

Newborn Screening



Alabama Department of Public Health, 1-866-928-6755

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Birthing Center Closings

- Cooper Green Mercy Hospital, Birmingham, AL
- Jackson Medical Center, Jackson, AL

Birthing Center Openings

- Madison Hospital, Madison, AL



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State Health Laboratory



The Newborn Screening Division of the Bureau of Clinical Laboratories processes approximately 155,000 newborn screening specimens annually. Their goal is to process these specimens in an accurate and timely manner.

Newborn Screening Laboratory personnel closely examine each specimen that arrives in the lab for quality and quantity before testing begins. They review filter forms in order to make sure that there is enough demographic information to identify the baby and run the blood test.

The filter forms are sorted by those deemed acceptable or not acceptable after review by the lab microbiologists. A final review is made by the lab supervisor.

The state lab reviews approximately 100 samples daily that are deemed unacceptable and about one third of those may be accepted once they are reviewed by the supervisor.

All samples are processed daily. The process may be delayed if the critical demographic information is not provided with the sample. It is also important to complete all of the demographic information that is requested so that timely testing and interpretation of test results can be provided. It is important that the amount and integrity of the sample is adequate for testing. Improper collection of the sample and inaccurate or inadequate information provided may lead to delayed diagnosis and treatment.

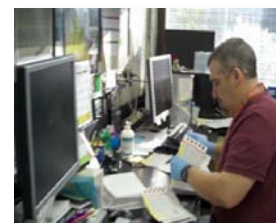


Photo: Derrick Kennedy
State Health Laboratory



Photo: Bureau of Clinical
Laboratories,
Montgomery, AL



Photo: State Health Lab
Supervisor reviews a
newborn screening
specimen for adequate
blood.

NBS Hearing Coordinator Departs

The Alabama Newborn Screening Program bids farewell to Amy Strickland, Au.D, CCC-A, after almost three years of service in her role as the Newborn Screening Hearing Coordinator. Dr. Strickland has contributed her clinical expertise to the NBS Hearing Program through the establishment of electronic reporting of hearing results, which has significantly increased the state's

hearing screening reporting rate.

She has been a valuable team member and advocate of hearing services for Alabama's smallest citizens. The Newborn Screening follow-up staff appreciates all her hard work and contributions to the Program. She will be greatly missed, and we wish her the best as she

transitions back to clinical practice.





There was a misprint in the Hospital Guidelines for Implementing Pulse Oximetry Screening for Critical Congenital Heart Disease (CCHD) on page 16, Pulse Ox Screening Algorithm. A corrected algorithm may be found on the newborn screening web site at the link below.

<http://www.adph.org/newbornscreening/assets/PulseOxScreeningAlgorithm.pdf>



Please be sure to report failed pulse ox screening results to ADPH via fax 334-206-3791.

First CCHD Baby Identified since Implementation of Universal Screening

The Alabama Department of Public Health (ADPH) has received its first report of a newborn identified with a Critical Congenital Heart Defect (CCHD) since the voluntary implementation of universal pulse oximetry screening. The birthing facility that reported the failed pulse oximetry result implemented screening on August 1, 2012, and the infant was identified a week later.

As of August 1, 2012, 47 of the 52 birthing facilities in the state report they have implemented universal pulse oximetry screening per the recommended guidelines in order to detect CCHD. The five other facilities report they plan to implement by the end of the year.

In March 2012, ADPH mailed out the *Hospital Guidelines for Implementing Pulse Oximetry Screening* to all birthing facilities in the state. The guidelines were adapted from the Children's National Medical Center CCHD Toolkit in order to assist each birthing facility with establishing its own policy and procedure for implementing a CCHD Screening Program.

Recommendations were made to establish clear, complete, and concise evidence-based policy. Equipment, training, screening, and educational requirements were also addressed.

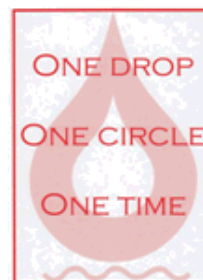
(Continued page 4)

Did You Know...?

Uneven saturation is the leading cause of rejection for newborn screening specimens by the State Health Laboratory. Uneven saturation is caused by touching the same circle on the filter paper to the blood drop several times or filling the circle on both sides of the filter paper.

In addition, if the filter paper is dried in a vertical position rather than a horizontal position, the serum can separate from the blood and cause uneven saturation. Here are steps to take in order to avoid uneven saturation:

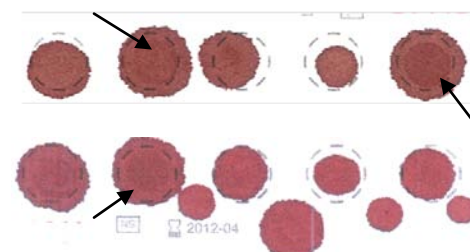
- Puncture the heel with a disposable lancet deep enough to reach the skin's primary blood supply; the lancet should not puncture more than 2 mm deep for an average size infant as not to damage the bone.
- Apply a large drop of blood evenly to the filter paper.
- Do not remove the filter paper until the blood has completely soaked through to the other side.
- Allow the specimen to completely dry in a horizontal position at least 4 hours and review the specimen for dark spots once dried.



