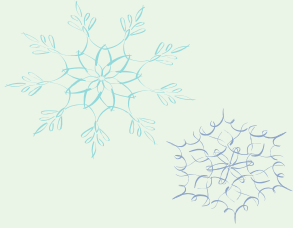


*Happy New Year!*



# Newborn Screening

Alabama Department of Public Health • January 2014

## Alabama EHDI Chapter Champion

Heather Taylor, M.D., University Medical Center, Tuscaloosa, AL



As an advocate for Early Hearing Detection and Intervention (EHDI), Dr. Heather Taylor has been an integral part of the Alabama Newborn Screening Program for the past five years. Her roles as a practicing pediatrician and an instructor of medical students provide an ideal bridge to advocate for early hearing loss detection measures to her peers and students, as well as the patients and families of her practice.

Dr. Taylor has served as Alabama's EHDI Chapter Champion for five years as well as served as the Chairperson of the Alabama Newborn Screening Advisory Committee. She received a grant for hearing screening education through the American Academy of Pediatrics and as a result initiated an outreach program in her community and surrounding counties in order to provide appropriate newborn hearing screening follow-up. Her practice offers Automated Auditory Brainstem Response testing free of charge for patients in her practice, as well as others in the community.

In addition, Dr. Taylor's input has been helpful with the development of hospital guidelines to implement universal pulse oximetry screening in birthing facilities. The newborn screening program is grateful to Dr. Taylor for her service to promote optimal outcomes for Alabama's babies. She is an outstanding champion of the Alabama Newborn Screening Program.

### INSIDE THIS ISSUE:

NBS Hearing Awards

NBS Advisory Committee

2013 AAP Fall Meeting

March of Dimes Recognizes  
NBS Leadership

New EHDI Coordinator

NBS Endocrinology Training

NBS Connect

2013 NBS Diagnoses



## Newborn Hearing Screening Coordinator Departs

The Alabama Newborn Screening Program said farewell to Ada Wall who served as the Newborn Hearing Screening Coordinator from September 2012 to October 2013. Ada served as a nurse with Public Health for eleven years. She did an excellent job ensuring Alabama's babies received the best follow-up hearing services during her time as the Newborn Hearing Screening Coordinator. Her dedication contributed to the success of the Alabama Newborn Hearing Screening Program. She was an asset to the program and will be missed.



## Newborn Screening Team

1-866-928-6755

**Cindy Ashley, BSN, RN-BC**  
Newborn Screening Program Director

**Rachael Montgomery, BSN, RN**  
Newborn Screening Follow-up Nurse  
Metabolic, Endocrine, CF, & CCHD

**Seratia Johnson, RN**  
Newborn Screening Nurse Educator  
Specimen Collection, Hgb, & Hearing

**Rovetta Hanna, BSN, RN**  
Newborn Hearing Screening Coordinator

**Melissa Richardson, MS, CCC-A**  
Newborn Screening Audiology Consultant

**Cassandra Hawthorne**  
Newborn Screening Administrative Assistant

**Tamika Shepherd**  
Newborn Hearing Administrative Assistant

**Danita Rollin, BS, MT (ASCP)**  
Microbiologist Laboratory Division Manager  
334-260-3400

**Deannie Morris, BS, MT (ASCP)**  
Newborn Screening Laboratory Supervisor  
334-260-3400

**Lynn Green, BS, MT (ASCP)**  
Newborn Screening Laboratory Supervisor  
334-260-3400

**Derek Kennedy, BS**  
Newborn Screening Laboratory Supervisor  
334-260-3400



## Newborn Hearing Screening Awards

In 2013, the Alabama Newborn Hearing Screening Program initiated a monthly awards program for 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 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 are separated into the four categories below based on the number of babies birthed annually. Each hospital is eligible for one award per calendar year. The award recipients for **May-August 2013** are listed below. Photos are shown below and on the next page in alphabetical order.

- **Facilities with less than 500 annual births:** Russell Medical Center, Bryan W. Whitfield Memorial Hospital
- **Facilities birthing between 500 and 1,000 annual births:** Walker Baptist Medical Center, DeKalb Regional Medical Center, Helen Keller Memorial Hospital, Trinity Medical Center, UAB Medical West
- **Facilities birthing between 1,000 and 2,000 annual births:** Eliza Coffee Memorial Hospital, Shelby Baptist Medical Center, Northport Medical Center, Providence Hospital, Jackson Hospital
- **Facilities with greater than 2,000 annual births:** St. Vincent's Hospital, USA Children's & Women's Hospital

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.



