

OUR BEST FOOT FORWARD

As we all continue to strive to put our best foot forward in newborn screening, this communication guide from the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) is a helpful tool to share abnormal newborn screening results with families.

Families who had abnormal newborn screening results suggested the following key points as important when helping families cope with the uncertainty of a result and understanding next steps needed to gain clarity. Just remember **SCREEN!**

Share the specific positive newborn screening result and associated condition with the family:

- Help the family understand that a positive newborn screening result is serious, but you are there to help guide them through next steps.

Comprehension: Assess the family's understanding of newborn screening:

- Assess if the family recalls and understands the process of newborn screening.

Reiterate what screening is and is not:

- Remind the family about the purpose of newborn screening and that it is not a diagnostic test. So, it is important that timely follow up confirmatory testing be done.

Engage with the family and provide information at their desired level and pace:

- Offer to provide the family additional result-specific information provided by the state newborn screening program and other reliable resources.
- Discuss information using non-medical terms at the family's pace and desired level of detail.

Explore the family's emotions:

- Explore with the family how they might use their support systems or other support resources now and as they go through the diagnostic process.

- Remember there is a wide spectrum of how families may cope with this result (anxiety to denial). Tailor your discussion to help the family hear and retain the information discussed.

Next Steps: Discuss a shared plan and provide resources:

- Assess the family's understanding of the medical visit and information provided using teach-back methods. Provide valid websites for them to get more information.
- Discuss with the family a shared plan that is concrete, specific, which includes the following:
 - Where, when, and with whom is the next appointment?
 - What testing will be considered and/or done?
 - What should they watch for in their child while they wait?
 - Who can they contact if they have additional questions or concerns?

ON THE RUN

In January 2020, DHEC welcomed the new Public Health Laboratory Director, Dr. A. Atwell Coleman, III. Before joining the DHEC team, he served more than 25 years in private pathology practice and clinical laboratory management. After this South Carolina native graduated from the University of South Carolina, he completed his anatomic and clinical pathology residency at the Medical University of South Carolina. He then finished a fellowship in hematopathology at the University of Pittsburg before returning to Columbia. Welcome to the team, Dr. Coleman!



ON THE SPOT

These hospitals had the lowest percentage of unsatisfactory newborn screening specimens for 2019!

- Prisma Health Greer Memorial Hospital
- McLeod Health-Clarendon
- St. Francis Eastside
- The Regional Medical Center of Orangeburg & Calhoun
- Carolina Pines Regional Medical Center
- Kershaw Health



Thank you for being champions for dried blood spot collection in your facilities!

Newborn Screening Diagnosed Cases

To date, the following hospitals collected newborn screens that had confirmed diagnosed cases in 2019:

Biotinidase Deficiency:

East Cooper Medical

Citrullinemia Type 1:

AnMed Health
Prisma Health Baptist

Congenital Adrenal Hyperplasia (CAH):

East Cooper Medical
Prisma Health Richland
Spartanburg Regional Medical Center

Congenital Hypothyroidism:

Anmed Health
Beaufort Memorial
Bon Secours St. Francis Xavier
East Cooper Medical
Lexington Medical Center
McLeod Regional Medical Center
MUSC
Prisma Health Baptist
Prisma Health Greenville
Prisma Health Greer
Prisma Health Patewood
Prisma Health Richland
Self Regional Healthcare
Spartanburg Regional Medical Center
Spartanburg Medical: Mary Black Campus
St. Francis Eastside
Summerville Medical Center
The Regional Center: Orangeburg

Cystic Fibrosis (CF)

Conway Medical Center
Prisma Health Greenville
Prisma Health Greer
Prisma Health Richland
Roper St. Francis: Mt Pleasant Hospital
Self Regional Healthcare

