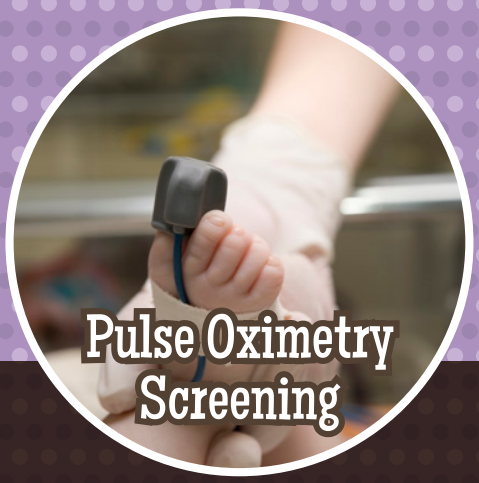
ALABAMA

Newborn Screening
PROGRAM







Newborn Screening Reference Manual for Medical Providers 2025

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ALABAMA NEWBORN SCREENING PROGRAM

The goal of the Alabama Newborn Screening Program is to ensure state laws, rules and regulations mandating newborn screening are carried out in order to identify specific genetic disorders early and provide appropriate follow-up care.

The Alabama Newborn Screening (NBS) Program is a comprehensive and coordinated system that provides education, screening, follow-up, diagnosis, evaluation, and management of disorders typically not apparent at birth. Newborn screening is mandated by Statutory Authority Code of Alabama 1975, Section 22-20-3. The screening allows treatment to be initiated within the first few weeks of life, preventing many of the complications associated with genetic and endocrine disorders. Early diagnosis can reduce morbidity, premature death, and developmental disabilities, including intellectual impairment. The Alabama NBS panel includes 35 of 38 disorders recommended by the U.S. Department of Health and Human Services Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. Each year, the Alabama NBS Program identifies approximately 150-200 infants with a metabolic, endocrine, hematological, or other congenital disorders that may not be apparent at birth.

The Alabama Newborn Early Hearing Detection and Intervention (EHDI) Program collaborates with the National Center for Hearing Assessment and Management (NCHAM) to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention. In addition, the program collaborates with Children's Rehabilitation Service (CRS) to ensure infants receive second tier follow-up screening and diagnostic confirmation of hearing loss by three months of age and the Alabama Early Intervention System (AEIS) to ensure infants with hearing loss are enrolled in early intervention services by six months of age.

The Bureau of Clinical Laboratories (BCL) performs blood analysis that aids in the diagnosis of 35 primary genetic disorders. In addition, screening is performed for over 15 secondary disorders, bringing the total to more than 45 disorders. All newborns identified with an abnormal result have access to a diagnostic evaluation through medical specialists throughout the state. These consultants work closely with the BCL, follow-up staff, and the primary care provider to coordinate prompt diagnostic testing and develop an appropriate treatment plan, when necessary. Treatment may include medications, dietary restrictions and/or supplements, and surgical intervention.

HIPAA

Dear Alabama Newborn Screening Providers:

Subject: HIPAA and Newborn Screening Information

In light of HIPAA, concerns have been raised regarding sharing information with the Alabama Department of Public Health regarding newborn screenings. Exchange of information regarding newborn screening is permissible under HIPAA because HIPAA allows the disclosure of protected health information without patient authorization if the disclosure is required by law or if the disclosure is required for public health activities. Disclosures regarding newborn screening fall into both of these categories.

Specifically, the HIPAA regulations state that they do not pre-empt laws "for the conduct of public health surveillance, investigation, or intervention." 45 CFR 160.203(a)(2)(c). The regulations further provide that disclosures can be made without patient consent if the disclosure is required by law or if the disclosure is required for public health activities such as "preventing and controlling disease, injury, or disability" and "the conduct of public health surveillance, public health investigation, and public health interventions." 45 CFR 164.512(a) and (b).

State law requires that health care providers report all results of the newborns tested to the Alabama Department of Public Health. Ala. Admin. Code r. 420-10-1.04(2). Therefore, providers must continue reporting newborn screening results to the Alabama Department of Public Health pursuant to state law and in compliance with HIPAA.

The U.S. Department of Health and Human Services (HHS), who promulgated the HIPAA regulations, and the Centers for Disease Control (CDC) emphasized the public health exception to HIPAA in guidance issued on April 1, 2003. The guidance states that covered entities may disclose protected health information to public health entities, without patient authorization, for the conduct of public health surveillance, investigations, or interventions, as well as for the purpose of preventing or controlling diseases. Additionally, the HHS Office of Civil Rights guidance issued on July 6, 2001 states that covered entities may rely on the judgment of a public health entity when requesting a disclosure as to the minimum amount of information that is needed by Public Health.

In conclusion, state law gives the State Board of Health the authority to designate newborn screenings and the authority to promulgate "such rules and regulations as it considers necessary to provide for the care and treatment of those newborn infants." Ala. Code §22-20-3(b). Pursuant to this authority, the Board of Health has adopted the above-described regulations that required the reporting of all newborn screenings. Because HIPAA does not pre-empt laws for the conduct of public health surveillance, investigation, or intervention and HIPAA allows disclosures for public health activities, you may continue to release newborn screening information without patient authorization to Public Health for the conduct of public health activities. Furthermore, you may rely on Public Health's judgment as to the minimum amount of information necessary in the disclosure request.

If you have any concerns or questions regarding these matters, please do not hesitate to contact me at 334-206-5209 or pamela.kendrick@adph.state.al.us.

Sincerely,
Pam Kendrick, Privacy Officer

ALABAMA NBS PANEL OF DISORDERS

There are thirty-five primary disorders which are currently included in the Alabama Newborn Screening Panel and over forty-five total disorders including the secondary conditions. Please see the appendix for a brief description and timeline of each primary disorder.