Bryan W. Whitfield  
Memorial Hospital



DeKalb Regional  
Medical Center

# Newborn Hearing Screening Awards Continued



Eliza Coffee  
Memorial Hospital



Helen Keller  
Memorial Hospital



Jackson Hospital



Northport  
Medical Center



Providence Hospital



Russell Medical Center



Shelby Baptist  
Medical Center



St. Vincent's Hospital



Trinity Medical Center



UAB Medical West



USA Children's &  
Women's Hospital



Walker Baptist  
Medical Center

# Alabama Newborn Screening Advisory Committee

The Alabama Newborn Screening Program has an active advisory committee that meets twice a year. The purpose of the Alabama Newborn Screening Advisory Committee (ANSAC) is to provide advice to the Alabama Department of Public Health on technical and program issues relative to newborn screening. In addition, the Committee addresses the newborn screening needs of the state, advises on policies for improving newborn screening services, and assists in presenting information about the newborn screening program. Membership consists of professionals and citizens who are knowledgeable in the area of newborn screening or who have an interest in newborn screening services. Membership is not limited, and every effort is made to have a balance between consumers of health care services, professional health care providers, and parent representatives.

The last ANSAC meeting took place on November 14, 2013, at the Robert Trent Jones Clubhouse at Capitol Hill in Prattville, Alabama. Topics of discussion included Severe Combined Immunodeficiency, electronic reporting of hearing results, recommendations from the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children, and plans for web-based access of newborn screening results. The Alabama Newborn Screening Program appreciates the commitment of committee members to improve policy and newborn screening services in the state.



Dr. Fred Goldman, Director of Blood and Marrow Transplant Program at Children's of Alabama.



Sharon Carlton, representing Dr. Thomas Howard, Pediatric Hematology, UAB.



Left to right: Dr. Mary McIntyre, Assistant State Health Officer for Disease Control & Prevention; Rosemary Blackmon, Alabama Hospital Association; Dr. Anne Marie Kaulfers, USA Pediatric Endocrinology; and Dr. Heather Taylor, University Medical Center, Tuscaloosa, AL.



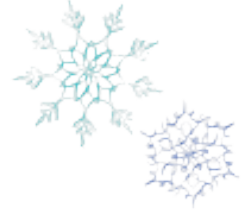
Left to right: Alicia Roberts, R.D., representing Dr. Lane Rutledge, UAB; and Tammy Tucker, St. Vincent's Hospital, Birmingham, AL.

# 2013 American Academy of Pediatrics (AAP) - Alabama Chapter Meeting & Fall Update

The 2013 Annual Meeting & Fall Pediatric Update was held at the Hyatt Regency in Birmingham, Alabama, on September 27-29. The Alabama Newborn Screening Program exhibited at the meeting and passed out educational material and shared resources with pediatric providers.

Some topics discussed at this year's meeting included:

- *Understanding Early Childhood Brain Development*
- *Pediatrician's Role in Advocating for Quality Early Childhood Programs*
- *Update on Surgical and Cath Lab-Based Treatment of Congenital Heart Disease*



Many pediatric providers were in attendance and shared their experiences, issues, and interests related to newborn screening. According to Cindy Ashley, "Several providers were asking about access to newborn screening results via a web-based system. This has been a goal of the Alabama Newborn Screening Program and we plan to continue efforts to implement this."



Left to right: Dr. Iris Fancher, Bessemer Health Center; Cindy Ashley, Alabama Newborn Screening Program Director; and Dr. Cathy Wood, Pediatric Partners, Montgomery, AL.



Left to right: Dr. DeeAnne Jackson, UAB Primary Care Clinic and Dr. Lucy Culpepper, Whatley Health Service, Tuscaloosa, AL.



Left to right: Seratia Johnson, Newborn Screening Nurse Educator and Rachael Montgomery, Newborn Screening Follow-up Nurse.



Left to right: Dr. Irfan Rahim, Pell City Pediatrics and Seratia Johnson, Newborn Screening Nurse Educator.

# March of Dimes Recognizes NBS Leadership

On September 18, 2013, the March of Dimes recognized newborn screening leadership in Alabama. State Health Officer, Dr. Donald Williamson, was pleased to accept the recognition presented by the March of Dimes on behalf of the many stakeholders whose expertise was crucial in implementing newborn screening for Critical Congenital Heart Disease (CCHD). Dr. Williamson thanked the members of the Newborn Screening Advisory Committee, the CCHD Workgroup, the Alabama Hospital Association, parent advocates, the Bureau of Family Health Services, and others involved in the process. According to the March of Dimes state director, Camille A. Epps, "The March of Dimes applauds Dr. Williamson for his unwavering commitment to newborn screening."

Mark Miller, parent advocate, spoke during the news conference about his daughter, Mary Beth, who was seven years old when she died after complications from a heart transplant. Mary Beth did not have a pulse oximetry screen but was identified with a heart murmur soon after birth and later diagnosed with a complex heart condition. Mark and Stacey Miller helped advocate for universal pulse oximetry screening to detect congenital heart defects in Alabama.

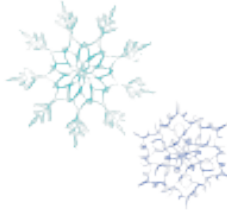
Ten Alabama newborns have been identified with congenital heart defects that might have gone undetected without pulse oximetry screening. As a result, these infants have been afforded access to diagnostic evaluation through pediatric specialists to receive specialized care and treatment that could prevent death or disability. Alabama remains ahead of the national average in screening its newborns. Alabama became the 22nd state to add CCHD to the state screening panel according to the March of Dimes.



