



Newborn Screening News

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URGENT NOTICE!

The 2004 NBS specimen collection devices **expire on December 31, 2005**. Specimens collected on these forms after December 31 **will be rejected**.

Contact 512- 458-7661 to order new forms. The cost of each Paid/CHIP/Insurance form is \$19.50, which includes envelopes and address labels if ordered. There is no cost for Medicaid collection devices.

Expired Medicaid forms may be destroyed. For *credit* of expired Paid forms contact 512-458-7111 x2936 for information.

Newborn Screening Project Charter Report

To view the Department of State Health Services departmental workgroup's review of the National Newborn Screening and Genetics Resource Center (NNSGRC) draft report go to the Newborn Screening Case Management homepage at <http://www.dshs.state.tx.us/newborn/>. This document focuses on the draft report received by the department on April 20, 2005. Although the department's review and report was completed before the final NNSGRC report was received, on September 9, 2005, the department is committed to continuing its review and taking the additional recommendations outlined, under consideration.

Publication Number 05-10897
www.dshs.state.tx.us/newborn/

Suggestions for Changes in the Newborn Screening Administrative Rules

HB 790 (reverse page) requires the Department of State Health Services (DSHS) to create an expanded newborn screening program. Within the constraints of available funding, DSHS must design an expanded program that maximizes the number of disorders for which screening will occur. An **RFP** requesting proposals to provide the laboratory testing for the expanded newborn screening program was released on Dec 1, 2005. The scope of the expansion is in the RFP.

The Newborn Screening Rules will need to be amended to accommodate the expanded panel required by HB 790. DSHS is seeking suggestions for possible amendments to the **Newborn Screening Rules** (Texas Administrative Code).

Input should be emailed to:

newborn@dshs.state.tx.us

or mailed to:

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Health Screening Branch - MC 1918
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NOTE: Please go to the Newborn Screening Case Management homepage at <http://www.dshs.state.tx.us/newborn/> to locate the RFP and Administrative Code.



To order free educational materials from the Newborn Screening Program for patients and specimen collection information for

submitters, please call 1-800-252-8023, ext. 2129 or order online:

<http://www.tdh.state.tx.us/newborn/pubs.htm>

relating to the conduct of newborn screening by the Department of State Health Services.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:

SECTION 1. The heading to Chapter 33, Health and Safety Code, is amended to read as follows:

CHAPTER 33. PHENYLKETONURIA, OTHER HERITABLE DISEASES, ~~[AND]~~
HYPOTHYROIDISM, AND CERTAIN OTHER DISORDERS

SECTION 2. Subchapter A, Chapter 33, Health and Safety Code, is amended by adding Section 33.004 to read as follows:

Sec. 33.004. STUDY ON NEWBORN SCREENING METHODOLOGY AND EQUIPMENT. (a) Not later than March 1, 2006, the department shall:

(1) conduct a study to determine the most cost-effective method of conducting newborn screening, including screening for disorders listed in the core uniform panel of newborn screening conditions recommended in the 2005 report by the American College of Medical Genetics entitled "Newborn Screening: Toward a Uniform Screening Panel and System" or another report determined by the department to provide more appropriate newborn screening guidelines, to protect the health and welfare of this state's newborns and to maximize the number of newborn screenings that may be conducted with the funding available for the screening;

(2) determine the disorders to be studied under Subdivision (1) and ensure the study does not examine screening and services provided under Chapter 47; and

(3) obtain proposals or information regarding the conduct of newborn screening and compare the costs of the department performing newborn screening services to the costs of outsourcing screening to a qualified laboratory with at least two years' experience performing newborn screening tests.

(a-1) Not later than October 1, 2005, the department shall review and study the National Newborn Screening and Genetics Resources Center's assessment of the screening program in this state. Based on the findings and recommendations in the assessment, the executive commissioner of the Health and Human Services Commission may adopt rules for the department to implement a newborn screening program. In adopting rules for the newborn screening program, the department and the executive commissioner:

(1) may seek input during the rulemaking process from individuals and groups with an interest or expertise in newborn screening;

(2) may use informal conferences or consultations to obtain opinions on the program as provided by Section 2001.031, Government

Code; and

(3) must provide an opportunity for the individuals and groups described by Subdivision (1) to appear before the department before a notice of proposed rules is given as required by Section 2001.023, Government Code.