1. 3-Hydroxy-3-methylglutaric aciduria (HMG)
2. 3-Methylcrotonyl-CoA carboxylase deficiency (3-MCC)
3. Argininosuccinic aciduria (ASA)
4. B-Ketothiolase deficiency (BKT)
5. Biotinidase deficiency (BIOT)
6. Carnitine uptake/ transport defect (CUD)
7. Citrullinemia type I (CIT)
8. Classic galactosemia (GALT)
9. Classic phenylketonuria (PKU)
10. Congenital adrenal hyperplasia (CAH)
11. Critical congenital heart disease (CCHD)
12. Cystic fibrosis (CF)
13. Glutaric acidemia type I (GA1)
14. Hearing loss (HEAR)
15. Hemoglobin S/Beta-thalassemia (Hb S/BTh)
16. Hemoglobin SC disease (HbS/C)
17. Hemoglobin SS disease (HbSS)
18. Homocystinuria (HCY)
19. Isovaleric acidemia (IVA)
20. Long-chain L-3 hydroxyacyl-CoA dehydrogenase deficiency (LCHAD)
21. Maple syrup urine disease (MSUD)
22. Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)
23. Methylmalonic acidemia, cobalamin disorders (Cbl A, B)
24. Methylmalonic acidemia, methylmalonyl-CoA mutase (MUT)
25. Holocarboxylase synthase deficiency (MCD)
26. Primary congenital hypothyroidism (CH)
27. Propionic acidemia (PROP)
28. Severe combined immunodeficiencies (SCID)
29. Spinal Muscular Atrophy (SMA)
30. Tyrosinemia type I (TYR I)
31. Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)
32 X-linked Adrenoleukodystrophy (X-ALD)
33. Mucopolysaccharidosis Type I (MPS-I, Hurler Syndrome)
34. Trifunctional Protein Deficiency
35. Pompe Disease

See alabamapublichealth.gov/newbornscreening/disorder-descriptions.html for a description of each condition.

MEDICAL PROVIDER RESPONSIBILITIES



Medical providers are notified of newborn screening results by mail as long as they are identified on the specimen collection form.



Medical providers are notified by immediate phone call for potential positives and/or abnormal results that are outside of set cutoff values.



Providers are encouraged to use Alabama's Secure Remote Viewer (SRV) to access newborn screening results.

Ensure that all newborn patients in their care have received complete and valid newborn screening results and that any invalid or screen positive results have been appropriately addressed.

Contact families about out-of-range or invalid screening results in a knowledgeable and sensitive fashion by educating themselves on the medical aspects of conditions included in the screening panel.

Facilitate repeat or confirmatory testing and appropriate subspecialty care and report the results of confirmatory tests and diagnosis to the Alabama Newborn Screening Program.

Collect a repeat newborn screen as soon as possible if the first test is unsatisfactory, and collect a routine repeat screen at 2-6 weeks of age on all infants since TSH elevations could be delayed.

Ensure that the recommended hearing screening method is used for the rescreening of all infants who fail their initial hearing screen.

Obtain a signed statement for parent refusal of newborn screenings, when applicable.

Ensure that medical provider contact information stays current with the state lab so that collection forms and test reports can be provided to the correct provider in a timely manner.

It is recommended that pediatric providers offer and explain newborn screening to families of children under their care. Pediatric providers may face professional liability for failing to adequately inform parents of each newborn screening test (Mallory vs. Meier, et al.). Newborn hearing results are reported electronically by birthing hospitals and may not always link to a blood spot record and appear on the lab report. Please be sure to verify newborn hearing screening is completed (see section 3).

Reference: Clinical and Laboratory Standards Institute (CLSI). *Newborn Screening Follow-up; Approved Guideline.* CLSI document I/LA27-A.

ALABAMA NBS MEDICAL CONSULTANTS

ENDOCRINE – CH/CAH

1. USA Medical Center, Endocrinology..... **(251) 405-5147**
2. Children's of Alabama, Endocrinology..... **(205) 638-9107**

HEMOGLOBINOPATHIES - SICKLE CELL DISEASE, TRAIT CONDITIONS AND OTHER HEMOGLOBINOPATHIES

1. USA Sickle Cell Center..... **(251) 405-5147 (#3)**
2. Children's of Alabama, Pediatric Hematology..... **(205) 638-9285**
3. St. Jude Clinic at Huntsville Hospital..... **(256) 265-5833**

CYSTIC FIBROSIS

1. Children's of Alabama CF Care Center..... **(205) 638-9583**

METABOLIC: AMINO ACID DISORDERS, FATTY ACID DISORDERS, LYSOSOMAL STORAGE DISORDERS, ORGANIC ACID DISORDERS AND X-ALD

1. UAB Genetics..... **(205) 996-6983**

CRITICAL CONGENITAL HEART DISEASE (CCHD)

1. UAB Pediatric Cardiology..... **(205) 934-3460 (direct), (800) UAB-MIST (paging)**
2. Pediatric Specialists of Montgomery..... **(334) 612-2111 (direct and paging)**
3. Cardiology Associates of Mobile..... **(251) 434-9177 (direct and paging)**
4. Diagnostic & Medical Clinic (Mobile)..... **(251) 435-1200**

SEVERE COMBINED IMMUNODEFICIENCY (SCID)

1. Children's of Alabama..... **(205) 638-9586**
2. UAB – Lowder Pediatric Blood and Marrow Transplantation Program
   Infants will be referred for bone marrow transplantation by immunologist, if indicated
3. Spinal Muscular Atrophy (SMA)..... **(205) 638-2007**

SECURE REMOTE VIEWER INSTRUCTIONS

Secure Remote Viewer (SRV) is a web-based system that allows healthcare providers access to newborn screening results. The system allows users to search, view, and print results immediately from their computer.

SRV REGISTRATION

The Secure Remote Viewer (SRV) requires registration with the Bureau of Clinical Laboratories (BCL). Physicians may register with the system by completing the registration form and faxing it to (334) 206-3780. We will verify that you are currently in the Alabama BCL system to be eligible to gain access to SRV.

Each physician is required to provide their state license number, National Provider Identifier (NPI), and an email address. On the registration form you will also be asked to provide three options for the account's username. Once registration is complete, the registrant will receive their username and password via the email account provided. The email will not include the link to the SRV website for security purposes. You will need to log into the link below to access the SRV once you receive your username and password.

