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. At the appropriate age, 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 1 year after the council renders such advice; 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.

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.

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.