FOOTNOTES



S.C. DHEC NEWBORN SCREENING NEWSLETTER



OUR BEST FOOT FORWARD

Welcome to our newest staff:

- Follow Up Program Coordinator II: Stephanie Bachman
- Follow Up Administrative Assistant: Marquia Edwards
- Lab Tech II: Christine Harrelson
- · Lab Tech II: Ashley Smith
- · Lab Tech II: William Petroff
- Lab Tech III: Robert Eaddy

Guidelines for Low Birth Weight Infants:

Established in 2016 by the Clinical Laboratory Standards Institute, the guideline regards specimen collection timing for pre-term, low birth weight, and sick infants. It is designed to assist NICU and healthcare providers on the best time for initial specimen collection and repeat collection for infants:

- ages < 34 weeks or <2000 grams at birth
- · who have received blood transfusions
- who require a transfer to higher level of care
- who are admitted for >28 days
- who require a repeat newborn screen prior to discharge

If you or your facility are not aware of these recommended guidelines you may find them on our website: https://www.scdhec.gov/health-professionals/lab-certification-services/newborn-screening

If you have questions please email newbornscreening@dhec.sc.gov.

What You Say Matters:

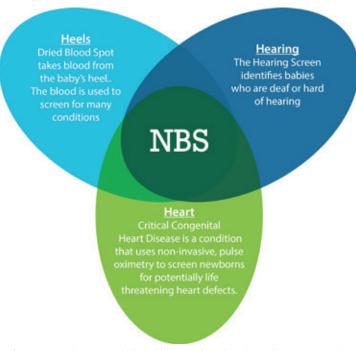
Imagine a SC family receives an urgent call regarding a follow up appointment needed for an abnormal newborn screen. When they bring their newborn to their repeat, a staff member says, **"You must be here for the PKU test."** Returning home, the family spends an entire weekend researching what a PKU test is. When they arrive for their appointment, they discover that their newborn was not suspected to have "Phenylketonuria (PKU)" at all. Instead, their infant was at risk for an entirely different condition.

Clinic staff must now spend a lot of time helping the family "unlearn" all of the information they gathered, a time-consuming task which could have been avoided had the correct terminology for newborn screening been used from the beginning.

What can be learned from this infant's story:

- The term "newborn screen" should be used in place of "PKU test"
- Using incorrect terminology for newborn screening is an important issue in clinical practice
- Using the term "PKU test" has tangible consequences
- Using inaccurate terminology may lead to incorrect follow up testing for the wrong medical disorder.

Newborn screen is widely used and has been accepted in our state and national health programs to refer to the collective group of conditions screened at birth, including:



References to "PKU test" should be updated to "Newborn Screen."

Source: https://www.babysfirsttest.org/newborn-screening/ resources/newborn-screening-more-than-a-pku-screen-fact-sheet



Newborn Screening Training Workshop Inspires Local Hospital to become Champions for Satisfactory Dried Blood Spot Collection

Receiving a call from DHEC is not how some hospital staff members may wish to start their day. For Debi Love-Ballard, R.N., Director of McLeod Health Clarendon's Women and Infant Services, the phone call to acknowledge their newborn dried blood spot screening collection achievement was not only unexpected, but welcomed. The NBS program asked Debi to discuss her team's journey to successful specimen collection in 2018. Here is their story:

I, along with the perinatal coordinator at the time, attended a training provided by DHEC Newborn Screening Program. We shared this knowledge and trained staff about what we learned regarding storage of the medical devices, prepping, collection, drying time and mailing. The following are positive changes and best practices we sought to champion after returning from the initial DHEC newborn screening specimen collection training workshop.

Storage of Medical Devices:

All metabolic screenings (prior to DHEC training and prior to blood draw) were not stored in the original plastic wrapping and/or in upright position all the time. We have since corrected this process of storage and continue to do so properly as recommended by DHEC. **This was a process change.**

Prep:

Elevate HOB to have leg in dependent position.

Warm Heel with heel warmer for approximately 3 minutes to ensure adequate blood flow. Add a large drop (no pipettes) just free flowing to each circle. Our collection techniques were varied. Not everyone warmed the heel for any specified time, nor position with HOB to allow for better blood flow prior to the heel stick. Layering the blood, as well as using pipettes were no longer done. **Another change in practice.**

Drying Time:

Each screening dries at least 4 hours and on a flat surface.

Mailing:

The entire mailing process changed with a more efficient workflow. In addition, we also changed the way we packaged the envelopes for shipping and now alternate the placement of each screening for mailing as taught in the DHEC training workshop.

ON THE SPOT

The hospitals listed below had 0% unsatisfactory specimens for 2018:

• McLeod Health Clarendon



Lessons Learned from Debi and her team's efforts:

- Attend Newborn Screening Dried Blood Spot Collection Training Workshop
- Share the knowledge obtained
- Evaluate current processes and implement standardized ones if needed
- · Identify newborn screening champions within your facility
- Encourage the achievement of zero percent unsatisfactory collection
- Partner with your perinatal coordinator or educator

I could not be prouder of my diligent and conscientious Women's Services team at McLeod Health Clarendon; they truly exemplify our mission of providing excellence in healthcare! We would also like to thank the SC DHEC newborn screening team for making such a positive impact in the healthcare of all South Carolina newborns!