Authorized users will be able to find and view the most recent newborn screening results for each patient after providing the required minimum search criteria.

The following is a listing of requirements in order to utilize the SRV application:

- **Web Browser:** compatible with Mozilla Firefox, Microsoft Edge, and Google Chrome
- **Pop-up Blocker:** must be turned off in thebrowser settings or a website exceptionadded in "Settings" to ensure authenticationand for the lab report (PDF) pop-ups toappear.
- **PDF Viewer:** must have to view lab report

SRV INSTRUCTIONS

1. You will receive an email from donotreply_srv@adph.state.al.us with your username and password(check SPAM or Junk Mail if you have not received it within 2 days of submitting your request).
2. To access SRV, go to: https://newbornwebportal.adph.state.al.us/
3. Log in using the username and password provided.
4. You will be prompted to reset your password.
5. Once you access the website, you may search with a form number or choose the second tab to search with the patient's information.
6. An infant's test results can be found by entering the infant's last name, mother's first name, date of birth, and hospital of birth in addition to any one of the following: mother's last name, infant's first name, mother's social security number or form number (6-digit numbers on filter form followed by last 2 digits of birth year).
7. Once the search criteria have been entered, select the "Perform Search" button at the lower right.
8. If the minimum criteria have not been entered,"Invalid Search Criteria" will be displayed.
9. If the system is unable to find an infant, "No Records Found" will be displayed.
10. If there are results matching the search criteria, they will be displayed along with the specimen's status (pending or reported) in the lower portion of the page under "SRV Search Results."
11. Once the infant's results are located, the user will check the box in the first column on the left and then select "Download" in the lower right corner. The report will be downloaded to the browser's default download location on the computer. More than one box may be checked if the infant has multiple reports.

SECURE REMOTE VIEWER REGISTRATION

Please complete this form if you would like access to the Secure Remote Viewer (SRV), which provides newborn screening results via the web. In order to gain access to SRV you must currently be registered to receive results via mail with the Bureau of Clinical Laboratories.

PLEASE PRINT

Name of Physician (first and last name)_____

Name of Facility _____

Facility Mailing Address _____

_____

Facility Area Code/Telephone Number _____

Work E-Mail Address _____
THIS IS REQUIRED: The registrant will receive an invitation via email.

Username (list three options and limit to ten characters each) _____

_____

Physician's State License # _____ NPI#_____

Signature of Physician/Nurse Practitioner _____

Please fax or mail to:

Alabama Department of Public Health
Bureau of Clinical Laboratories
P.O. Box 1000
Prattville, Alabama 36067
Fax: 334-206-3780

If you have any questions, please call 334-290-3097.

Disclaimer: You must agree that you are a healthcare professional providing care for those infants whose records you will view and agree to keep confidential all information made available to you before gaining access to the SRV system. Any unauthorized access, use, and/or disclosure of information may result in loss of access privileges and may be subject to penalties, fines, and criminal charges in accordance to the Health Insurance Portability and Accountability Act of 1996 (HIPAA), Public Law 104-91.

NEWBORN SCREENING EDUCATION MATERIAL

Newborn screening material may be ordered directly online at the following site https://www.alabamapublichealth.gov/Extranet/Forms/Form.asp?ss=s&formID=5561 or by completing the information below and faxing to (334) 206-3791.

Newborn Screening materials are reserved for Alabama Newborn Screening Providers. There is a limit to the volume of materials that can be ordered at one time.

PLEASE USE A SEPARATE ORDER FORM FOR EACH ITEM ORDERED

Hospital/Practice Name _____

Mailing Address _____

City/Zip Code _____

Telephone Number_____

Contact Person_____

Education Material Number: ADPH-FHS- _____

Quantity Requested _____
FHS-533 comes in packets of 50 and FHS-537/538 comes in packets of 100, limit of 10 packets

FHS-533



Description: Booklet that includes bloodspot, hearing, and pulse ox screening information. Spanish version also available.

FHS-537 (5x8 card)



Description: Single 5x8 card for expecting parents. Includes four statements parents need to know about newborn screening. English on one side and Spanish on other side.

FHS-538



Description: Pamphlet with hearing information for parents. Spanish version also available.

NEWBORN SCREENING REFUSAL FORM

The American Academy of Pediatrics and the Alabama Department of Public Health strongly recommend Newborn Screening for all infants. Parents have a right to refuse newborn screening. Parents should be provided education regarding the risks of not screening their baby and should sign a refusal form for informed consent if refusing any part of the newborn screening.

Child's Name _____

Date of Birth _____ Name of Delivery Hospital: _____

Parent/Legal Guardian _____

My child's medical provider,_____ , has advised me that my child (named above) should participate in the newborn screening program.

As the parent or legal guardian of my child (named above), I choose to decline participation in my state's newborn screening program, on the grounds that such tests conflict with my religious tenets and/or practices (as allowed by the Code of Alabama 1975, 22-20-3).

- ❑ I choose not to have my child receive the newborn bloodspot screening from the Alabama Department of Public Health for life threatening diseases screened for by the Newborn Screening Program.
- ❑ I choose not to have my child screened for hearing loss.
- ❑ I choose not to have my child screened for critical congenital heart disease.

I have been provided information about newborn screening in my state and the importance of early identification of the disorders. I had the opportunity to discuss these with my child's medical provider, who has answered my questions regarding the recommended screening. I understand the following:

- The purpose and need for newborn screening to include bloodspot screening, hearing screening, and pulse oximetry screening.
- **If my child does not participate in newborn screening, the consequences of a late diagnosis may include delayed development, intellectual disability, or death.**
- My child's medical provider, the Alabama Department of Public Health, and the American Academy of Pediatrics strongly recommend that all newborns be screened for certain disorders.
- If my child has one of my state's screened conditions, failure to participate in newborn screening may endanger the health or life of my child.

Nevertheless, I have decided at this time to decline participation in the newborn screening program for my child as indicated by checking the box above.

