383.14. Screening for metabolic disorders, other hereditary and congenital disorders, and environmental risk factors

(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 newborns born in Florida for 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 newborns 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, 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 safeguards 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 by
the State Public Health Laboratory, in coordination with Children's Medical Services, at such times and in such manner as is prescribed by the department after consultation with the Genetics and Newborn Screening Advisory Council and the Office of Early Learning.

(c) Release of screening results.--Notwithstanding any law to the contrary, the State Public Health Laboratory may release, directly or through the Children's Medical Services program, the results of a newborn's hearing and metabolic tests or screenings to the newborn's health care practitioner. As used in this paragraph, the term health care practitioner means a physician or physician assistant licensed under chapter 458; an osteopathic physician or physician assistant licensed under chapter 459; an advanced registered nurse practitioner, registered nurse, or licensed practical nurse licensed under part I of chapter 464; a midwife licensed under chapter 467; a speech-language pathologist or audiologist licensed under part I of chapter 468; or a dietician or nutritionist licensed under part X of chapter 468.

(2) Rules.--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, prior to becoming 1 week 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. 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.

(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 phenylketonuria and such other disorders for which testing may be required from time to time shall be reported to the department.
(c) Promote education of the public about the prevention and management of metabolic, hereditary, and congenital disorders and dangers associated with environmental risk factors.
(d) Maintain a confidential registry of cases, including information of importance for the purpose of followup services to prevent intellectual disabilities, to correct or ameliorate physical disabilities, 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 Nutrition 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 newborns may benefit from available knowledge of the condition.

(g) Have the authority to charge and collect fees for the administration of the newborn screening program authorized in this section, as follows:

1. A fee not to exceed $15 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 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 newborn 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 newborn screening program.

(h) Have the authority to bill third-party payors for newborn screening tests.

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.

(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.

(b) Procedures for collection and transmission of specimens and recording of results.

(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.

Credits

West's F. S. A. § 383.14, FL ST § 383.14