A bill to be entitled
An act relating to newborn screenings; amending s. 383.14, F.S.; requiring the Department of Health, upon the advice of the Genetics and Newborn Screening Advisory Council, to expand within a specified period the statewide screening of newborns to include any condition on the federal Recommended Uniform Screening Panel; requiring the council to determine whether a condition should be included in the state’s screening program within a specified period after its addition to the federal panel; requiring the department to submit a legislative budget request to fund additional testing; providing an effective date.

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

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

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

(2) RULES.—

(a) After consultation with the Genetics and Newborn Screening Advisory Council, the department shall adopt and enforce rules requiring that every newborn in this state shall:
1. Before, prior to becoming 1 week of age, be subjected to a test for phenylketonuria;
2. Be tested for any condition included on the federal Recommended Uniform Screening Panel which the council advises the department should be included under the state’s screening
program. After the council recommends that a condition be included, the department shall submit a legislative budget request to seek an appropriation to add testing of the condition to the newborn screening program. The department shall expand statewide screening of newborns to include screening for such conditions within 18 months after the council renders such advice, if a test approved by the United States Food and Drug Administration or a test offered by an alternative vendor which is compatible with the clinical standards established under part I of chapter 483 is available. If such a test is not available within 18 months after the council makes its recommendation, the department shall implement such screening as soon as a test offered by the United States Food and Drug Administration or by an alternative vendor is available; and

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

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

(c) The department shall adopt such additional rules as are found necessary for the administration of this section and s. 383.145, including rules providing definitions of terms, rules relating to the methods used and time or times for testing as accepted medical practice indicates, rules relating to charging and collecting fees for the administration of the newborn screening program authorized by this section, rules for
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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
Screening Panel, the council shall consider whether the condition should be included under the state’s screening program.

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