I acknowledge that I have read this document or it has been read to me in its entirety, and I fully understand it.

Parent/Legal Guardian Signature _____ Date_____

Witness _____ Date_____

I had the opportunity to discuss my decision not to participate in my state's newborn screening program and still decline the recommended participation.

ALABAMA BIRTHING HOSPITALS

Birthing Hospital	Births in 2021
Huntsville Hospital	4,472
University of Alabama at Birmingham (UAB) Hospital	3,914
Baptist Medical Center East	3,693
Ascension St. Vincent's Birmingham	3,628
Brookwood Baptist Medical Center	3,048
Grandview Medical Center	2,844
University of South Alabama (USA) Children's & Women's Hospital	2,389
East Alabama Medical Center	2,191
Regional Medical Center Anniston	1,913
DCH Regional Medical Center	1,639
Springhill Medical Center	1,517
Flowers Hospital	1,490
Northport Medical Center	1,468
Southeast Health	1,458
Providence Hospital	1,414
Crestwood Medical Center	1,338
North Alabama Medical Center	1,334
Thomas Hospital	1,295
Madison Hospital	1,293
Jackson Hospital	1,210
Medical Center Enterprise	907
Mobile Infirmary	809
Walker Baptist Medical Center	809
Gadsden Regional Medical Center	804

Birthing Hospital	Births in 2021
Marshall Medical Center South	793
Helen Keller Memorial Hospital	751
Baptist Medical Center South	708
South Baldwin Regional Medical Center	637
Cullman Regional Medical Center	605
Marshall Medical Center North	574
Princeton Baptist Medical Center	547
DeKalb Regional Medical Center	537
Coosa Valley Medical Center	531
Athens-Limestone Hospital	414
Shelby Baptist Medical Center	399
Decatur Morgan Hospital	377
Vaughan Regional Medical Center	371
UAB Medical West	333
Highlands Medical Center	291
Russell Medical Center	286
Andalusia Health	271
North Baldwin Infirmary	236
Monroe County Hospital	230
D.W. McMillan Memorial Hospital	169
Grove Hill Memorial Hospital	125
Bibb Medical Center	64
Out of Hospital Births	474
All Other Hospitals	10

Data based on 2021 Centers for Health Statistics at alabamapublichealth.gov/healthstats/assets/avs2021.pdf

WHY USE AN ACCREDITED CYSTIC FIBROSIS CENTER?

Accredited Cystic Fibrosis (CF) Care Centers are required to meet nationally accepted standards that have been developed by the Cystic Fibrosis Foundation (CFF) and the Clinical and Laboratory Standards Institute (CLSI).

National standards for diagnostic sweat testing are imperative to ensure the results are consistently accurate and reliable. CFF accredited centers offer a multidisciplinary approach to the management of cystic fibrosis and include the following clinic personnel:

- Physicians
- Registered nurses
- Respiratory therapists
- Dieticians/nutritionists
- Social workers
- Geneticist or genetic counselors

Having these specialists available in a single location increases the convenience of treatment for CF. Families are able to make a single appointment at the CF Center, rather than separate appointments for each specialist.

Babies referred to an accredited CF Center in Alabama also get referred to Children's Rehabilitation Service (CRS) which offers medical, financial, and support services to families and children facing a variety of special health care needs. These clinics provide state-of-the-art care for infants and children with CF in Alabama. Every county in Alabama is served through a network of 14 community based CRS offices.

For your convenience, contact information for the CFF accredited center in Alabama is included below. Transportation assistance is available to families who qualify.

University of Alabama at Birmingham/Children's of Alabama Cystic Fibrosis Center

Dr. Hector Gutierrez, Pediatric Pulmonologist

1600 7th Avenue South, Lowder 620

Birmingham, AL 35233 · (205) 638-5494

SECTION 2 - SPECIMEN COLLECTION

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Newborn Screening Provider Update Form 32

Provider Lab Result Form 33


ONE DROP
ONE CIRCLE
ONE TIME

ALABAMA DEPARTMENT OF PUBLIC HEALTH
BUREAU OF CLINICAL LABORATORIES

Newborn Screening Collection Guidelines

Revised January 1, 2025

ALABAMA PUBLIC HEALTH

Alabama Department of Public Health • Bureau of Clinical Laboratories • Newborn Screening Division
204 Legends Court, Prattville, AL 36066-7893, P.O. Box 1000, Prattville, AL 36067-9901
Phone: 334-290-3097 • FAX: 334-206-3708

Sharon P. Massingale , PhD, HCLD/CC(ABB), Public Health Laboratory Director
Aretha M. Williams, PhD, Assistant State Health Laboratory Director
Stacey Hall, Newborn Screening Laboratory Manager

NEWBORN SCREENING COLLECTION GUIDELINES

Section 22-20-3 (as amended in 1987) of the Code of Alabama states that all infants must be administered a reliable test for PKU, Cystic Fibrosis, Hypothyroidism, CAH, Galactosemia, Abnormal Hemoglobins, Biotinidase Deficiency, Severe Combined Immunodeficiency, Amino Acid Disorders, Fatty Acid Disorders, Organic Acid Disorders, Lysosomal Storage Disorders, Spinal Muscular Atrophy, and X-ALD and that the testing be performed by the Public Health Laboratory.

