



The Awards Issue!

Alabama Newborn Screening

September 2013 ♦ Volume 2, Issue 2 ♦ Alabama Department of Public Health ♦ 1-866-928-6755

Inside this issue:

Alabama Hospitals Recognized for Quality Specimen Collection	2
NBS Hearing Awards	3
NBS Hearing Awards Continued	4
Family Highlight	5
Sickle Cell Disease Awareness Month	5
Pulse Ox Screening	5
Healthy Woman™ 2013 Baby & Toddler Expo	6

Newborn Screening Celebrates 50 Years

Newborn screening, one of public health's greatest achievements, celebrates 50 years of saving babies' lives. For the past 50 years, newborn screening has been responsible for saving about 12,000 babies each year from death or disability in the United States. In recognition of the fiftieth anniversary of newborn screening, the Association of Public Health Laboratories has published the book, *The Newborn Screening Story: How One Simple Test Changed Lives, Science, and Health in America*, which does a wonderful job of capturing the impact of newborn screening.

The first test for newborn screening was developed in 1963 by Dr. Robert Guthrie to detect phenylketonuria, otherwise known as PKU. It is a serious metabolic disorder in which the body is unable to metabolize certain amino acids, and it can lead to permanent mental retardation if not detected and treated early. Children with PKU were once institutionalized before the inception of newborn screening.

Newborn screening has continued to expand over the years and currently includes more than thirty disorders. In the early 2000s, the introduction of the sophisticated tandem mass spectrometry device allowed for multiple newborn screening tests to be performed simultaneously, resulting in quick, accurate, and cost effective screening.

In Alabama, screening for PKU began in 1965 with the addition of congenital hypothyroidism in 1978, hemoglobinopathies (sickle cell) in 1987, galactosemia in 1992, congenital adrenal



newborn screening
50 years of saving babies' lives

www.50yearsavingbabies.org

hyperplasia in 1994, and other metabolic disorders detected through tandem mass in 2004. In 2008, Alabama began screening for cystic fibrosis and officially added universal newborn hearing screening to its panel of disorders, even though most facilities had begun voluntarily screening in 2001. This year, Alabama added screening for critical congenital heart disease, increasing the number of primary disorders to 30.

Each year in Alabama, 150-200 babies are identified with metabolic and endocrine disorders, hemoglobinopathy, or other congenital disorders, through newborn screening. These babies usually look and act healthy at birth. The newborn screening and follow-up give them the opportunity to grow up healthy and develop normally.



September is Newborn Screening Awareness Month! You can help promote public awareness about newborn screening by changing your profile to the badge above throughout the month of September on Facebook, Twitter and any other sites. To get the badge visit www.savebabies.org.

Alabama Hospitals Recognized for Quality Specimen Collection



1. Springhill Medical Center



2. Northeast Alabama Medical Center



3. Highlands Medical Center



4. Russell Medical Center



4. Cullman Regional Medical Center

Beginning in 2009, the Alabama Newborn Screening Program began recognizing those birthing facilities in the state with the lowest unsatisfactory specimen rates. The state goal is to have a 5% or less unsatisfactory or rejected specimen rate. Cindy Ashley, Newborn Screening Director, and Rachael Montgomery, Newborn Screening Follow-up Nurse, had the pleasure of presenting awards to hospital nursery staff for efforts to submit high quality newborn screening specimens during the period of January 2012-March 2013. Quality specimen collection results in timely diagnosis and treatment for babies that may have a disorder, as well as avoids unnecessary repeat sticks and anxiety to the infant's parents.

The following hospitals were recognized for their outstanding efforts to submit quality newborn screening specimens to the State Health Laboratory during this period:

1. Springhill Medical Center – 2.2%
2. Northeast Alabama Regional Medical Center – 4.0%
3. Highlands Medical Center – 4.5%
4. Russell Medical Center and Cullman Regional Medical Center – 4.9%

Congratulations to these birthing facilities for their outstanding effort to continually strive for high quality specimen collection.

Newborn Hearing Screening Awards



In 2013, the Alabama Newborn Hearing Screening Program initiated a monthly awards program for the hospitals that meet or exceed the benchmarks set forth by the Joint Committee on Infant Hearing (JCIH). The standard is a 4% refer rate and a no input or non-reported rate of less than 5%. The JCIH supports the concept of regular measurements of performance and recommends routine monitoring of these measures for interprogram comparison and continuous quality improvement. The benchmarks represent a consensus of expert opinion in the field of newborn hearing screening and are the minimal requirements that should be attained by high-quality hearing programs.

Hospitals were separated into four categories based on the number of babies birthed annually, allowing for each hospital to be eligible for one award per calendar year. The award recipients for January-April 2013 are listed below. For facilities with less than 500 annual births, George Lanier Memorial Hospital, Cullman Regional Medical Center, Andalusia Regional Hospital, and Coosa Valley Medical Center were recognized. Facilities birthing between 500 and 1,000 newborns annually that received recognition included Decatur Morgan Hospital, Mobile Infirmary Medical Center, Thomas Hospital, and Medical Center Enterprise. East Alabama Medical Center, DCH Regional Medical Center, Southeast Alabama Medical Center, and Northeast Alabama Regional Medical Center were recognized from facilities that have between 1,000 and 2,000 annual births. For facilities with greater than 2,000 annual births, Brookwood Medical Center, Huntsville Hospital, and Baptist Medical Center East were recognized. Hospital photos are shown below and on the next page in alphabetical order.