Hemoglobinopathies

- **HB C:**
 - McLeod
 - MUSC
 - Prisma Health Richland Hospital
 - Spartanburg Medical Center
- **HB EE:**
 - Aiken Regional Medical Center
 - Lexington Medical Center
 - Piedmont Medical Center
 - Prisma Health Richland
 - Summerville Medical Center
- **SC disease:**
 - Aiken Regional Medical Center
 - Beaufort Memorial Hospital
 - Carolina Pines Regional Medical Center
 - Lexington Medical Center
 - McLeod Health Dillon
 - McLeod Regional Medical Center
 - MUSC

Prisma Health Richland
Prisma Health Baptist
Prisma Health Baptist: Parkridge
Prisma Health Greenville
The Regional Medical Center
St. Francis Eastside
St. Francis Xavier
Self Regional Medical Center
Summerville Medical Center

- **SS Disease:**
 - Beaufort Memorial Hospital
 - Bon Secours St Francis Xavier
 - Coastal Carolina Hospital
 - East Cooper Medical Center
 - Kershaw Health
 - Lexington Medical Center
 - McLeod Regional Medical Center
 - McLeod Dillon
 - McLeod Loris
 - MUSC
 - MUSC Health Florence
 - Piedmont Medical Center
 - Prisma Health Baptist
 - Prisma Health Tuomey
 - Prisma Health Patewood
 - Prisma Health Richland
 - Prisma Health Greenville
 - Spartanburg Medical: Mary Black Campus
 - St. Francis Eastside
 - Summerville Medical Center
 - Tidelands Georgetown Memorial

Thalassemia:

MUSC
MUSC Health Florence
Prisma Health Tuomey

Inborn Errors of Metabolism:

- **PKU**
 - Prisma Health Greer
 - Prisma Health Tuomey
- **MCAD**
 - Prisma Health Laurens
 - Prisma Health Greenville
- **VLCAD**
 - Prisma Health Greenville

NBS COLLECTION TRAINING OPPORTUNITIES:

May 29, 2020

1st Session: 10AM
2nd Session 1PM

McLeod Family Medicine Building
(Building N),
Classroom A & B
144 N. Ravenel St.
Florence, SC 29506

June 4, 2020

1st Session: 10AM
2nd Session 1PM

South Park Plaza
Community Training Center
1 South Park Circle
Charleston, SC 29407

Please email:

nbscollectiontraining@dhec.sc.gov
to register attendees.

EDUCATIONAL INFORMATION:

Are you educating parents about Newborn Screening?

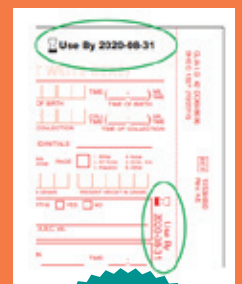
Visit scdhec.gov/health-professionals/newborn-screening to find our *updated* newborn screening brochure and educational handouts for parents and providers

Are you in need of NBS brochures (ML-000032, Eng. and ML-025096, Spa.)?

Visit scdhec.gov/about-dhec/educational-materials-library-product-order-site.

Are you in need of NBS collection forms?

You can now email PHL-supply@dhec.sc.gov to receive collection forms for your office or facility or call 803-896-0913.



NOTE:
The new batch of filter paper expires on 08-31-2020

COVID-19 AND NEWBORN SCREENING

In light of the COVID-19 pandemic, the SC DHEC Newborn Screening Program remains dedicated to supporting the needs of all infants, families, healthcare providers and residents of South Carolina. Essential newborn screening laboratory and follow-up services, including free metabolic formula for eligible residents of South Carolina, continue to be available. Please continue to collect newborn screening specimens during the recommended time frame of 24-48 hours after birth and send to the SC DHEC Public Health Laboratory as soon as possible.

As COVID-19 response efforts progress, thank you for your commitment to the health and safety of the youngest members of our great state. Please take time to care for your own health and safety, as well as family, friends and neighbors in your community. If you need any newborn screening or metabolic formula assistance, we encourage you to contact us. Please see contact information below.

Stay safe and be well,

SC DHEC Newborn Screening Program



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.