Left to right: Dr. Donald Williamson, State Health Officer; and Robin Collins, March of Dimes.



Left to right: Camille A. Epps, March of Dimes Director; Dr. Donald Williamson, State Health Officer; Yvonne Willis, Baptist Medical Center East Newborn Nursery; and Mark Miller, parent advocate.



*Welcome, Rovetta!*  
*Alabama's Newborn Hearing Screening*  
*Coordinator*

**Alabama's Listening!**  
UNIVERSAL NEWBORN HEARING SCREENING

# NBS Endocrinology Training

Gail Mick, M.D., and Leslie Pitts, CRNP, with the Division of Pediatric Endocrinology at the University of Alabama at Birmingham, discussed *Preventing Morbidity and Mortality in Children with Congenital Hypothyroidism (CH) and Congenital Adrenal Hyperplasia (CAH)* during a live webcast held on November 14, 2013. The training program was produced by the Alabama Department of Public Health (ADPH), a partner in the Public Health Training Network, with a total of 347 registered participants from 23 states.

Topics presented included diagnostic criteria and the screening process for CH and CAH, review of case studies highlighting various presentations of each condition, and the importance of submitting a routine repeat newborn screen, and collecting serum testing. In addition, the discussion included the value of long-term management following diagnosis, as well as common challenges encountered in the treatment process.

If you missed the opportunity to watch the training program via webcast it is not too late. You may view the On Demand program at the following link [www.adph.org/alphtn](http://www.adph.org/alphtn). Non-ADPH employees are charged a fee to receive continuing education certificates. Nurses may receive continuing education units for up to two years after the live broadcast is aired.

# NBS Connect Patient Registry

The Newborn Screening Connect patient registry (NBS Connect) is a web-based, self-reporting patient registry curated by professionals. This resource is for those affected by certain disorders included in the newborn screening panel. The registry has been developed by national experts in the field of NBS disorders at the Department of Human Genetics at Emory University, and serves as a support network for parents, guardians, and individuals with inborn errors of metabolism.

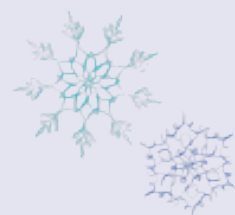
Extensive development of the registry is occurring via a phased approach, which began with the launch of NBS-PKU Connect for Phenylketonuria. Beta testing has now concluded and the next phase has launched with NBS-MSUD Connect for Maple Syrup Urine Disease. Expansion of the registry will continue to include other disorders in the NBS panel recommended by the American College of Medical Genetics.

NBS Connect brings together patients, families, parent organizations, and professionals in one forum. Professionals are able to share clinical trial information with patients; professionals have access to de-identified patient survey data; and families are able to connect with one another and access useful tools such as recipes and educational resources.

Register at [www.nbsconnect.org](http://www.nbsconnect.org) today! For questions, please contact Yetsa Osara, MPH, at [coordinator@nbsconnect.org](mailto:coordinator@nbsconnect.org) or 404-778-0553.



From left to right: Dr. Gail Mick, Leslie Pitts, CRNP, and Annie Vosel, Public Health Nurse.



Cindy Ashley, Newborn Screening Program Director, was interviewed on September 26, 2013, by WAKA, a CBS affiliate in Montgomery, AL, in recognition of the fiftieth anniversary of Newborn Screening.

# 2013 Newborn Screening Diagnoses

## NBS Follow-up Team



Left to right: Rovetta Hanna, NBS Hearing Coordinator; Cindy Ashley, NBS Program Director; Seratia Johnson, NBS Nurse Educator; Rachael Montgomery, NBS Follow-up Nurse; Cassandra Hawthorne, Metabolic Administrative Assistant; Tamika Shepherd, Hearing Administrative Assistant.

## Disorder

## Newborns Identified

Carnitine Uptake Defect	1
Classical Galactosemia	1
Congenital Adrenal Hyperplasia	2
Congenital Hypothyroidism	36
Critical Congenital Heart Defect	2
Cystic Fibrosis	13
Hearing Loss	31
Hemoglobinopathies	53
Hyperphenylalaninemia	3
Long Chain Acyl CoA Dehydrogenase Deficiency	1
Maple Syrup Urine Disease	1
Medium Chain Acyl CoA Dehydrogenase Deficiency	3
Methylmalonic Acidemia	1
Phenylketonuria	4
Very Long Chain Acyl CoA Dehydrogenase Deficiency	1

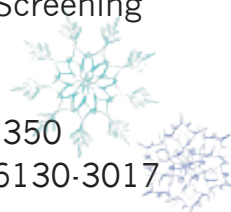
Alabama Newborn Screening

P.O. Box 303017

201 Monroe Street

RSA Tower - Suite 1350

Montgomery, AL 36130-3017



## Phone

334-206-5556

1-866-928-6755

## Fax

334-206-3791



[www.adph.org/newbornscreening](http://www.adph.org/newbornscreening)