Alabama to Implement Pilot Screening for Critical Congenital Heart Disease

On September 21, 2011, Secretary of Health and Human Services, Kathleen Sebelius, adopted the Advisory Committee on Heritable Disorders in Newborns and Children's recommendation to add Critical Congenital Heart Disease (CCHD) to the Recommended Uniform Screening Panel.

The Alabama Department of Public Health followed by convening a work group of professionals on November 29, 2011, and on December 13, 2011, which included pediatric cardiologists, neonatologists, pediatricians, parent advocates, insurance representatives, hospital personnel, and public health staff. The work group met to discuss recommended procedures and to develop guidance for conducting and administering universal pulse oximetry screening to detect CCHD in Alabama.

The Alabama Newborn Screening Program mailed out the Hospital Guidelines for Implementing Pulse Oximetry Screening last month to all birthing facilities in the state. To access online visit www.adph.org/newbornscreening/Default.asp?id=2201.

In Alabama, about 70 babies born every year will have a congenital heart defect. There are seven defects classified as critical congenital heart defects: Hypoplastic Left Heart Syndrome, Pulmonary Atresia (with intact septum), Tetralogy of Fallot, Total Anomalous Pulmonary Venous Return, Transposition of the Great Arteries, Tricuspid Atresia, and Truncus Arteriosus.

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Public Health would like to recognize and thank those birthing facilities that began universal pulse oximetry screening prior to these efforts.

2011 Confirmed Newborn Screening Disorders

The Alabama Department of Public Health currently screens for 29 primary disorders and over 40 total disorders including secondary conditions.

In 2011, 212 infants were identified with a primary newborn screening condition.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number identified:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carnitine Transporter Defect (CUD)</td>
<td>2</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>19</td>
</tr>
<tr>
<td>Congenital Adrenal Hyperplasia</td>
<td>5</td>
</tr>
<tr>
<td>Congenital Hypothyroidism</td>
<td>33</td>
</tr>
<tr>
<td>Glutaric Acidemia</td>
<td>1</td>
</tr>
<tr>
<td>Hearing Loss</td>
<td>68</td>
</tr>
<tr>
<td>Hyperphenylalaninemia (hyperphe)</td>
<td>5</td>
</tr>
<tr>
<td>Medium Chain Acyl Co-A</td>
<td></td>
</tr>
<tr>
<td>Dehydrogenase Deficiency (MCADD)</td>
<td>5</td>
</tr>
<tr>
<td>Methylmalonic Acidemia (MMA)</td>
<td>1</td>
</tr>
<tr>
<td>Phenylketonuria (PKU)</td>
<td>5</td>
</tr>
<tr>
<td>Sickle Cell Disease</td>
<td>67</td>
</tr>
<tr>
<td>Very Long Chain Acyl Co-A</td>
<td></td>
</tr>
<tr>
<td>Dehydrogenase Deficiency (VLCAD)</td>
<td>1</td>
</tr>
</tbody>
</table>
Have You Heard…?

The Alabama Public Health Training Network (ALPHTN) is a division of the Alabama Department of Public Health and provides training and public information to health professionals across the nation.

It was formally established in 1992 in collaboration with the Centers for Disease Control and Prevention and is a nationally recognized provider of public health training and education programs.

Newborn Hearing

Amy Strickland, Au.D., CCC-A
Melissa Richardson, M.S., CCC-A

The Alabama Newborn Screening Program would like to say a big thanks to all of the hospital nursing staff for doing such a great job with newborn hearing screening. We could never get hearing impaired babies in Alabama screened, diagnosed, and enrolled in Early Intervention without your diligence! Our goal is to have intervention by six months of age, which can only happen with a team effort that starts with the birthing facility.

Many hospitals schedule the babies that “refer” on the initial hearing screening to return to their nursery for the initial out-patient follow-up test. Then, if there still isn’t a “pass,” they are referred elsewhere for diagnostic testing. However, other hospitals rely solely on out-patient test sites for all follow-up testing. Reminder: If your hospital does not do any out-patient testing, then the baby must be scheduled by your staff prior to discharge. There is a list of approved test sites on the newborn screening web-site at www.adph.org/newbornscreening under Newborn Hearing Screening on the left of the page.

If you are having difficulty locating an out-patient test site for your babies, please let us know. Also, if your babies are not being seen in a timely manner (2-3 weeks), please let us know as it is unacceptable to wait longer. Children’s Rehabilitation Service (CRS) is a good source for follow-up testing if there is a CRS Clinic in your area. Please also see the NBS web-site for a list of CRS Clinics.

