



State of Tennessee

Department of Health

# Newborn Screening Newsletter



Newborn Screening Follow Up  
 Phone: 615-532-8462  
 Fax: 615-532-8555

<http://health.state.tn.us/MCH/NBS.shtml>

## Special Points of Interest

CCHD Roles and Questions

Inside this issue:	
Critical Congenital Heart Disease (CCHD) Screening	1
Health Dept Roles in CCHD Screening	1
Questions & Answers for CCHD Screening	2

## Upcoming State Holidays

- ◆ February 18: President's Day
- ◆ March 29: Good Friday
- ◆ May 27: Memorial Day

### **Important Newborn Screening Phone Numbers at a Glance**

#### **NBS F/U - Metabolic & Hearing**

Ph 615-532-8462  
 Toll Free 855-202-1357  
 Fax 615-532-8555

#### **Filter Papers**

Ph 615-262-6391  
 Fax 615-262-6455

#### **ICD9 Codes**

Ph 615-262-6300

#### **NBS State Laboratory**

Ph 615-262-6473  
 Fax 615-262-6447

#### **Billing**

Ph 615-262-6300  
 Fax 615-262-6396

#### **Voice Response System**

615-262-3041  
 866-355-6132

## CCHD SCREENING IS HERE!

Beginning January 1 all infants born in Tennessee will have a pulse oximetry screening to identify some forms of critical congenital heart disease (CCHD). The January 1 start date is the culmination of many years of research, legislation, and a year long implementation process headed by the Tennessee Department of Health Newborn Screening Program, aided by the CCHD workgroup committee and the Genetics Advisory Committee.

Pulse oximetry is a painless, non-invasive method of determining oxygen saturation in the blood. It can detect some forms of CCHD. The test is a point-of-care test. This means that the screen will be conducted in the hospital within 24-48 hours of birth and questionable results will be addressed immediately by the staff. The NBS Program will not be calling the primary care provider (PCP) on failed or referred results. The program will send out follow up letters to the PCP

on infants identified with a failed result or when referred to cardiology.

All 67 birthing hospitals in Tennessee were provided a training to implement CCHD screening, referral, and reporting by our Regional Perinatal Outreach Educators. The Outreach Educators also conducted training sessions for 5 birthing centers, the 2 transfer hospitals and a number of midwifery clinics statewide. Training was also conducted at annual meetings of two midwife associations

New filter forms have been designed to capture pulse oximetry pass and fail results and are now available. The parent pamphlets have been revised to include information on CCHD. Additional information, including the CCHD screening packet is available on our website.

<http://health.state.tn.us/MCH/NBS.shtml>

### **Local County Health Department's Role**

- ◆ If the birthing facility did not submit the pulse oximetry results with the dried blood specimen it **will not** be the responsibility of the county health departments to obtain and submit those results.
- ◆ If an infant failed the CCHD screen at the birthing facility and the county health department was listed as the primary care provider on the newborn screening form, you may receive a letter requesting information about the final diagnosis. Please forward this request to the primary care provider and notify the newborn screening follow-up program of the updated provider information.

## Questions & Answers (Q&A) for Critical Congenital Heart Disease (CCHD) Screening

### **How do I submit the CCHD screening information if it was not done or mistakenly left blank on the initial blood specimen collection?**

CCHD screening fields should not be left blank unless the infant was on oxygen when the blood specimen was collected. At this time, there is not a mechanism in place for hospitals to report CCHD screening information to the State if it was mistakenly left blank on the blood collection form. The Newborn Screening (NBS) follow-up program will send a report to hospitals listing infants who had a blood specimen submitted without CCHD screening information. The report will not be used as a punitive measure but will be used as a tool in an effort to increase compliance. It is important to perform the screen for CCHD between 24-48 hours of age, ideally at the same time the blood specimen is collected.

Note:

- ◆ CCHD screening information can also be reported on a repeat (if repeat specimen is needed) blood collection form if the infant was on oxygen during the initial blood collection.
- ◆ The hearing only forms or the pink hearing screening copy (with a picture of the ear) of the blood collection form is **only** used for documenting **hearing screen** results that were not done with the initial blood specimen.

### **Is there a time limit to wait before doing the pulse oximetry test for the special care infant once weaned off oxygen?**

If the special care nursery infant...

