

Summer 2013

# Newborn Screening Newsletter

## Arkansas Department of Health

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### ***Critical Congenital Heart Disease (CCHD): by W. Robert Morrow, MD, FAAP & B. Allison Rose, MPH, CHES***

Congenital heart disease is the most common congenital malformation, affecting approximately eight out of every 1,000 newborns. Approximately 25% of these infants, or approximately 7,200 per year in the United States, have so-called “critical” congenital heart disease (CCHD) in which pulmonary or systemic blood flow depends on the ductus arteriosus.

Infants with CCHD often appear well during routine exams, but may become critically ill within the first few hours to days of life if the diagnosis is not recognized and promptly treated. Infants with CCHD may rapidly deteriorate due to cyanosis or low cardiac output as the ductus arteriosus closes, either in the newborn nursery or following hospital discharge at home, and are high risk for morbidity and mortality once these symptoms develop.

Because babies with CCHD often appear to be healthy, routine screening for these conditions is warranted. Although practically all forms of congenital heart disease can be recognized prenatally, in practice, only about half with significant congenital heart disease are diagnosed prenatally in the United States. Several studies in large populations over the past decade have shown that measurement of oxygen saturation in the upper and lower extremities of infants at least 24 hours of age can identify, with high sensitivity, infants at risk for critical congenital heart disease. While pulse oximetry cannot identify all forms of congenital heart disease, seven main screening targets include hypoplastic left heart syndrome, pulmonary atresia (with intact septum), tetralogy of Fallot, total anomalous pulmonary venous return, transposition of the great arteries, tricuspid atresia, and truncus arteriosus.

Recognizing the value of screening for CCHD prior to hospital discharge, in October 2010 the US Health and Human Services Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children recommended that screening for CCHD be added to their recommended uniform screening panel (RUSP). The recommendation was later endorsed by the Secretary of the US Department of Health and Human Services. Twenty-six states now systematically conduct pulse oximetry screening for CCHD in birthing facilities, either as a result of legislation or an executive order. Arkansas became one of those states this year when the 89th General Assembly produced **Act 768**, which requires all birthing facilities to screen newborns for CCHD prior to discharge.

The American Academy of Pediatrics (AAP) guidelines indicate that infants with a positive screening result should be evaluated by the nursery’s pediatrician to explore alternative causes of low oxygen saturation in the infant (such as pneumonia and sepsis). The guidelines further state that these infants should also receive a prompt pediatric cardiology consultation, which will typically involve an echocardiogram, prior to hospital discharge, as CCHD can be missed with a physical exam alone.

Birthing facilities already engaged in conducting CCHD screening via pulse oximetry are encouraged to review the **AAP protocol** to ensure that your hospital’s screening protocol is in alignment with the AAP evidence-based guidelines. For those who are just beginning the journey toward development of a hospital screening program, there are a number of resources available on the **Arkansas Children’s Hospital (ACH) website**. ACH is also convening a CCHD Training Advisory Group to explore needs and resources for pediatricians, family practice physicians, nursing staff, imaging staff, and administrators, and will be adding to the website on a regular basis. In the interim, as you begin planning, feel free to call the Medical Affairs office at ACH for guidance. You may reach us at 501.364.7800 or **RoseBA@archildrens.org**.

#### **References:**

Centers for Disease Control and Prevention: <http://www.cdc.gov/ncbddd/pediatricgenetics/CCHDscreening.html>

Martin GR, Beekman RH III, Mikula EB, Fasules J, Garg LF, Kemper AR, Morrow WR, Pearson GD, Mahle WT. **Implementing Recommended Screening for Critical Congenital Heart Disease.** *Pediatrics* 2013, Jul;132(1):e185-92.

American Academy of Pediatrics, State Advocacy– [www.aap.org/stateadvocacy](http://www.aap.org/stateadvocacy).

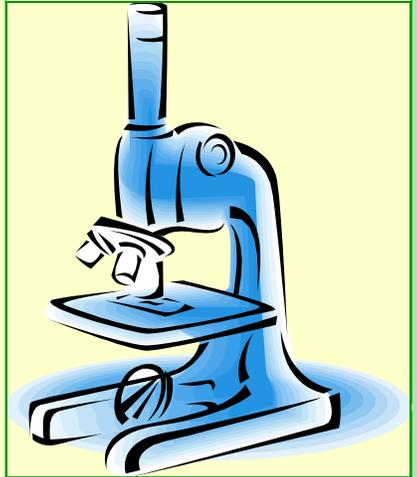
## ***Notes from the Lab: by Leslie Himstedt***

Check the expiration date of the collection card prior to use. Do not use cards with an expiration date of 2013-05.

The recommended method of collection is the heel stick. If another method is used it is imperative the only thing to come into contact with the filter paper is the drop of blood.

Make sure the preprinted circle is completely filled, but not overfilled, and the blood is soaked through to the other side of the filter paper in a uniform manner.

One large drop of blood should be sufficient to completely saturate one circle.



Leslie

## ***Notes from Mary Jean: Improvement in Specimen Submission Time***

We continue to encourage all hospitals to submit newborn screening samples promptly so that they arrive at the ADH Public Health Lab within 48 hours of collection. Our aim is for at least 75% of the specimens to arrive within this time frame.

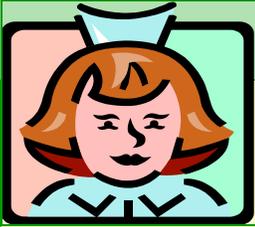
We would like to congratulate UAMS for consistent and steady progress improved specimen delivery times. They demonstrated a 14 percentage point improvement from the first to second quarter this year and will receive a certificate signed by Dr. Nate Smith, State Health Officer and Interim Director of ADH.

Conway Regional Medical Center had a 16 percentage point increase from first to second quarter in the number of specimens reaching the lab within 48 hours, and will receive a signed certificate from Dr. Nate Smith for most improved in the State.

Congratulations to UAMS and Conway Regional for significant improvements that directly impact the newborn screening program's primary goal of rapid diagnosis and treatment of disorders identified through newborn screening!

Thanks so much to all our hospitals and nurseries for the effort it takes to keep the system running and improving.





## **Nursing Station**

As you are aware our strategy is to improve sample delivery times. Newborn Screening Program is recognizing the recent success of two hospitals that have made good efforts and strides.

**Certificate of Recognition  
is awarded to  
UAMS**

With 40-50% of their samples arriving on time and with steady improvement over 2 years; especially during the first to second quarter of this year going from 57% to 67% of samples coming in on time.

**Certificate of Most Improved  
is awarded to  
CONWAY REGIONAL HOSPITAL**

With a steady improvement of going from 5% to 21% of samples arriving on time from first to second quarter.

**Please share in our CONGRATULATIONS!!!!!!!!!!!!**





## **HAPPY 50<sup>TH</sup> BIRTHDAY TO NEWBORN SCREENING!**

A public health success for 50 years, newborn screening reaches more than 4 million babies in the United States each year, saves lives, and prevents serious medical and developmental problems. About 75 Arkansas babies a year are diagnosed and promptly treated for disorders identified through newborn screening.

### **CCHD-cont' from page 1**

ADH Newborn Screening Program will keep you posted on progress with training and data entry procedures that are required before actual implementation of the CCHD law. Meanwhile contact us or ACH for questions or concerns.

