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; 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. 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
processing requests and releasing test and screening results,
and rules requiring mandatory reporting of the results of tests
and screenings for these conditions to the department.

(5) ADVISORY COUNCIL.—There is established a Genetics and
Newborn Screening Advisory Council made up of 15 members
appointed by the State Surgeon General. The council shall be composed of two consumer members, three practicing pediatricians, at least one of whom must be a pediatric hematologist, one representative from each of the four medical schools in the state, the State Surgeon General or his or her designee, one representative from the Department of Health representing Children’s Medical Services, one representative from the Florida Hospital Association, one individual with experience in newborn screening programs, one individual representing audiologists, and one representative from the Agency for Persons with Disabilities. All appointments shall be for a term of 4 years. The chairperson of the council shall be elected from the membership of the council and shall serve for a period of 2 years. The council shall meet at least semiannually or upon the call of the chairperson. The council may establish ad hoc or temporary technical advisory groups to assist the council with specific topics which come before the council. Council members shall serve without pay. Pursuant to the provisions of s. 112.061, the council members are entitled to be reimbursed for per diem and travel expenses. It is the purpose of the council to advise the department about:

(a) Conditions for which testing should be included under the screening program and the genetics program. Within 1 year 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.