TIMING OF SCREENING:

FIRST TEST ("A" FORM) – ***This specimen is tested for Hypothyroidism, CAH, Cystic Fibrosis, Galactosemia, Severe Combined Immunodeficiency, Hemoglobinopathies, Biotinidase Deficiency, Amino Acid Disorders, Fatty Acid Disorders, Spinal Muscular Atrophy, Organic Acid Disorders, Lysosomal Storage Disorders, and X-ALD.***

Full Term Infants	A newborn screening test should be collected when the infant is 24-48 hours of age. If the infant is discharged prior to 24 hours of age, a specimen MUST be obtained before discharge, and the parent or guardian must be informed of the importance of obtaining a repeat test before one week of age.
Home Births	The Newborn Screening Statute applies to all infants born in Alabama. The birthing attendant is responsible for collecting the newborn screening test. It is recommended that the test be collected at 24-48 hours of age.
Extended Hospital Stay (low birth weight/ sick infants)	It is recommended that a specimen be collected upon admission to the NICU if the infant is expected to receive TPN or transfusions unless the infant is so unstable that it cannot be done safely. Refer to the Alabama Newborn Screening Sick Infant Blood Collection Guidelines on page 27.
Transitioning Infants	Infants admitted to NICU for short term observation but who are not receiving TPN or transfusions should have a specimen collected according to the Full Term Infant Protocol.
Dying Infants	If an infant is likely to die, it is appropriate to collect a newborn screening specimen. While dying infants may have abnormal results as a response to organ failure, the specimen may also provide a diagnosis of an early onset screening disorder.
Older Infants	The American Academy of Pediatrics recommends that physicians know the screening status of all children in their care. While older infants may enter the practice without evidence of a newborn screen, the Alabama Department of Public Health's Newborn Screening Program has established standards and cutoffs for newborns and infants and therefore **cannot accept specimens on children older than 12 months of age.**

SPECIAL CONSIDERATIONS:

Transfused Infants	A specimen should be collected prior to transfusion regardless of age or treatments unless the infant is so unstable it cannot be done safely. If the specimen is not collected prior to transfusion, collect a specimen greater than 72 hours post transfusion. Another specimen should be collected at 3-4 months post transfusion for Hemoglobinopathies, Biotinidase Deficiency, and Galactosemia. If a Galactosemia condition is suspected and the specimen was not collected prior to transfusion, place the infant on a galactose-free diet until a definitive diagnosis can be made.
Transferred Infants	The transferring facility must collect a specimen prior to transfer regardless of age or treatments unless the baby is so unstable that it cannot be done safely. If the specimen cannot be obtained prior to transfer, the transferring facility must ensure that the next facility is aware of the need for collection of the newborn screening specimen.
Parent Refusal	Parents may refuse newborn screening only for religious reasons. Parents who refuse under this condition should sign a statement that is placed in the infant's medical record. **A newborn screening collection form should be filled out completely with a statement as to the refusal and mailed to the State Laboratory.**

NEWBORN SCREENING COLLECTION GUIDELINES

SECOND TEST ("B" FORM) – *This specimen is tested for Hypothyroidism, CAH, Cystic Fibrosis, Galactosemia, Biotinidase Deficiency, Amino Acid Disorders, Fatty Acid Disorders, and Organic Acid Disorders.*

Note: This specimen is not routinely tested for Hemoglobinopathies. If no valid test has been done for this disorder, please see instructions below for collection of requested repeat specimens, "Requested Repeat."

1. A second newborn screening specimen should be collected at 2-6 weeks of age (4 weeks optimal) on all full term infants with a normal first test screen.
2. If the first test specimen was collected when the infant was greater than one week of age but less than two weeks of age, the second test specimen should be collected at 4-6 weeks of age.
3. If the first test specimen was collected after two weeks of age, a second ("B") specimen need NOT be collected.

Requested Repeat ("B" form)

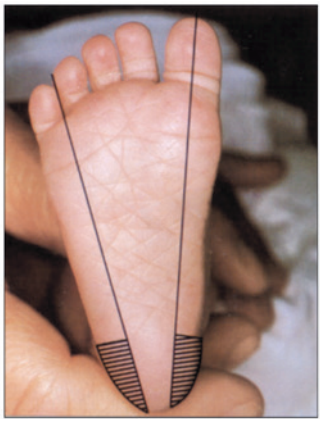
1. A repeat specimen may be requested by the State Laboratory when the results are abnormal or questionable. The specimen should be collected in the time frame indicated by the report. The "Retest-Prior Abnormal" box must be marked on the collection form.
2. If the first test is unsatisfactory for testing, a repeat test should be collected as soon as possible. The "Retest-Prior Unsat" box must be marked on the collection form.

COLLECTION OF FILTER PAPER BLOODSPOT SPECIMEN

Materials needed for Blood Collection:

1. Gloves
2. 70% isopropyl alcohol pads
3. Dry sterile gauze pads
4. Sterile sticking device with a point not greater than 2.0 mm in depth (the most effective method is the use of scalpel bladed lancets)
5. Newborn Screening filter paper collection form (CL-89) with protective envelope

Bleeding Procedure:



1. The preferred puncture site is indicated by the shaded areas on the heel. The least hazardous sites for heel puncture are medial to a line drawn posterior from the middle of the big toe to the heel or lateral to a similar line drawn on the other side extending from between the 4th and 5th toe to the heel.
2. Warm the infant's foot if necessary using warm water, a towel, or a chemical pack. Heat sources should not exceed 42°C and should not be left in contact with the skin for a prolonged period.
3. Disinfect the skin with alcohol pads and allow to air dry. Vigorous rubbing during this step stimulates blood flow to the area.
4. Puncture the skin in one continuous motion using a sterile sticking device with a tip <2.0 mm. **THE USE OF LONGER TIPS MAY DAMAGE THE HEEL BONE.**
5. Wipe away and discard the first drop of blood since it may be contaminated by alcohol or tissue fluid.
6. Allow the second drop of blood to form by the spontaneous free flow of blood.

NEWBORN SCREENING COLLECTION GUIDELINES

Collecting the Blood Spots:

1. Before collecting the blood, fold back the protective flap to expose the filter paper. Do not touch or handle the filter paper before or after applying the blood.
2. Lightly touch the filter paper against a large drop of blood and allow a sufficient quantity of blood to soak through to completely fill the circle. Apply blood to one side of the filter paper only, allowing full saturation of each circle. Either side of the filter paper may be chosen. Fill all circles. Do not layer successive small drops of blood to the same circle. Avoid touching or smearing the blood spots.
3. If blood flow is diminished, repeat the bleeding procedure with sterile equipment.
4. Once all the circles have been filled, press a sterile gauze pad to the puncture site and hold the infant's foot above the level of the heart until bleeding has stopped.
5. Dry the blood spots on a level, non-absorptive surface away from direct sunlight and at room temperature for at least 4 hours.
6. After blood spots are completely dry, replace the protective flap over the specimen and place form in the protective envelope (do not use plastic) and mail to the State Laboratory within 24 hours.

