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.

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 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.
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
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.
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.”
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 Stacee 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.
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. 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 today! For questions, please contact Yetsa Osara, MPH, at coordinator@nbsconnect.org or 404-778-0553.
2013 Newborn Screening Diagnoses

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Newborns Identified</th>
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<tbody>
<tr>
<td>Carnitine Uptake Defect</td>
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</tr>
<tr>
<td>Classical Galactosemia</td>
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</tr>
<tr>
<td>Congenital Adrenal Hyperplasia</td>
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<tr>
<td>Congenital Hypothyroidism</td>
<td>36</td>
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<tr>
<td>Critical Congenital Heart Defect</td>
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<tr>
<td>Cystic Fibrosis</td>
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<tr>
<td>Hearing Loss</td>
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<td>Hyperphenylalaninemia</td>
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<tr>
<td>Maple Syrup Urine Disease</td>
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<tr>
<td>Medium Chain Acyl CoA Dehydrogenase Deficiency</td>
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<tr>
<td>Methylmalonic Acidemia</td>
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<tr>
<td>Phenylketonuria</td>
<td>4</td>
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<tr>
<td>Very Long Chain Acyl CoA Dehydrogenase Deficiency</td>
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</tr>
</tbody>
</table>

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