

By Senator Book

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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.

12
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. At the appropriate age, be tested for any condition
26 included on the federal Recommended Uniform Screening Panel
27 which the council advises the department should be included
28 under the state's screening program. The department shall expand
29 statewide screening of newborns to include screening for such

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30 conditions within 1 year after the council renders such advice;
31 and

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

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

40 (c) The department shall adopt such additional rules as are
41 found necessary for the administration of this section and s.
42 383.145, including rules providing definitions of terms, rules
43 relating to the methods used and time or times for testing as
44 accepted medical practice indicates, rules relating to charging
45 and collecting fees for the administration of the newborn
46 screening program authorized by this section, rules for
47 processing requests and releasing test and screening results,
48 and rules requiring mandatory reporting of the results of tests
49 and screenings for these conditions to the department.

50 (5) ADVISORY COUNCIL.—There is established a Genetics and
51 Newborn Screening Advisory Council made up of 15 members
52 appointed by the State Surgeon General. The council shall be
53 composed of two consumer members, three practicing
54 pediatricians, at least one of whom must be a pediatric
55 hematologist, one representative from each of the four medical
56 schools in the state, the State Surgeon General or his or her
57 designee, one representative from the Department of Health
58 representing Children's Medical Services, one representative

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59 from the Florida Hospital Association, one individual with
60 experience in newborn screening programs, one individual
61 representing audiologists, and one representative from the
62 Agency for Persons with Disabilities. All appointments shall be
63 for a term of 4 years. The chairperson of the council shall be
64 elected from the membership of the council and shall serve for a
65 period of 2 years. The council shall meet at least semiannually
66 or upon the call of the chairperson. The council may establish
67 ad hoc or temporary technical advisory groups to assist the
68 council with specific topics which come before the council.
69 Council members shall serve without pay. Pursuant to the
70 provisions of s. 112.061, the council members are entitled to be
71 reimbursed for per diem and travel expenses. It is the purpose
72 of the council to advise the department about:

73 (a) Conditions for which testing should be included under
74 the screening program and the genetics program. Within 1 year
75 after a condition is added to the federal Recommended Uniform
76 Screening Panel, the council shall consider whether the
77 condition should be included under the state's screening
78 program.

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