Remember that if the baby was tested via Otoacoustic emission (OAE), they may receive OAE or Automated Auditory Brainstem Response (AABR) testing as an out-patient. However, if the baby was tested through AABR, then they must have an AABR as an out-patient. Please make sure you are sending your babies to have the appropriate test and let the follow-up site know which test has been completed as in-patient.

One final note, if you rescreen babies that failed at other facilities, you are to follow the same method guidelines regarding using OAE vs. AABR and if you don’t know what method the infant failed initially, call us!

Again, thank you for your efforts in making this program all that it can be!
March of Dimes Award

On February 27, 2012, Dr. Donald E. Williamson, Alabama State Health Officer, accepted the Franklin D. Roosevelt Leadership Award on behalf of the Alabama Department of Public Health. This award was presented by the March of Dimes to recognize the efforts of Public Health to include the 29 screening disorders, as recommended by the U.S. Health and Human Services Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children and endorsed by the March of Dimes.

The March of Dimes applauded the leadership of the State Health Officer and the State Committee of Public Health for making Alabama a national leader in newborn screening.

Legislative Resolution

The House of Representatives of the Alabama Legislature passed a resolution on April 3, 2012, commending the Alabama Department of Public Health for the efforts made to implement a policy requiring pulse oximetry screening on all newborns for the detection of Critical Congenital Heart Disease. In addition, the Alabama Hospital Association, the Medical Association of Alabama, the American Academy of Pediatrics, and the American Heart Association were commended for their collaborative effort working in conjunction with Public Health to achieve this very important policy in the health care of newborns in Alabama.

Test Your Knowledge on Specimen Collection

True or False: (Answers next page)

1. A specimen should be allowed to dry at least four hours before mailing.
2. It is acceptable to squeeze the puncture site to promote bleeding.
3. If there is not enough blood to fill a single circle it is acceptable to add a second drop.
4. A single drop of blood per circle should be applied to only one side of the filter paper.
5. The first large drop that forms should be applied to the filter paper.
6. Specimens should be dried vertically.
7. All demographic data should be completed on the specimen card, especially highlighted fields to include date of collection and time of collection.
Answer Key

1. **True**: Specimens should be allowed to dry at least 4 hours before mailing.

2. **False**: Milking or squeezing the puncture site might cause hemolysis and mix tissue fluid with the specimen.

3. **False**: Each printed circle should only be filled with a single drop of blood.

4. **True**: Blood may be applied to either the front or back of the filter paper; however, it can only be applied to one side per application.

5. **False**: The first drop of blood that forms at the puncture site is contaminated with the alcohol used to prep the area and must be wiped away in order to avoid diluting the specimen.

6. **False**: Specimens should be dried in a horizontal position in order to avoid serum separation from the blood.

7. **True**: All demographic data is vital for interpretation of newborn screening results and identification of infants.

About Our Organization

The Alabama Newborn Screening Program establishes protocol to ensure early identification and follow-up of infants affected with certain genetic or metabolic conditions. Early diagnosis may reduce morbidity, premature death, mental retardation, and other developmental disabilities.

The program works in partnership with pediatric specialists throughout the state to ensure all babies identified with abnormal results receive appropriate follow-up.

Kudos!

We would like to recognize those birthing facilities that met the state goal of 5% or less specimen rejection rate and that had a zero “no input” rate for newborn hearing results during January 2012. Congratulations!

★ indicates 0%

January 2012 - 5% or less rejected specimen rate

★ Crenshaw Community Hospital

- Athens-Limestone Hospital
- Baptist Medical Center East
- Baptist Medical Center South
- D.W. McMillan Memorial Hospital

- East Alabama Medical Center
- Eliza Coffee Memorial Hospital
- Highlands Medical Center
- Mobile Infirmary
- Northeaster Alabama Regional Medical Center
- North Baldwin Infirmary
- Russell Medical Center
- Spring Hill Memorial Hospital
- St. Vincent’s East
- St. Vincent’s Hospital
- UAB Medical West

January 2012 - zero “no input” hearing result rate

- Andalusia Regional Hospital
- Athens-Limestone Hospital
- Crenshaw Community Hospital
- Crestwood Medical Center
- D.W. McMillan Memorial Hospital
- Decatur General Hospital
- Dekalb Regional Medical Center
- East Alabama Medical Center
- Grove Hill Memorial Hospital
- Helen Keller Hospital
- Highlands Medical Center
- Jacksonville Medical Center
- Mobile Infirmary
- Monroe County Hospital
- North Baldwin Infirmary