Guidelines and Possible Sources of Error:

The following guidelines may help eliminate unsatisfactory specimens or erroneous test results.

1. Do not touch any part of the filter paper circles before, during, or after collection.
2. Collect the specimen on the proper Newborn Screening collection form.
3. Complete all demographic data. This information is vital for interpretation of newborn screening results and for identification and location of infants for follow-up of abnormal test results.
   a) Always note any transfusion of red blood cells.
   b) Mark TPN feeding if TPN is being administered at time of collection.
   c) NPI # should be provided for the Ordering Physician (physician ordering the NBS screen).
4. Wipe away the first drop of blood to remove tissue fluids and alcohol. Do not "milk" the puncture site.
5. Do not expose the specimen to heat or humidity at any time. Do not dry on heater, in microwave, with a hair dryer, or in the sunlight. Do not place in plastic bags, leave in hot mailbox, or hot car; proteins and enzymes will be destroyed.
6. Ensure that the specimen is properly dried before replacing the protective flap and before placing in the protective envelope.
7. Dry specimens in a horizontal position. Hanging wet specimens will cause heavier red cells to migrate to the end of the circle causing an uneven saturation.
8. Do not superimpose blood drops on top of each other.
9. Apply blood to only one side of the filter paper.
10. Collecting blood samples after feeding promotes better blood flow.
11. Do not allow specimens to come in contact with water, feeding formulas, antiseptics, urine, etc.

NEWBORN SCREENING COLLECTION GUIDELINES

TIMING & TRANSPORT (i)

1. Specimens should be shipped or transported by mail, major courier services*, or other express delivery services to the public health laboratory as soon as they are dry (minimum of four hours) and no later than 24 hours after collection. If mailed to the lab, please send to the following address:

   Alabama Department of Public Health
   Bureau of Clinical Laboratories
   Mailing Address: P.O. Box 1000, Prattville, Alabama 36067-9901
   Physical Address: 204 Legends Court, Prattville, Alabama 36066-7893

   *Daily courier transport is recommended whenever possible to control environmental conditions and minimize delays in shipment.

2. Appropriate documentation for all stages in specimen transit should be tracked and maintained, from collection to delivery.

3. Dried blood spots (DBS) are nonregulated and an exempt human specimen, posing no occupational exposure to blood or other potentially infectious material. Standard precautions should be followed in preparing these specimens for shipment.

4. It is **NOT** recommended that DBS specimens be packaged in airtight, leak-proof sealed containers (e.g., plastic or foil bags) because the lack of air exchange causes heat buildup and moisture accumulation that is detrimental to the stability of the DBS specimen.

5. Do **NOT** place in outside mailboxes or drop boxes because fluctuating temperature and humidity may damage specimens.

6. The inclusion of desiccant packs may aid in preventing moisture accumulation.

7. The use of preaddressed envelopes for mailing may help decrease the transport time, and thus decrease time from collection to diagnosis in affected newborns.

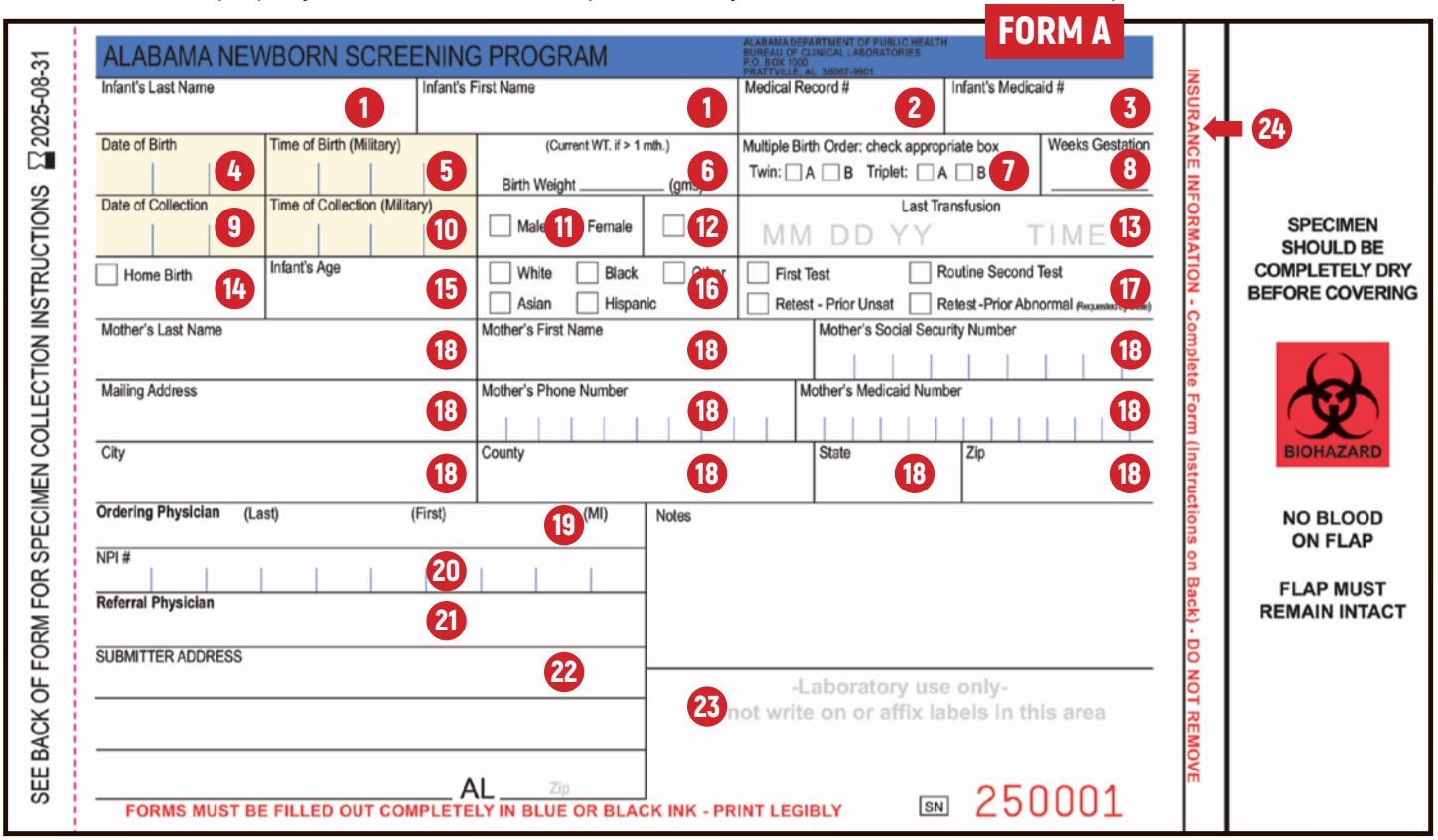
8. To mail DBS specimens, please use the basic triple-packaging system:
   - Primary container – filter paper that contains absorbed and dried blood
   - Secondary container – fold over flap envelope to secure the contents
   - Third container – outer envelope of sturdy, high quality paper