(a-2) This subsection and Subsection (a-1) expire January 1, 2007.

(b) In accordance with rules adopted by the executive commissioner of the Health and Human Services Commission, the department may implement a newborn screening program.

(b-1) Not later than March 1, 2006, the department shall file with the governor's office a written report of the results and conclusions of the study conducted by the department under Subsection (a). This subsection expires January 1, 2007.

(c) If the department determines under Subsection (a) that the department's performance of newborn screening services is more cost-effective than outsourcing newborn screening, the department shall obtain the use of screening methodologies, including tandem mass spectrometers, and hire the employees necessary to administer newborn screening under this chapter.

(d) If the department determines under Subsection (a) that outsourcing of newborn screening is more cost-effective, the department shall contract for the resources and services necessary to conduct newborn screening using a competitive procurement process.

(e) The department shall periodically review the newborn screening program as revised under this section to determine the efficacy and cost-effectiveness of the program and determine whether adjustments to the program are necessary to protect the health and welfare of this state's newborns and to maximize the number of newborn screenings that may be conducted with the funding available for the screening.

(f) The department may adjust the amounts charged for newborn screening fees, including fees assessed for follow-up services, tracking confirmatory testing, and diagnosis.

SECTION 3. Section 33.011, Health and Safety Code, is amended by amending Subsection (a) and adding Subsection (a-1) to read as follows:

(a) The physician attending a newborn child or the person attending the delivery of a newborn child that is not attended by a physician shall subject the child to screening tests approved by the department for phenylketonuria, other heritable diseases, ~~[and]~~ hypothyroidism, and other disorders for which screening is required by the department.

(a-1) To the extent funding is available for the screening, the department shall require newborn screening tests to screen for disorders listed in the core uniform panel of newborn screening conditions recommended in the 2005 report by the American College of Medical Genetics entitled "Newborn Screening: Toward a Uniform Screening Panel and System" or another report determined by the department to provide more appropriate newborn screening guidelines to protect the health and welfare of this state's newborns.

SECTION 4. Section 33.014(a), Health and Safety Code, is amended to read as follows:

(a) If, because of an analysis of a specimen submitted under Section 33.011, the department reasonably suspects that a newborn child may have phenylketonuria, another heritable disease, ~~[or]~~ hypothyroidism, or another disorder for which the screening tests are required, the department shall notify the person who submits the specimen that the results are abnormal and provide the test results to that person. The department may notify one or more of the following that the results of the analysis are abnormal and recommend ~~[that]~~ further testing when [is] necessary:

(1) the physician attending the newborn child or the physician's designee;

(2) the person attending the delivery of the newborn child that was not attended by a physician;

(3) the parents of the newborn child;

(4) the health authority of the jurisdiction in which the newborn child was born or in which the child resides, if known; or

(5) physicians who are cooperating pediatric specialists for the program.

SECTION 5. Section 33.031(a), Health and Safety Code, is amended to read as follows:

(a) All newborn children and other individuals under 21 years of age who have been screened, have been found to be presumptively positive through the newborn screening program for phenylketonuria, other heritable diseases, hypothyroidism, or another disorder for which the screening tests are required, and may be financially eligible may be referred to the department's services program for children with special health care needs.

SECTION 6. Section 33.032(a), Health and Safety Code, is amended to read as follows:

(a) Within the limits of funds available for this purpose and in cooperation with the individual's physician, the department may provide services directly or through approved providers to individuals of any age who meet the eligibility criteria specified by board rules on the confirmation of a positive test for phenylketonuria, other heritable diseases, ~~[or]~~ hypothyroidism, or another disorder for which the screening tests are required.

SECTION 7. Not later than November 1, 2006, the Department of State Health Services shall implement the expanded newborn screening program using the most cost-effective methods as determined by the department under Section 33.004, Health and Safety Code, as added by this Act.

SECTION 8. This Act takes effect September 1, 2005