



Newborn Screening News

Volume 6, Issue 4

October 2005

REMINDER!

Specimens are UNACCEPTABLE and will be REJECTED when:

- received WITHOUT a date of collection
- received on EXPIRED collection forms

In August, 2005, the Newborn Screening Program experienced an alarming number of unsatisfactory initial newborn screening specimens – 708. This number represents 2% of all initial newborn screening specimens. It is absolutely vital specimen collection be completed in the appropriate manner as specimen rejection places Texas newborns at risk of mental retardation and even death.

The **#1** unsatisfactory specimen reason was *Patient Information Incomplete or Invalid (434 specimens rejected)*. Specifically, this cause for rejection is due to **specimens received WITHOUT a date of collection.**

The **#2** unsatisfactory specimen reason was *Blood Did Not Soak Through Paper – Incomplete Saturation (67 specimens rejected)*. The **#3** unsatisfactory specimen reason was *Specimen Too Old Upon Receipt (63 specimens rejected)*. The NBS laboratory cannot accept specimens **more than 13 days after collection** (day one is the day of collection).

The Newborn Screening Program has several educational materials to assist you with specimen collection. Please call 1-800-252-8023 ext. 2129 to inquire about these materials.

General submission guidelines for all specimen types submitted for testing can be found at our website:

http://www.dshs.state.tx.us/lab/MRS_intro.shtm.

If we can be of assistance in interpreting these guidelines, please contact us at 1-888-963-7111, ext. 7333.

NBS Specimen Demographic Information for Special Cases

Patient demographic information is needed by Case Management for rapid follow-up of abnormal results to ensure that appropriate confirmatory testing and treatment occurs.

Clarification for Child Protective Services (CPS), Foster and Adopted children:

When patient demographic information is hard to obtain or unavailable for completing the newborn screening card, such as for children that are under the care of or monitored by Child Protective Services, or some cases of foster care, fill in any information that is available and complete the remaining portions of the form as follows:

- Baby's last name field - enter an all alpha character identifier which will allow the submitting facility, when contacted, to identify the child
- Baby's first name field - enter the CPS or foster care case number or record number
- Mom's last name field - enter the word "CPS", "foster" or "adopted"

- Mom's first name field - enter the CPS or foster agency name
- Patient's area/telephone # field – enter the telephone number for the CPS or foster agency contact person

In cases of adoption, it is acceptable to use the adoptive mother's name and contact information.

HIPAA and Newborn Screening

The Health Insurance Portability and Accountability Act (HIPAA) does not prevent the disclosure of private health information to the Newborn Screening Program. Section 164.512(b) permits covered entities to **release private health information to a public health authority** that is authorized by law to collect and receive information for preventing and controlling disease, injury, or disability. This information includes reporting of disease, injury, vital statistics like births, deaths, marriages, divorces, etc., public health investigations, and public health interventions. Under this exception, you are authorized to release information to DSHS, or other public health authorities. Disclosure can be initiated either by the public health authority, such as the DSHS NBS Program, or by the health care provider, for any of the above reasons.

NEWBORN SCREENING BOOKMARKS

The Newborn Screening Program has recently revamped their educational bookmarks. To order call 1-800-252-8023 ext. 2129 or order online at: <http://www.dshs.state.tx.us/newborn/pubs.shtm>



NBS Celebrates 40th Birthday

The Texas Newborn Screening Program was officially "born" by legislative statute in 1965. The

first disorder for which infants were screened was Phenylketonuria (PKU).

In subsequent years, galactosemia (1979), congenital hypothyroidism (1980), hemoglobinopathies (1983), and congenital adrenal hyperplasia – CAH (1989) were added to the panel.

Currently, DSHS receives approximately 750,000 neonatal specimens annually, screening each specimen for seven disorders (three hemoglobinopathies). This translates to more than 3,750,000 tests performed per year. The annual number of specimens received by the NBS Laboratory increases approximately 2% each year.

The conditions screened for by the Texas Newborn Screening Program are chosen because:

- the disorder occurs with significant frequency
- an inexpensive and reliable method of testing exists
- an effective treatment/intervention exists
- if untreated, the baby may die or develop severe mental retardation
- the affected baby may appear normal at birth.

On behalf of the Texas Newborn Screening Program, I wish to thank all of you for working with our program to help us ensure early identification of conditions that can lead to catastrophic health problems for our most vulnerable Texans.

Margaret Drummond-Borg, MD, Manager
Health Screening Branch



To order free education 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>