- ◆ ...never required oxygen during their stay proceed with the screening protocol.
- ◆ ...required oxygen but has been weaned to room air proceed with the screening protocol at least 24 hours after weaning to room air.
- ◆ If infant is being discharged home on oxygen,

obtain an echocardiogram (if one was not obtained during their neonatal course). Mark "YES" for cardiology referral on the blood collection form.

- ◆ In all cases (except infants going home on oxygen who should be echo'd), screening should occur prior to discharge from the hospital.

### **What if the CCHD screen could not be done because the infant was on oxygen when the initial blood specimen was collected then the infant died?**

Hospitals are asked to notify the NBS program when an infant dies. Documentation including infant's last name and date of birth, mother's first and last name and the date the infant died should be faxed to (615) 532-8555. The follow-up program will document in the case management system that the infant died and cancel any pending letters. The case will be closed with a disposition of 'Expired Infant' and will not be counted against the hospital.

### **If the CCHD screen could not be done because the infant was on oxygen when the initial blood specimen was collected but was done once off oxygen, how do we submit the CCHD screening information?**

- ◆ At this time, there is not a mechanism in place for hospitals to report CCHD screening information to the State if it was not documented on the blood collection form.
- ◆ According to NBS program recommendations, infants weighing <1500 grams at birth should have a repeat blood specimen between 30-45 days of age to screen for congenital hypothyroidism. If the infant is on oxygen when the initial blood specimen is collected and the CCHD screen could not be performed but the infant needs a repeat blood test, document the CCHD screening infor-

## Questions & Answers (Q&A) for Critical Congenital Heart Disease (CCHD) Screening (Continued)

mation on the repeat blood collection form. It can be documented even if the CCHD screen was not performed at the same time.

- ◆ Example: The infant is on oxygen when the initial blood screen was collected, oxygen was discontinued at 2 weeks of age and the CCHD screen was done the next day. The 2 week CCHD screen can be documented on the collection form when the repeat blood screen is done at 30 days of age.

### **If the blood specimen is being collected prior to 24 hours of age because the baby is going to receive a blood transfusion, should we screen for CCHD at that time?**

Yes, if a NBS blood specimen is being collected at <24 hours of age due to the status of the infant and the infant is not on oxygen, screen for CCHD and document it on the blood collection form.

### **If an infant is to be transferred to another facility do we perform the CCHD screen?**

Prior to transfer, all infants should have a blood specimen collected (even if <24 hours of age) by the birthing facility. The CCHD screen can be done at that time and documented on the blood collection form.

### **What if a fetal ultrasound (FUS) indicates that the infant has CCHD?**

If the infant is known to have CCHD, Mark YES for cardiology referral on the blood collection form; leave the other areas blank. You do not have to follow the algorithm on known CCHD infants.

### **What determines if I should mark YES in the field “Referred to Cardiology”?**

Mark YES if the infant has had an echocardiogram or is being seen by a pediatric cardiologist.

### **What if a parent refuses to have NBS screening on their infant?**

The parent should fill out the [NBS Refusal Form](#) which allows parents to refuse based on religious tenets and practices. The case will be closed with a disposition of ‘Refused’ and will not be counted against the hospital.

### **Who will get the letter requesting details about final diagnosis if the infant is in the NICU?**

The NBS follow-up program will send a letter to the provider listed on the blood collection form and will only generate if “failed” and/or “referred to cardiology” was marked. If the NICU lists the neonatologist they will get the letter. If they list the primary care provider, he/she will get the letter. The letter will be sent at 4 weeks and repeated at 6 weeks if no response. If by 8 weeks there is still no response a call will be made by the NBS follow-up nurse.

### **As a midwife, when I have a birth at home or at a birthing facility and the infant leaves before 24 hours of age, should I still collect the screen as the algorithm states?**

Before the infant leaves the birthing center or before the midwife leaves the home, an oxygen saturation should be obtained for CCHD screening, even if done before 24 hours of age. If the infant passes the screen, document PASS on the blood collection form. If the infant fails the screen, do not document on the blood collection form, instead the baby should be re-screened when the midwife returns for the metabolic (blood specimen) screen at 24-48 hours of age and documented at that time. If during assessment, clinical signs show distress the midwife should take necessary steps for further evaluation.