# **FOOTNOTES** S.C. DHEC NEWBORN SCREENING NEWSLETTER



## NEWBORN SCREENING AWARENESS MONTH: A BABY'S FIRST TEST

No matter how healthy a newborn might look, it's essential they are checked for unexpected medical conditions. Newborn screening is the practice of testing every newborn for certain harmful or potentially fatal disorders that aren't otherwise apparent at birth. When such conditions are detected early, diagnosed and treated, newborns stand a much better chance of avoiding disabilities and living a full, productive life.

September is **Newborn Screening Awareness Month**, a time set aside to recognize the importance of early detection and intervention to identify infants at risk and provide linkage to care. You can learn more about the impact and benefits of newborn screening by visiting "**Baby's First Test**" at <u>www.babysfirsttest.org</u> and <u>www.scdhec.gov/newbornmetabolicscreening</u>.

## **OUR BEST FOOT FORWARD**

#### It's not just the PKU test!

The Department of Health and Environmental Control (DHEC) **Newborn Screening Program** currently screens for 53 disorders. The lab test panel that checks for hidden health disorders in newborns is called Newborn Bloodspot Screening. The program originally began testing for just one metabolic disorder, phenylketonuria (PKU).

The test panel has since evolved to include multiple disorders such as cystic fibrosis, congenital hypothyroidism, congenital adrenal hyperplasia, hemoglobinopathies and traits such as sickle cell, SCID (severe combined immunodeficiency), and various inborn errors of metabolism.

For a complete list and description, please visit <u>www.scdhec.gov/</u><u>newbornmetabolicscreening</u>.



In addition, the Newborn Hearing Screening Program, **First Sound**, monitors infants to detect hearing loss and every birthing hospital in the state screens for critical congenital heart disease (CCHD) to ensure newborns' hearts are healthy.

#### How is the newborn tested?

In South Carolina, newborn screening averages 57,000 births per year. The blood test is collected 24-48 hours after birth by pricking an infant's heel and collecting five blood spots on a special filter paper. The specimen is then sent to the DHEC Public Health Laboratory for testing.

You may wonder how the state decides which disorders to screen for various conditions. The U.S. Department of Health and Human Services (HHS) Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) uses an evidence-based process to evaluate candidate conditions to add to the Recommended Uniform Screening Panel (RUSP). Most US newborn screening programs follow the RUSP in determining the conditions for which infants are screened.

#### What happens when a newborn has a positive screen?

The newborn screening follow-up program staff work closely with a pediatric medical consultant and many medical specialists around the state. Healthcare providers are notified of abnormal results by follow-up staff to ensure infants are getting the care required for the specific disorder they screen positive. These patients are tracked until a diagnosis is made by the primary care provider or the specialist to whom they are referred.

#### **Newborn Screening Diagnosed Cases**

To date, the following hospitals collected newborn screens that had confirmed diagnosed cases in 2017:

#### Inborn Errors of Metabolism:

Aiken Regional Medical Center Conway Medical Center East Cooper Medical Center Greenville Memorial Palmetto Health Richland Lexington Medical Center Palmetto Health Baptist Carolina Pines Regional Medical Center Spartanburg Regional Medical Center

#### Congenital Adrenal Hyperplasia:

Palmetto Health Baptist Spartanburg Regional Medical Center St. Francis Xavier Hospital

#### Congenital Hypothyroidism:

Aiken Regional Medical Center Anmed Health Conway Medical Center Greenville Memorial McLeod Health: Cheraw McLeod Health: Clarendon Palmetto Health Baptist Spartanburg Regional Medical Center

#### Hemoglobinopathies

HR C. Lexington Medical Center HB SE: Coastal Carolina SS Disease: Aiken Regional Medical Center Beaufort Memorial Hospital **Conway Medical Center** Carolina Hospital System: Marion Lexington Medical Center Mary Black Hospital Mary Black-Gaffney McLeod Health MUSC Palmetto Health Baptist Palmetto Health Richland Palmetto Health Tuomey Self Regional Healthcare St. Francis: Eastside

SC disease: Aiken Regional Medical Center Beaufort Memorial Hospital Greenville Memorial Hospital Lexington Medical Center McLeod Health: Cheraw MUSC Palmetto Health Richland Summerville Medical Center Trident Medical Center

**Are you educating your parents about Newborn Screening?** Visit our website at **www.scdhec.gov/newbornmetabolicscreening** to find our newborn screening brochure and educational handouts for parents and providers.

### **ON THE RUN**

#### To our hospitals:

Have you enrolled in the Fed Ex program offered by the Public Health Newborn Screening Laboratory? If not, or if you have questions, contact Toshiro Washington at 803-896-0795 to obtain information, a user name, and password.

#### Lab Holiday Closings:

Labor Day: Monday, Sept. 4, 2017

Veteran's Day: Saturday, Nov. 11, 2017

Thanksgiving: Nov. 23-24, 2017

Christmas: Dec. 22, 2017 and Dec. 25, 2017



### **ON THE SPOT**

The hospitals listed below had 0% unsatisfactory specimens for the  $2^{nd}$  quarter of 2017:

- Coastal Carolina Medical Center
- Hilton Head Hospital
- McLeod Health: Cheraw
- McLeod Loris
- Newberry County
  Memorial Hospital

# SICKLE CELL EDUCATIONAL INFORMATION

To our primary care providers: September is also Sickle Cell Awareness Month. Did you know the NCAA requires student athletes to have documentation of their Sickle Cell status to play sports? If you have a patient that is college age and requires a Sickle Cell result, call 803-896-0795 at least 30 days in advance. Alternatively, students can be tested by one of the Sickle Cell foundations below:

#### Cobra Human Services Agency Sickle Cell Program

3692 Rivers Avenue Charleston, SC 29405 843-225-4866

#### James R. Clark Memorial Sickle Cell Foundation

1420 Gregg Street Columbia, SC 29201 803-865-9916



#### Louvenia D. Barksdale Sickle Cell Anemia Foundation

345 South Church Street Spartanburg, SC 29306 864-582-9420

#### **Orangeburg Area Sickle Cell Foundation**

825 Summers Avenue Orangeburg, SC 29115 803-534-1716

## **CONTACT US. WE'RE HERE TO HELP!**

DHEC Newborn Screening Follow Up: (803) 898-0593 or (803) 898-1969

Public Health Laboratory: (803) 896-0891

**Keep us on our toes.** Please give us feedback on what you would like to see in our next Footnotes Edition. Email <u>newbornscreening@dhec.sc.gov</u> with your suggestions.

## **EDUCATIONAL INFORMATION:**

#### Need NBS brochures? (ML-000032 for English and ML-025096 for Spanish version):

Please go to www.scdhec.gov/Agency/EML.