

By Representative Heyman

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

12  
13 Be It Enacted by the Legislature of the State of Florida:

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

17           383.14 Screening for metabolic disorders, other  
18 hereditary and congenital disorders, controlled substances,  
19 HIV infection,and environmental risk factors.--

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

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

16 (a) Prenatal screening.--The department shall develop  
17 a multilevel screening process that includes a risk assessment  
18 instrument to identify women at risk for a preterm birth or  
19 other high-risk condition. The primary health care provider  
20 shall complete the risk assessment instrument and report the  
21 results to the Office of Vital Statistics so that the woman  
22 may immediately be notified and referred to appropriate  
23 health, education, and social services.

24 (b) Postnatal screening.--A risk factor analysis using  
25 the department's designated risk assessment instrument shall  
26 also be conducted as part of the medical screening process  
27 upon the birth of a child and submitted to the department's  
28 Office of Vital Statistics for recording and other purposes  
29 provided for in this chapter. The department's screening  
30 process for risk assessment shall include a scoring mechanism  
31 and procedures that establish thresholds for notification,

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

24 (2) RULES.--

25 (a) After consultation with the Genetics and Infant  
26 Screening Advisory Council, the department shall adopt and  
27 enforce rules requiring that every infant born in this state  
28 shall:7

29 1. Prior to becoming 2 weeks of age, be subjected to a  
30 test for phenylketonuria and, at the appropriate age, be  
31 tested for such other metabolic diseases and hereditary or

1 congenital disorders as the department may deem necessary from  
2 time to time.

3 2. Be tested for controlled substances.

4 3. Be tested for human immunodeficiency virus (HIV)  
5 infection.

6 (b) After consultation with the State Coordinating  
7 Council for Early Childhood Services, the department shall  
8 also adopt and enforce rules requiring every infant born in  
9 this state to be screened for environmental risk factors that  
10 place children and their families at risk for increased  
11 morbidity, mortality, and other negative outcomes.

12 (c) The department shall adopt such additional rules  
13 as are found necessary for the administration of this section,  
14 including rules relating to the methods used and time or times  
15 for testing as accepted medical practice indicates, rules  
16 relating to charging and collecting fees for screenings  
17 authorized by this section, and rules requiring mandatory  
18 reporting of the results of tests and screenings for these  
19 conditions to the department.

20 (3) DEPARTMENT OF HEALTH; POWERS AND DUTIES.--The  
21 department shall administer and provide certain services to  
22 implement the provisions of this section and shall:

23 (a) Assure the availability and quality of the  
24 necessary laboratory tests and materials.

25 (b) Furnish all physicians, county health departments,  
26 perinatal centers, birthing centers, and hospitals forms on  
27 which environmental screening and the results of tests for  
28 controlled substances, for human immunodeficiency virus (HIV)  
29 infection, and for phenylketonuria and such other disorders  
30 for which testing may be required from time to time shall be  
31 reported to the department.

1           (c) Promote education of the public about the  
2 prevention and management of metabolic, hereditary, and  
3 congenital disorders and human immunodeficiency virus (HIV)  
4 infection, and the dangers associated with environmental risk  
5 factors, including substance abuse.

6           (d) Maintain a confidential registry of cases,  
7 including information of importance for the purpose of  
8 followup services to prevent mental retardation, to correct or  
9 ameliorate physical handicaps, and for epidemiologic studies,  
10 if indicated. Such registry shall be exempt from the  
11 provisions of s. 119.07(1).

12           (e) Supply the necessary dietary treatment products  
13 where practicable for diagnosed cases of phenylketonuria and  
14 other metabolic diseases for as long as medically indicated  
15 when the products are not otherwise available. Provide  
16 nutrition education and supplemental foods to those families  
17 eligible for the Special Supplemental Food Program for Women,  
18 Infants, and Children as provided in s. 383.011.

19           (f) Promote the availability of genetic studies and  
20 counseling in order that the parents, siblings, and affected  
21 infants may benefit from available knowledge of the condition.

22           (g) Have the authority to charge and collect fees for  
23 screenings authorized in this section, as follows:

24           1. A fee of \$20 will be charged for each live birth,  
25 as recorded by the Office of Vital Statistics, occurring in a  
26 hospital licensed under part I of chapter 395 or a birth  
27 center licensed under s. 383.305, up to 3,000 live births per  
28 licensed hospital per year or over 60 births per birth center  
29 per year. The department shall calculate the annual  
30 assessment for each hospital and birth center, and this  
31 assessment must be paid in equal amounts quarterly. Quarterly,

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

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

17  
18 All provisions of this subsection must be coordinated with the  
19 provisions and plans established under this chapter, chapter  
20 411, and Pub. L. No. 99-457.

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

27 (4)~~(5)~~ ADVISORY COUNCIL.--There is established a  
28 Genetics and Infant Screening Advisory Council made up of 12  
29 members appointed by the Secretary of Health. The council  
30 shall be composed of two consumer members, three practicing  
31 pediatricians, at least one of whom must be a pediatric

1 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  
8 elected from the membership of the council and shall serve for  
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  
12 assist the council with specific topics which come before the  
13 council. Council members shall serve without pay. Pursuant  
14 to the provisions of s. 112.061, the council members are  
15 entitled to be reimbursed for per diem and travel expenses.  
16 It is the purpose of the council to advise the department  
17 about:

18 (a) Conditions for which testing should be included  
19 under the screening program and the genetics program;

20 (b) Procedures for collection and transmission of  
21 specimens and recording of results; and

22 (c) Methods whereby screening programs and genetics  
23 services for children now provided or proposed to be offered  
24 in the state may be more effectively evaluated, coordinated,  
25 and consolidated.

26 Section 2. Paragraph (b) of subsection (3) of section  
27 383.318, Florida Statutes, is amended to read:

28 383.318 Postpartum care for birth center clients and  
29 infants.--

30 (3) Postpartum evaluation and followup care shall be  
31 provided, which shall include:

