



Newborn Screening News

Volume 8, Issue 4

October 2007

It's Not Just PKU

Confusion among doctors, hospitals and parents is created when newborn screening tests are called "PKU tests" or "PKU's".

The term "An Abnormal PKU" is often used and misinterpreted as an abnormal result for any 1 of 27 disorders. Parents look for information on PKU, when in fact, another disorder is in question.

To avoid misleading parents please make every effort to call the test a "Newborn Screening Test" rather than a "PKU".

THANK YOU.
Texas Newborn Screening



When a child or teenager has a serious medical condition, everyone in the family is affected. For more than two decades, Starlight Starbright Children's Foundation has dedicated itself to helping seriously ill children and their families cope with their pain, fear and isolation through entertainment, education and family activities. Starlight Starbright's programs have been proven to distract children from their pain, help them better understand and manage their illnesses, and connect families facing similar challenges so that no one feels alone. Serving more than 180,000 children each month, Starlight Starbright's array of outpatient,

hospital-based and Web offerings provide ongoing support for children and families — before, during and after medical treatment. To learn more visit www.starlight.org.

Laboratory Web-based System

The NBS Program is in the process of developing a web-based system with access to NBS data entry screens and final NBS test result reports. Features of the system will include:

- Secure web-based entry of NBS patient demographic information at the hospital site (with accompanying labels)
- Secure online access to final NBS test result reports
- Secure HL7 electronic transfer of NBS patient demographic information and test results for facilities with file transfer capabilities

If your facility is interested in participating, please e-mail Donna Williams at your earliest convenience, as there will be a limited number of facilities set up in the initial phase of this project. Please e-mail your facility name, Submitter ID, contact name and phone number to: Donna.Williams@dshs.state.tx.us. For general questions, you may also contact Ms. Williams at 1-888-963-7111 ext. 2715, and technical questions can be directed to Tony Banks at 1-888-963-7111 ext. 7319.

Specimen Collection Form "05" Expiration Date Important Information:

Specimens received on "05-" forms will be **REJECTED**. Any form with a **serial number beginning with "05-" expired on Dec. 31, 2006**. The 2005 forms were printed with the **wrong Date of Expiration**. The **first two digits** of the **form serial number** are the **Year**

of **Manufacture**. Specimen collection forms expire two years following manufacture.

UNSATISFACTORY SPECIMENS!

The **number 1** cause of an unsatisfactory specimen which must be rejected by the Newborn Screening Laboratory is **Patient information incomplete or invalid**.

This is usually due to specimens being submitted without a **DATE OF COLLECTION**. The specimen Date of Collection must include the YEAR and must be LEGIBLE!

The Clinical Laboratory Improvement Amendments (CLIA) of 1988 require that all laboratory specimens **without a date of collection be rejected** to ensure the quality of test results. To maintain CLIA licensure the state laboratory must be in compliance with CLIA requirements.

It *is* also important to provide complete demographic information about the newborn in order to obtain accurate results and to assist the Newborn Screening Case Management Branch to locate an infant with an abnormal screen.

Please do not hesitate to contact the Newborn Screening Laboratory with questions regarding specimen collection at:
1-800-252-8023 ext. 7333 or email us at newborn@dshs.state.tx.us

REMINDER! Specimen Collection Form "06" Expiration Date 12/31/2007 Important Information:

Specimens received on "06-" cards that are collected after 12/31/2007 will be **REJECTED**. Any form with a **serial number beginning with "06-" will expire on Dec. 31, 2007**. Use these forms first.

The **first two digits** of the form **serial number** are the **Year of Manufacture**. Specimen Collection Forms Expire Two Years following manufacture.

Year of Manufacture	Date of Expiration
2005	12/31/2006
2006	12/31/2007
2007	12/31/2008

Specimens collected on Expired Forms are **REJECTED**.

Questions can be addressed to newborn@dshs.state.tx.us or by calling 1-800-252-8023 ext. 7333.

Genetic Testing for Galactosemia

The DSHS Laboratory Services Section is pleased to announce the DNA Analysis Laboratory is now offering a molecular testing Service for Galactosemia. This test detects three common Classic Galactosemia mutations, and a frequent Duarte variant in the galactose-1-phosphate uridyl transferase (GALT) gene. This service is part of the Newborn Screening Program.


Fee-for-service testing is available to provide genetic testing of the GALT gene in other individuals with Galactosemia or to determine carrier status in family members of the patients. Specimens will need to be submitted to the DSHS Laboratory by physician request on the G-1B form.

If you have any questions, please contact the DNA Analysis Laboratory at 512-458-7158.

PROGRAM NOTE:

Please notify the DSHS Laboratory of any changes in your mailing address, phone and/or fax numbers. Email the changes to newborn@dshs.state.tx.us or call 1-800-252-8023 ext. 7333 with the correct information. Please include your submitter number and a contact person.

Thank you.



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: <https://www.dshs.state.tx.us/newborn/pubs.shtm>