

**Tennessee Department of Health
Women's Health & Genetics**

630 Hart Lane
Nashville, TN 37247
Phone # 615-262-6304
Fax # 615-262-6458



[Newborn Hearing](#)
Phone # 615-262-6160

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Newborn Screening adds new disease for 2008

Tennessee NBS Program is now screening for a total of 41 disorders. It is truly not just a "PKU" anymore. A NBS is required on every baby born in this state and should be done between 24-48 hours after birth unless there are extenuating circumstances. These circumstances include a baby being transfused or transferred which would warrant the NBS to be done prior to either of these events even if it's less than 24 hrs. By collecting the NBS in a timely manner, it allows prompt treatment of a baby once a disorder is found.

Prompt treatment means prevention of mental retardation and even death in some cases.

Some of these disorders screened for (although not inclusive) include: Galacto-

semia, Hemoglobinopathies, Congenital Adrenal Hyperplasia, Congenital Hypothyroidism, Biotinidase Deficiency, Cystic Fibrosis, and multiple Amino Acid, and Organic and Fatty Acid Disorders.

Babies with these disorders usually appear completely normal at birth, but can become very sick if not diagnosed and treated early. All tests and follow-up are absolutely necessary!

Keep in mind, the NBS is only a SCREEN, not a diagnostic test. Results can be affected by baby's age, medical or treatment status at time of collection, quality and quantity of the specimen, environmental factors, and other factors. The possibility of false negative or false positive results should always be considered.

Diagnostic evaluations should be per-

formed on infants with initial abnormal results, and/or clinical symptoms.

Here's a history of NBS in TN:

- 1968 PKU (Phenylketonuria)
- 1980 Congenital Hypothyroidism
- 1988 Sickle Cell and other Hemoglobinopathies
- 1992 Galactosemia
- 2000 CAH (Congenital Adrenal Hyperplasia)
- 2001 Newborn Hearing Screening
- 2003 Biotinidase Deficiency
- 2004 Expanded Screening utilizing Tandem Spectrometry for multiple analytes (includes amino acid, fatty and organic disorders)
- 2008 Cystic Fibrosis

NBS Welcomes New Staff:

Cindy Wallace, Director
Genetics & Newborn Screening
Carie Kane, Follow-up Nurse

NBS Fee Increase—Dec 28, 2007

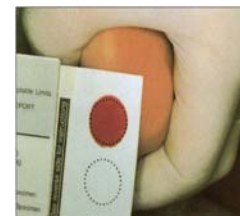
The fee for conducting the NBS on newborn blood samples submitted to the state public health laboratory was increased to \$75.00.

NBS Materials:

- Revised pamphlets with CF are now available
Fax orders to: 615-262-6458
- Educational CD's:
Call Jane Clark: 615-262-6345

State Holidays (Apr-Jun)

May 26 Memorial Day

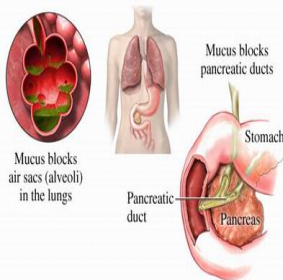


Lab Updates

- The NBS Lab is updating equipment and adding a new test to their current panel. Testing in the lab is done by punching several (4 to 6) 1/8 inch round punches from each blood spot on the filter paper. Additional punches will be needed for the new test for Cystic Fibrosis. Therefore, the lab will NO LONGER BE ABLE TO accept as satisfactory samples that do not have the circles completely filled. Educational CD's are available by request: see NBS Materials.
- The filter cards have been revised. They are now yellow and contain spaces for submitter's address and for birth and current weights.

What is Cystic Fibrosis?

Cystic Fibrosis is an autosomal recessive disorder that affects many organs in the body, especially the respiratory and digestive systems. The body produces large amounts of thick and sticky mucus that can obstruct the airways and lead to infections in the lungs and breathing problems. There may be chronic coughing,



wheezing and lung damage. Mucus also blocks the ducts of the pancreas which interferes with digestion, which can lead to diarrhea, greasy, bulky stools, malnutrition, poor growth and weight loss.

All of this is due to a faulty gene involving a cell protein called CFTR (cystic fibrosis transmembrane conductance regulator). CFTR regulates the movement of salt and water into and out of cells which produce high levels of salt in the sweat.

Thus, CF diagnosis is confirmed using a sweat test, DNA studies, or both. ◇

CF Centers in Tennessee

MEMPHIS—University of TN at LeBonheur Children's Medical Center
▪ (901) 287-5222

NASHVILLE—Vanderbilt University Medical Center ▪ (615) 343-7617

CHATTANOOGA—T.C.Thompson's Children's Hospital ▪ (423) 778-2001

KNOXVILLE—East TN Children's Hospital ▪ (865) 637-8481/541-8698

Newborn Hearing Screening



Legislation for Newborn Hearing Screening has passed and will be effective July, 2008!

- "Claire's Law" HB2753 by Pruitt SB3191 by Harper
- Requires birthing facilities to provide newborn hearing screening
- Requires newborn hearing screening to be covered by insurance



- Tennessee birthing hospitals and facilities have done an excellent job of screening infants for hearing loss. 92% of all infants were reported as screened in 2007. A mandate will assure that all infants are screened and reported to the Department of Health Newborn Screening program so that follow-up testing can be tracked to assure infants receive needed services. ◇

Resources for families of infants with hearing loss:

- Family Voices (FV) Newborn Hearing Parent Consultants - 1-888-643-7811 FV consultants and resource specialists are parents of special needs children, including those with hearing loss. One-on-one support is available to families by a parent with similar experiences. FV consultants may advocate to find financial and insurance resources, obtain appropriate educational services and to assist families in learning about communication opportunities for infants and children with hearing loss.
- Tennessee Early Intervention System (TEIS) - 1-800-852-7157 The Department of Education, TEIS program provides coordination of services to children with special needs, including hearing loss, from birth to three years of age at no cost to families. TEIS will assist families in locating a medical home provider, specialty providers, obtain therapeutic services (speech, audiology, respite, physical therapy) and enroll in educational programs. Service Coordinators work with individual families. TEIS may assist with financial coverage of some services.
- Children's Special Services (CSS) - 615-741-7353 The Tennessee Department of Health CSS program provides medical services and care coordination for children, birth to age 21 years, that have a chronic illness or medical condition such as hearing loss. Families must meet financial guidelines. Care Coordinators work with individual families. Cost of hearing services may be provided. ◇

For additional information contact Jacque Cundall RN, BSN, Newborn Hearing Coordinator 615-262-6160 or email: Jacque.Cundall@state.tn.us