By Senator Harris

24-924-98 See HB 3145

A bill to be entitled
An act relating to infant health care; amending ss. 383.14, 383.318, and 467.019, F.S.; providing requirements for screening of infants born in the state for controlled substances and human immunodeficiency virus (HIV) infection; providing duties of the Department of Health, birth centers, and midwives; requiring adoption of rules; deleting an exemption from infant health screening requirements; providing an effective date.

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

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15 16 Section 1. Section 383.14, Florida Statutes, is amended to read:

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383.14 Screening for metabolic disorders, other hereditary and congenital disorders, controlled substances, HIV infection, and environmental risk factors.--

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(1) SCREENING REQUIREMENTS.--To help ensure access to the maternal and child health care system, the Department of Health shall promote the screening of all infants born in Florida for phenylketonuria and other metabolic, hereditary, and congenital disorders known to result in significant impairment of health or intellect, as screening programs accepted by current medical practice become available and practical in the judgment of the department. The department shall also promote the identification and screening of all infants born in this state for controlled substances and human

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immunodeficiency virus (HIV) infection. The department shall

also promote the identification and screening of all infants

 born in this state and their families for environmental risk factors such as low income, poor education, maternal and family stress, emotional instability, substance abuse, and other high-risk conditions associated with increased risk of infant mortality and morbidity to provide early intervention, remediation, and prevention services, including, but not limited to, parent support and training programs, home visitation, and case management. Identification, perinatal screening, and intervention efforts shall begin prior to and immediately following the birth of the child by the attending health care provider. Such efforts shall be conducted in hospitals, perinatal centers, county health departments, school health programs that provide prenatal care, and birthing centers, and reported to the Office of Vital Statistics.

- (a) Prenatal screening.—The department shall develop a multilevel screening process that includes a risk assessment instrument to identify women at risk for a preterm birth or other high-risk condition. The primary health care provider shall complete the risk assessment instrument and report the results to the Office of Vital Statistics so that the woman may immediately be notified and referred to appropriate health, education, and social services.
- (b) Postnatal screening.—A risk factor analysis using the department's designated risk assessment instrument shall also be conducted as part of the medical screening process upon the birth of a child and submitted to the department's Office of Vital Statistics for recording and other purposes provided for in this chapter. The department's screening process for risk assessment shall include a scoring mechanism and procedures that establish thresholds for notification,

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further assessment, referral, and eligibility for services by professionals or paraprofessionals consistent with the level of risk. Procedures for developing and using the screening instrument, notification, referral, and care coordination services, reporting requirements, management information, and maintenance of a computer-driven registry in the Office of Vital Statistics which ensures privacy safequards must be consistent with the provisions and plans established under chapter 411, Pub. L. No. 99-457, and this chapter. Procedures established for reporting information and maintaining a confidential registry must include a mechanism for a centralized information depository at the state and county levels. The department shall coordinate with existing risk assessment systems and information registries. The department must ensure, to the maximum extent possible, that the screening information registry is integrated with the department's automated data systems, including the Florida On-line Recipient Integrated Data Access (FLORIDA) system. Tests and screenings must be performed at such times and in such manner as is prescribed by the department after consultation with the Genetics and Infant Screening Advisory Council and the State Coordinating Council for Early Childhood Services.

(2) RULES.--

(a) After consultation with the Genetics and Infant Screening Advisory Council, the department shall adopt and enforce rules requiring that every infant born in this state shall:

1. Prior to becoming 2 weeks of age, be subjected to a test for phenylketonuria 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.

- 2. Be tested for controlled substances.
- $\underline{\mbox{3. Be tested for human immunodeficiency virus (HIV)}}$ infection.
- (b) After consultation with the State Coordinating Council for Early Childhood Services, the department shall also adopt and enforce rules requiring every infant born 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, including 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 screenings authorized by this section, and rules requiring mandatory reporting of the results of tests and screenings for these conditions to the department.
- (3) DEPARTMENT OF HEALTH; POWERS AND DUTIES.--The department shall administer and provide certain services to implement the provisions of this section and shall:
- (a) Assure the availability and quality of the necessary laboratory tests and materials.
- (b) Furnish all physicians, county health departments, perinatal centers, birthing centers, and hospitals forms on which environmental screening and the results of tests for controlled substances, for human immunodeficiency virus (HIV) infection, and for phenylketonuria and such other disorders for which testing may be required from time to time shall be reported to the department.

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- CODING: Words stricken are deletions; words underlined are additions.