- Debi Love-Ballard, R.N., Director of McLeod Health Clarendon's Women and Infant Services

Quie

Meet some of the NBS champions from McLeod Health Clarendon

Newborn Screening Diagnosed Case

To date, the following hospitals collected newborn screens that had confirmed diagnosed cases in 2018:

Biotinidase Deficiency:

Spartanburg Medical Center: Mary Black Campus Prisma Health Richland Hospital Summerville Medical Center

Classic Galactosemia:

Lexington Medical Center The Regional Medical Center: Orangeburg

Congenital Adrenal Hyperplasia:

Prisma Health Baptist Hospital Prisma Health Richland Hospital

Congenital Hypothyroidism:

Aiken Regional Medical Center Anmed Health Conway Medical Center Grand Strand Medical Center Lexington Medical Center **MUSC**

Prisma Health Baptist Hospital Prisma Health Richland Hospital Piedmont Medical Center Spartanburg Regional Medical Center

Bon Secours St. Francis: Eastside The Regional Medical Center: Orangeburg

Cystic Fibrosis

Conway Medical Center McLeod Regional Medical Center MUSC

Spartanburg Regional Medical

Bon Secours St. Francis Xavier Hospital

Hemoglobinopathies HB C

MUSC

Prisma Health Richland Hospital Bon Secours St. Francis Xavier Hospital

C/B+ Thalassemia

Prisma Health Richland Hospital

S/B+ Thalassemia

Spartanburg Medical Center: Mary Black Campus

Prisma Health Baptist: Parkridge Hospital

SC disease:

Aiken Regional Medical Center Beaufort Memorial Hospital MUSC Health Florence MUSC Prisma Health Baptist Hospital Prisma Health Richland Hospital Piedmont Medical Center

Bon Secours St. Francis: Eastside Bon Secours St. Francis Xavier Hospital

SS Disease:

Aiken Regional Medical Center Beaufort Memorial Hospital MUSC Health Florence Coastal Carolina Hospital Colleton Regional Hospital East Cooper Regional Kershaw Health **Lexington Medical Center** Spartanburg Medical Center: Mary Black Campus Cherokee Medical Center McLeod Health McLeod Health: Clarendon

Mount Pleasant Hospital

MUSC

Prisma Health Baptist Hospital Prisma Health Baptist: Parkridge

Prisma Health Richland Hospital Prisma Health Tuomey Hospital Self Regional Healthcare Bon Secours St. Francis: Eastside

Bon Secours St. Francis Xavier Hospital

Trident Medical Center

Summerville Medical Center

The Regional Medical Center: Orangeburg

Inborn Errors of Metabolism:

Grand Strand Medical Center Greer Memorial Hospital Tidelands Georgetown Memorial Hospital

Isovaleric Acidemia:

Bon Secours St. Francis Eastside

MCADD:

Lexington Medical Center

NBS Collection Training Opportunity: Please email nbscollectiontraining@dhec.sc.gov to inquire about training.

ON THE RUN

Good news! The Public Health Laboratory has begun electronic reporting of newborn screening results. *eReports*, a module in the Specimen Gate Laboratory Information Management System, is a secure web portal where our newborn screening clinical partners can directly access newborn screening test results in real time. Once the results have been obtained and reviewed for release by laboratory protocol, they will be available for viewing and/or downloading at hospitals, birthing centers, pediatricians, specialists and midwifery facilities. Access to electronic reports will result in an overall decreased turnaround time from specimen collection to receipt of laboratory results. We can all appreciate that every effort to improve timeliness is important in newborn screening.

To enroll, please complete a user agreement (DHEC form 3268) available at https://www.scdhec.gov/sites/default/files/Library/D-3268.pdf and email it to NBSLab@dhec.sc.gov (or fax to 803-896-3862). An informational flyer has been mailed to newborn screening partners. For additional information, please see the flyer, email the above address or call the laboratory LIMS administration office at 803-896-4777.

Thanks to the users who have already enrolled!

Educational Information:

Check out our new and improved website!

Are you educating your parents about Newborn Screening? Visit: https://www.scdhec.gov/health-professionals/labcertification-services/newborn-screening

To find our updated newborn screening brochure and educational handouts for parents and providers

Are you in need of NBS brochures?

ML-000032 for English and ML-025096 for Spanish

Go to: http://www.scdhec.gov/Agency/EML/placeorder.aspx

CONTACT US. WE'RE HERE TO HELP!

DHEC Newborn Screening Program:

(803) 898-0767

Newborn Screening Lab: (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 newbornscreening@ dhec.sc.gov with your suggestions.