Example of Good Blood Spots:



Example of Uneven Blood Spots:



Alabama's Listening Melissa Richardson, MS, CCC-A, Newborn Screening Audiology Consultant

Hearing screen results do not always stay the same as the initial results, especially for babies with "high risk" criteria for hearing loss as set forth by the Joint Committee on Infant Hearing (JCIH). The results of the hearing screen show how a baby is hearing at the time of the test. So, the tracking system for keeping up with all babies' hearing screening results is very important. The state goal is to achieve a low no-input or "not reported" rate to ensure repeat hearing results are reported.

There are several steps to take in order to achieve a low no-input hearing result rate. First, make sure to screen all babies prior to discharge, preferably with an AABR, or at least a 2-step process with no more than 2 attempts via OAE method followed by AABR prior to discharge. Second, report hearing results electronically via FTP upload by the 10th of each month. This allows us to match what was received on the initial blood spot form with the results downloaded directly from the

screening device. Third, limit hospital report corrections. The hospital reports are generated around the 20th of each month and reflect the information that is sent via FTP. If results are sent by the 10th, then there is time to update the hospital report before it is generated; therefore, there should be very few corrections to be made and sent back.

In addition, it may be helpful to have updated equipment that is in good working order and is compatible for easy export of hearing results. If your birthing facility is in need of updated equipment, contact the ADPH NBS Program to be placed on the equipment grant list. Grants are awarded when funding is available. Thanks for all the hard work, time, and effort to those that continue to upload hearing results each month.



Dr. Prescott Atkinson, Professor
Director, UAB
Allergy/Immunology
Division Director

Severe Combined Immunodeficiency (SCID) Update

Severe Combined Immunodeficiency (SCID), also known as "bubble-boy disease," is a group of rare but serious, and potentially fatal, inherited immune disorders in which T lymphocytes fail to develop and B lymphocytes are either absent or compromised as defined by the American College of Medical Genetics.

On May 21, 2010, Kathleen Sebelius, Secretary of Health and Human Services, adopted SCID to the Recommended Uniform Screening Panel (RUSP).

Dr. Prescott Atkinson, Professor and Director of the Division of Pediatric Allergy, Asthma, and Immunology at UAB, provided an update at the Alabama Newborn Screening Advisory Committee held May 17, 2012. Dr. Atkinson and Dr. Fred Goldman, Children's of Alabama Transplant Director, recently attended a Pediatric Infectious Disease- Immunodeficiency Transplantation meeting in Boston.

According to Dr. Atkinson, there are over 300 genetic immunodeficiency conditions, of which about 20 SCID syndromes are classified as so severe that they are not compatible with life beyond the first year.

Treatment for almost all of these conditions is a bone marrow or stem cell transplant. It is easier to transplant infants with SCID

since they lack the ability to fight off the transplant. Untreated patients develop life-threatening infections due to bacteria, viruses, and fungi, such as pneumonia, meningitis, or bloodstream infections. In addition, live vaccines present a deadly challenge for these infants.

Dr. Atkinson reports that they are not seeing these patients in Alabama because they usually die without being identified. He expects to see 1 to 2 babies every year with these conditions once screening is implemented in Alabama.

At this time, there is no FDA approved screening kit for SCID.



Dr. Fred Goldman,
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CCHD Update (continued)

ADPH would like to remind birthing facilities to continue to report failed pulse oximetry screening results via fax to 334-206-3791. Again, if a newborn is transferred to another facility or referred to a specialist, please include the name of the hospital or provider to which the newborn is transferred or referred.

It is recommended that the

Failed Screen Reporting Form, provided in the *Hospital Guidelines for Implementing Pulse Oximetry Screening for CCHD (page 18)*, be used to report failed results at this time.

Additional Failed Screen Reporting Forms may be requested by completing the CCHD Material Order Form, found on page 29 of the *Hospital Guidelines*.

In addition, ADPH plans to mandate pulse oximetry screening on all newborns in early 2013. ADPH is excited to continue the partnership with birthing facilities in the state on this initiative, which has the potential to save lives and improve outcomes for many of our babies.

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

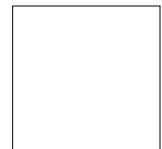
may reduce morbidity, premature death, mental retardation, and other developmental disabilities.

The program works in partnership with pediatric specialists throughout the

state to ensure all babies identified with abnormal results receive appropriate follow-up



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