c2

30 program. After the council recommends that a condition be
31 included, the department shall submit a legislative budget
32 request to seek an appropriation to add testing of the condition
33 to the newborn screening program. The department shall expand
34 statewide screening of newborns to include screening for such
35 conditions within 18 months after the council renders such
36 advice, if a test approved by the United States Food and Drug
37 Administration or a test offered by an alternative vendor which
38 is compatible with the clinical standards established under part
39 I of chapter 483 is available. If such a test is not available
40 within 18 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 available; and

44 3. and, 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 are
53 found necessary for the administration of this section and s.
54 383.145, including rules providing definitions of terms, rules
55 relating to the methods used and time or times for testing as
56 accepted medical practice indicates, rules relating to charging
57 and collecting fees for the administration of the newborn
58 screening program authorized by this section, rules for

576-03777-17

20171124c2

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

576-03777-17

20171124c2

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.