Andalusia Regional Medical Center



Baptist Medical Center East



Brookwood Medical Center



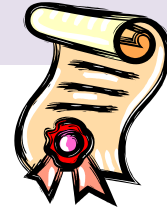
Coosa Valley Medical Center



Cullman Regional Medical Center



DCH Regional Medical Center



Newborn Screening Hearing Awards Continued

We congratulate these award recipients and appreciate their efforts to report newborn hearing results in a timely manner. We encourage other birthing facilities to contact us if we can be of assistance in achieving these gold standards of care. We are always at your service to provide training and resolutions to reporting issues.



Decatur Morgan Hospital



East Alabama Medical Center



George Lanier Memorial Hospital



Huntsville Hospital



Mobile Infirmary Medical Center



Northeast Alabama Regional
Medical Center



Southeast Alabama Medical
Center



St. Vincent's Hospital



Thomas Hospital

Newborn Screening Saved My Baby's Life!



First time parents Kyle and Leslie Ethridge had an uneventful pregnancy and birth with their first child Grayson in December 2012. Grayson was evaluated by his pediatrician after delivery, and the new parents were told everything was fine. Prior to his release, from the

hospital, the nurse took Grayson for routine vital signs and also performed the pulse oximetry screen, which revealed 97% oxygen saturation in his right hand and 87% oxygen saturation in his foot.

Grayson was quickly transferred to Baptist Medical Center South and then flown to Birmingham for open heart surgery. He was diagnosed with ventricular/atrial septal defect and an interrupted aortic arch. Grayson sees a pediatric cardiologist on a regular basis and has superb news during every visit.

According to Mrs. Ethridge, "Family, friends, and faith kept us sane during this trial. We have come out stronger and are very proactive in raising awareness for the pulse oximetry screening to detect heart defects. Newborn screening saved my baby's life."



On June 21, 2013, the Alabama State Board of Public Health voted to amend the state health law to include mandatory pulse oximetry screening in the well baby nursery to detect critical congenital heart disease (CCHD). Since April 2012, four babies have been identified with a CCHD and six babies have been identified with other congenital heart defects through screening.

National Sickle Cell Awareness Month

September is National Sickle Cell Awareness Month. The Sickle Cell Disease Association of America's goal is to reflect on those whose lives have been affected by this disease and to educate and provide public awareness about the disorder.

Sickle Cell Disease is the most frequently identified newborn screening disorder in Alabama. Approximately, 50-60 infants are identified with sickle cell disease each year in Alabama, and another 1600-2000 babies

are found to have sickle cell trait in Alabama each year. Although these disorders occur primarily in African-Americans, they are also found in other racial and ethnic groups.

The Southeast Alabama Sickle Cell Association, Inc., one of seven community based organizations in the state, raises money for clients and their families who suffer with sickle cell disease. The organization assists families with transportation, medication, hotel fees, and utilities. They also

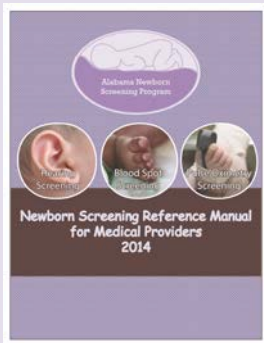
provide genetic counseling and education for parents of children with hemoglobinopathies identified through the newborn screening program.

In addition, newborns identified with sickle cell disease are referred to one of three hematology specialists in Alabama. Timely referrals to specialty care allows for early treatment before dangerous infections occur. Infections are the leading cause of death in children with sickle cell disease.



Temisha Young (left) and NBS Program Director Cindy Ashley (right) hold their 3rd place prize after participating in the Southeast Alabama Sickle Cell Association 9th Annual W.L. Strain Charity Golf Tournament at Auburn Links at Mills Creek Golf Course.

New for 2014!



We will be updating the NBS Reference Manual for Medical Providers by the end of the year. Be on the lookout for your copy to be sent in early 2014.

Phone
(334) 206-5556

Fax
(334) 206-3791



We're on the Web!
See us at:
www.adph.org/newbornscreening

Healthy Woman™ 2013 Baby & Toddler Expo

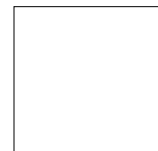
The Healthy Woman™ 2013 Baby & Toddler Expo was held on August 3, 2013, at the Enterprise City School Service Center and was sponsored by Medical Center Enterprise. It is a free event for new and expectant parents in Enterprise and the surrounding area.

Parents had the opportunity to experience, meet, and interact with area healthcare, retail, and educational providers. Door prizes, child safety demonstrations, and physician guest speakers were available. Cindy Ashley and Rachael Montgomery, Alabama Newborn Screening Program staff had the opportunity to serve as vendors, handing out educational material and speaking with parents and physicians about newborn screening.



Above, Rachael Montgomery (left), NBS Follow-up Nurse, shares newborn screening information with Dr. Sharon Bush (right), Obstetrician/Gynecologist with *Ladies First*. Several other obstetricians and pediatricians were also in attendance. According to Rachael Montgomery, "Many parents did not know about newborn screening. The Baby Expo served as a valuable opportunity to provide families with newborn screening resources."

Alabama Newborn Screening
P.O. Box 303017
201 Monroe Street
RSA Tower – Suite 1350
Montgomery, AL 36130-3017



MEDICAL PROVIDER

STREET ADDRESS

Address 2

CITY, ST ZIP Code