# Florida

## Newborn Genetic Testing & Surveillance System

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<td>FL</td>
<td>STATUTE: F.S. Title XXIX, Chapter 383</td>
<td>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</td>
<td>383.14. …(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.</td>
<td>381.0032 Epidemiological research. (1) The [health] department may conduct studies concerning the epidemiology of diseases of public health significance, such as acquired immune deficiency syndrome and other diseases in Florida. These studies may not duplicate national studies but shall be designed to provide special insight and understanding into Florida-specific problems given this state's unique climate and geography, demographic mix,</td>
<td>NO</td>
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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.

(1)...(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

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<td>The provider shall request any pregnant woman who objects to prenatal risk screening, after the purpose of the screening has been fully explained, to indicate her objection in writing on the screening instrument, and to sign the instrument. The screening instrument to be used is the Healthy Start Prenatal Risk Screening Instrument, DOH Form 3134, 2/01 (English version),</td>
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<td>(2) Epidemiological studies designed by the department shall emphasize practical applications and utility in the control of diseases of public health significance, such as acute or chronic diseases caused by infectious agents, host factors, or toxic substances. These studies shall, to the maximum extent possible, use state and local public health workers as field teams, study design team members, reviewers, and co-authors. Epidemiological studies conducted pursuant to this section shall be directed by the State Health Officer or his</td>
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Updated August 2012. All state statutes and department rules originally accessed online July/Aug 2008. Statute/Rule data not inclusive. For comprehensive or updated language, access complete statute and rules online, at local library or through the state legislature. www.cchfreedom.org
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 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. 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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...

(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 behavioral research on human subjects which is funded or supported in any manner by the department.

The provider is to complete the demographic items (name, address, phone number and type of provider) in the provider section and sign and date the form. [emphasis added]

(2) The provider shall request any parent or guardian who objects to infant (postnatal) risk screening of their child or ward, after the purpose of the screening has been fully explained, to indicate the objection in writing on the screening instrument, and to sign the

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Environmental risk factors that place children and their families at risk for increased morbidity, mortality, and other negative outcomes.

(3)...(d) Maintain a confidential registry of cases, including information of importance for the purpose of follow-up 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)** [public access to records held by public agencies].

**64C-7.006 Newborn Screening Records.** (1) The State Public Health Laboratory and Children’s Medical Services shall maintain records of the results of all screening and follow up testing for these conditions in accordance with department records management procedures. (2) The department shall maintain a confidential newborn screening registry of all abnormal screening results, for the purpose of service delivery and program administration and the registry instrument. The screening instrument to be used is the Healthy Start Infant (Postnatal) Risk Screening Instrument, DOH Form 3135, 2/01 (English version), or DOH Form 3135 H, 2/01 (Creole version), or DOH Form 3135 S, 2/01 (Spanish version), which are incorporated by reference. Copies of the Healthy Start Infant (Postnatal) Risk Screening Instrument can be obtained by writing to: the Office of Maternal and Child Health, Bin A-13 (HSFFM),
will be maintained in accordance with the department’s confidentiality requirements as stated in Rule 64F-10.008, F.A.C.

64C-7.010 Prenatal and Infant (Postnatal) Risk Screening Records.
(1) Prenatal Risk Screening Records
(a) The health care provider shall maintain a completed copy of the Healthy Start Prenatal Risk Screening Instrument in the pregnant women’s medical record.
(b) The provider of care coordination shall initiate documentation on every Healthy Start pregnant woman. That documentation shall contain, at a minimum, a scored prenatal risk screening instrument and record of case disposition, except for participants who are referred based on other factors subsequent to the initial screen. For those participants, documentation in the record shall include documentation of the participant’s risk factors and the record of case disposition.
(c) The department shall maintain a confidential registry of the risk screening results on all pregnant women received from health care providers.

4052 Bald Cypress Way, Tallahassee, FL 32399-1723. If the parent or guardian refuses to sign the instrument, this refusal shall be indicated on the patient’s signature line. The provider is to complete the demographic items (name, address, phone number and type of provider) in the provider section and sign and date the form.

(3) Prenatal and infant (postnatal) risk screening shall not be conducted if the affected pregnant women received from health care...
providers, [emphasis added]

(2) Infant (Postnatal) Risk Screening Records
(a) The health care provider shall assure that a completed copy of the Healthy Start Infant (Postnatal) Risk Screening Instrument is placed in the infant’s medical record.
(b) The provider of care coordination shall initiate documentation on every Healthy Start infant. That documentation shall contain, at a minimum, a scored infant (postnatal) risk screening instrument and record of case disposition, except for participants who are referred based on other factors subsequent to the initial screen. For those participants, documentation in the record shall include documentation of the participant’s risk factors and the record of case disposition.
(c) The department shall maintain a confidential registry of the risk screening results on all infants received from the health care providers. [all emphasis added] woman, parent, or guardian objects to the screening.