CLSI. *Blood Collection on Filter Paper for Newborn Screening Programs; Approved Standard–Sixth Edition.* CLSI document NBS01-A6. Wayne, PA: Clinical and Laboratory Standards Institute; 2013.

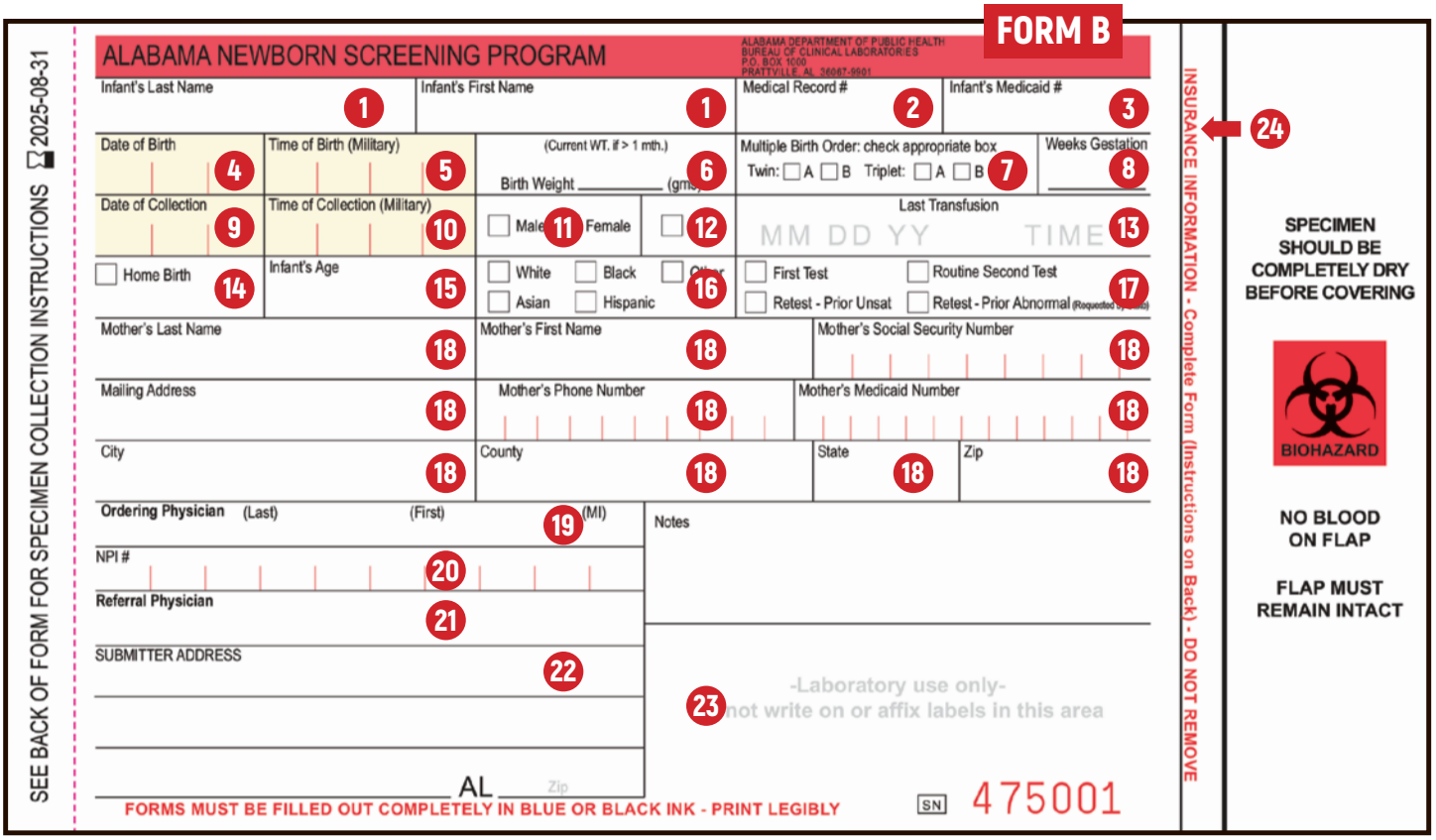
NEWBORN SCREENING COLLECTION GUIDELINES

Always complete the specimen collection form using a black or blue ball point pen and print legibly to ensure that the patient is identified properly. These forms are examples and may not be current. These forms expire 8-31-2025.

