Newborn Screening News

Volume 7, Issue 4 October 2006

Expanded Newborn Screening Frequently Asked Questions

Q. When will the program expansion be implemented?

A. Screening for 27 disorders will begin in early 2007.

Q. After expansion of the program in early 2007, what will the screening cover?

A. Beginning in early 2007, newborns will be screened for 27 disorders. They are:
Six amino acid disorders: argininosuccinic acidemia, citrullinemia, homocystinuria, maple syrup urine disease, phenylketonuria (PKU) and tyrosinemia type I;
Two endocrine disorders: congenital adrenal hyperplasia and congenital hypothyroidism;
Five fatty acid oxidation disorders: medium chain acyl-coenzyme A dehydrogenase (MCAD) deficiency, carnitine uptake defect, long-chain hydroxyacyl-coenzyme A dehydrogenase deficiency, trifunctional protein deficiency and very long-chain acyl-coenzyme A dehydrogenase deficiency;
Three hemoglobinopathies: sickle cell anemia, sickle beta thalassemia and sickle-hemoglobin C disease;
Nine organic acid disorders: 3-methylcrotonyl-coenzyme A carboxylase deficiency, beta-ketothiolase deficiency, glutaric acidemia type I, hydroxymethylglutaric aciduria, isovaleric acidemia, methylmalonic acidemia (Cbl A and Cbl B forms), methylmalonic acidemia (mutase deficiency form), multiple carboxylase deficiency and propionic acidemia; and
Two other disorders: biotinidase deficiency and galactosemia.

Q. Why are two screens required in Texas?

A. Standard practice is to take the first sample early, during the hospital stay, to detect some disorders at the earliest possible chance. In some cases, the first sample may not identify all abnormal screens, and a disorder may be detected only on the second screen.

Q. Why is the program being expanded?

A. Nationally, the American College of Medical Genetics (ACMG), with the support of the federal Health Resources and Services Administration (HRSA), recommends that all states screen for a specific set of disorders. In Texas, the 79th Legislature in 2005 mandated that DSHS expand to the ACMG-recommended panel of disorders as funding allowed.

Q. Can parents opt out of having their newborn screened?

A. Yes. A parent can refuse the screen for religious reasons.

Q. Will screening for these new disorders mean more blood will be needed from babies?

A. No, the amount of blood required will remain the same.

Q. Will the expansion mean an increase in the price of the test and materials?

A. The cost for test and materials currently is $19.50. The expanded testing, materials and follow-up are anticipated to cost $29.50.

Q. Who pays for the screening?

A. The health care provider or facility sending the specimen to the laboratory buys the specimen collection kit for private pay patients. How these patients are billed is determined by the commercial insurance carrier. DSHS provides specimen collection kits at no cost to those covered by Medicaid and Title V. DSHS is reimbursed by Medicaid and Title V.

Q. What needs to be done for the expansion?

A. The laboratory must be made ready to receive new technology. New staff will need to be hired and trained to perform the additional tests and to follow up on abnormal results.

Q. How many additional laboratory staff members will be added to the laboratory for the expansion?

A. A total of 17 staff members will be added: 13 in the analytical area, one in demographic entry area and three in the specimen receiving area.

Q. How many machines will be installed?

A. The DSHS laboratory will install 10 Tandem Mass Spectrometers (MS/MS).

Q. With so few cases diagnosed, why is the screening of all children important?

A. While ultimately a small number of children are identified with disorders, the impact of these conditions on the physical and emotional health and financial resources of these children and their families would be much more significant without early identification and treatment.

Q. What will be the turnaround time for the new testing?

A. It is anticipated that preliminary abnormal results will be reported to case management and follow-up staff within three days. Reports of final results will be available within five days. This time is based on the receipt of a quality specimen with complete information.

Q. Why not add screening for cystic fibrosis?

A. The 79th Texas Legislature in 2005 mandated that DSHS expand to the ACMG-recommended panel of disorders as funding allowed and appropriated $3.1 million. The startup funding allows 20 additional disorders to be added to the screening panel. Cystic fibrosis startup would require an additional $2 million to $3 million.

Q. Do newborns receive a hearing screening?

A. All newborns in Texas born in a hospital or birthing center must either be offered a hearing screen or referred to a facility that offers one. About 98 percent of all newborns are screened for hearing. When the law was enacted in 1999, some birth facilities in sparsely populated areas of the state were given an exemption from the law. Since that time, most exempt birth facilities in Texas have chosen to offer the hearing screen, and there currently are fewer than 10 birth facilities that do not provide the hearing screen. Those that do not offer the screen refer families to facilities that do provide the hearing screen. Families who have home births should ask their midwife for a referral to a local pediatric audiologist for a hearing screen.

Q. What can parents do to get a hearing screen for their newborn?

A. If parents are not offered a hearing screen or a referral for a hearing screen for their child or do not receive the results of the screen, they should ask their health care provider about it.

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

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REMINDER!

Specimen Collection Form Expiration Date Important Information:

Specimens received on "05-" cards that are collected after 12/31/2006 will be **REJECTED**. The 2005 forms were printed with the **wrong Date of Expiration**. Any form with a **serial number beginning with "05-" will expire on Dec. 31, 2006.** 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

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

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TEXAS Department of State Health Services

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