(c) Promote education of the public about the

prevention and management of metabolic, hereditary, and

- followup services to prevent mental retardation, to correct or ameliorate physical handicaps, and for epidemiologic studies, if indicated. Such registry shall be exempt from the provisions of s. 119.07(1).
- (e) Supply the necessary dietary treatment products where practicable for diagnosed cases of phenylketonuria and other metabolic diseases for as long as medically indicated when the products are not otherwise available. Provide nutrition education and supplemental foods to those families eligible for the Special Supplemental Food Program for Women, Infants, and Children as provided in s. 383.011.
- (f) Promote the availability of genetic studies and counseling in order that the parents, siblings, and affected infants may benefit from available knowledge of the condition.
- (g) Have the authority to charge and collect fees for screenings authorized in this section, as follows:
- 1. A fee of \$20 will be charged for each live birth, as recorded by the Office of Vital Statistics, occurring in a hospital licensed under part I of chapter 395 or a birth center licensed under s. 383.305, up to 3,000 live births per licensed hospital per year or over 60 births per birth center per year. The department shall calculate the annual assessment for each hospital and birth center, and this assessment must be paid in equal amounts quarterly. Quarterly,

the department shall generate and mail to each hospital and birth center a statement of the amount due.

2. As part of the department's legislative budget request prepared pursuant to chapter 216, the department shall submit a certification by the department's inspector general, or the director of auditing within the inspector general's office, of the annual costs of the uniform testing and reporting procedures of the infant screening program. In certifying the annual costs, the department's inspector general or the director of auditing within the inspector general's office shall calculate the direct costs of the uniform testing and reporting procedures, including applicable administrative costs. Administrative costs shall be limited to those department costs which are reasonably and directly associated with the administration of the uniform testing and reporting procedures of the infant screening program.

All provisions of this subsection must be coordinated with the provisions and plans established under this chapter, chapter 411, and Pub. L. No. 99-457.

(4) OBJECTIONS OF PARENT OR GUARDIAN. -- The provisions of this section shall not apply when the parent or guardian of the child objects thereto. A written statement of such objection shall be presented to the physician or other person whose duty it is to administer and report tests and screenings under this section.

 $\underline{(4)(5)}$ ADVISORY COUNCIL.--There is established a Genetics and Infant Screening Advisory Council made up of 12 members appointed by the Secretary of Health. The council shall be composed of two consumer members, three practicing pediatricians, at least one of whom must be a pediatric

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hematologist, one representative from each of the four medical 2 schools in the state, the Secretary of Health or his or her 3 designee, one representative from the Division of Children's 4 Medical Services, and one representative from the 5 Developmental Services Program Office of the Department of 6 Children and Family Services. All appointments shall be for a 7 term of 4 years. The chairperson of the council shall be elected from the membership of the council and shall serve for 8 9 a period of 2 years. The council shall meet at least 10 semiannually or upon the call of the chairperson. The council 11 may establish ad hoc or temporary technical advisory groups to assist the council with specific topics which come before the 12 13 council. Council members shall serve without pay. Pursuant to the provisions of s. 112.061, the council members are 14 entitled to be reimbursed for per diem and travel expenses. 15 It is the purpose of the council to advise the department 16 17 about:

- (a) Conditions for which testing should be included under the screening program and the genetics program;
- (b) Procedures for collection and transmission of specimens and recording of results; and
- (c) Methods whereby screening programs and genetics services for children now provided or proposed to be offered in the state may be more effectively evaluated, coordinated, and consolidated.
- Section 2. Paragraph (b) of subsection (3) of section 383.318, Florida Statutes, is amended to read:
- 383.318 Postpartum care for birth center clients and infants.--
- (3) Postpartum evaluation and followup care shall be provided, which shall include:

1 Infant Metabolic screening tests required by s. 383.14. 2 3 Section 3. Subsection (2) of section 467.019, Florida 4 Statutes, is amended to read: 5 467.019 Records and reports.--6 (2) The midwife shall instruct the parents regarding 7 the requirement for an infant screening blood tests test for metabolic diseases, controlled substances, and human 8 9 immunodeficiency virus (HIV) infection, as required by s. 10 383.14 and rules promulgated pursuant thereto, and shall notify the county health department in the county where the 11 birth occurs, within 48 hours following delivery, unless other 12 arrangements for the test have been made by the parents. 13 14 Section 4. This act shall take effect October 1 of the 15 year in which enacted. 16 17 18 HOUSE SUMMARY 19 Requires screening of all infants born in the state for controlled substances and human immunodeficiency virus (HIV) infection. Provides duty of the Department of Health to promote screening and education and adopt and enforce rules. Conforms provisions relating to duties of birth contents and midwires with respect to graphs. 20 21 birth centers and midwives with respect to such 22 screening. Removes a provision that exempts infants from health screening requirements when the parents or guardians object thereto. 23 24 25 26 27 28 29 30 31