

## CHAPTER 2017-78

### Committee Substitute for Committee Substitute for Senate Bill No. 1124

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 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.

Approved by the Governor June 9, 2017.

Filed in Office Secretary of State June 9, 2017.