FORM A



FORM B



NEWBORN SCREENING COLLECTION GUIDELINES

1	**Name field –** enter the patient's last name and first name (if applicable).
2	**Medical Record field –** enter the patient's medical record number. This number is for the submitting facility to identify the patient when the report is received.
3	**Medicaid field –** enter the infant's Medicaid number if applicable.
4	**Birth date field –** enter the birth date in the format MM/DD/YY (required field).
5	**Time of Birth field –** enter in military format, failure to use military format may result in erroneous test results since many lab tests are based on the age of the infant at the time of collection.
6	**Birth Weight field –** enter the infant's birth weight in **grams.** If the infant is more than one month of age, enter the current weight. The laboratory sets standards and cutoffs for some tests using weight. Indicating the weight helps to ensure accurate test results and eliminate the need for unnecessary repeat specimens.
7	**Multiple Birth Order field –** complete **only** if there is a multiple birth. Enter the birth order as A, B, C, etc.
8	**Gestational Age field –** enter the gestational age as number of completed weeks.
9	**Date of Collection –** enter the date of collection in the format MM/DD/YY (required field).
10	**Time of Collection –** enter the time of collection in military format (required field)
11	**Sex field –** check appropriate box
12	**TPN field –** If infant is receiving TPN feeding at time of collection, check the box
13	**Last Transfusion field –** Complete this box with the date and time of the infant's last transfusion of **red blood cells.** Date should be entered as MM/DD/YY and time in military format. The date and time of transfusion are important for the laboratory to determine whether the results are valid. Failure to indicate transfusions can result in an infant with a NBS disorder being missed due to the presence of donor cells in the specimen.
14	**Home birth field –** check the home birth box if the infant was born outside of the birthing facility with a birthing attendant present.
15	**Infant's Age field –** enter the infant's age at the time of specimen collection.
16	**Race field –** mark the appropriate box for the infant's race.
17	**Type of Tests field -** mark the "First Test" box if the specimen is the first one collected on this infant. Mark the "Routine Second Test" box if the specimen is the routine second test specimen collected on this infant. If a prior test on this infant was reported as unsatisfactory, mark the "Retest-Prior Unsat" box. If a prior test on this infant was abnormal and the State Laboratory requested a repeat sample, mark the "Retest-Prior Abnormal" box.
18	**Mother's Information fields –** enter the mother's information in the appropriate fields. ***Mother's social security number should be entered accurately.*** This will allow the submitting facility to access test results more readily and ensures that infants needing immediate follow-up can be located quickly.
19	**Ordering Physician field –** enter the **full name** of the physician who has ordered the NBS tests. ***This information is required to be provided and complete.***
20	**NPI field -** enter the National Provider Identification **9 digit** number for the **ordering physician.** ***This information is required to be provided and complete.***
21	**Referral Physician field –** enter the **full name** of the physician who will be caring for the infant. This physician will be contacted if the infant has a potential NBS disorder and his/her name will be listed as the physician on the NBS laboratory report. (This physician may be the same as the ordering physician – but should be entered in this field as instructed)
22	**Submitter field –** enter the name and address of the facility submitting the specimen. Do not use abbreviations as there are facilities with similar names. An address label may be attached in this area as long as it does not obscure other fields or hang off of the edge. ***This information is required to be complete and accurate.***
23	**Lab use field -** Do not write or place labels in this area. This space is used by the laboratory to attach a unique identification number to the specimen for use in the laboratory.
24	**INSURANCE FORM - Insurance information MUST be entered completely and accurately. This sheet should not be removed from the NBS form.**

EXAMPLES

SEE BACK OF FORM FOR SPECIMEN COLLECTION INSTRUCTIONS ☑ 2025-08-31

ALABAMA NEWBORN SCREENING PROGRAM

ALABAMA DEPARTMENT OF PUBLIC HEALTH
BUREAU OF CLINICAL LABORATORIES
P.O. BOX 1000
PRATTVILLE, AL 36067-9901

Infant's Last Name: DOE	Infant's First Name: BABY	Medical Record #: 134521	Infant's Medicaid #: 500001234567

Date of Birth: 01 / 15 / 21	Time of Birth (Military): 0 3 2 0	(Current WT. if > 1 mth.) Birth Weight: 2250 (gms)	Multiple Birth Order: check appropriate box — Twin: [X] A [ ] B Triplet: [ ] A [ ] B [ ] C	Weeks Gestation: 38 WKS
Date of Collection: 01 / 16 / 21	Time of Collection (Military): 0 3 0 0	[ ] Male [X] Female [ ] TPN	Last Transfusion: MM / DD / YY TIME 01/ 16 / 21 01:50
[ ] Home Birth	Infant's Age: 24 HRS	[ ] White [ ] Black [ ] Other [X] Asian [ ] Hispanic	[X] First Test [ ] Routine Second Test [ ] Retest - Prior Unsat [ ] Retest - Prior Abnormal (Requested by State)

Mother's Last Name: DOE	Mother's First Name: JANE	Mother's Social Security Number: 4 9 9 9 9 9 9 9 9
Mailing Address: 123 NEW BABY DR	Mother's Phone Number: 3 3 3 2 9 5 3 3 3 3	Mother's Medicaid Number: 5 0 0 0 0 9 9 9 9 9 9 9
City: HUNTSVILLE	County: MADISON	State: AL / Zip: 35801

Ordering Physician (Last): HOWSER (First): DOOGIE (MI):

NPI #: 1 4 1 1 3 4 4 1 1 1

Referral Physician: PEDIATRIC PEDS

SUBMITTER ADDRESS: EASTMAN HOSPITAL
456 HOSPITAL DR
HUNTSVILLE AL 35801 ZIP

Notes

-Laboratory use only-
Do not write on or affix labels in this area

FORMS MUST BE FILLED OUT COMPLETELY IN BLUE OR BLACK INK - PRINT LEGIBLY

SN 250001

INSURANCE INFORMATION - Complete Form (Instructions on Back) - DO NOT REMOVE

SPECIMEN SHOULD BE COMPLETELY DRY BEFORE COVERING

BIOHAZARD

NO BLOOD ON FLAP

FLAP MUST REMAIN INTACT

SEE BACK OF FORM FOR SPECIMEN COLLECTION INSTRUCTIONS ☑ 2025-08-31

ALABAMA NEWBORN SCREENING PROGRAM

ALABAMA DEPARTMENT OF PUBLIC HEALTH
BUREAU OF CLINICAL LABORATORIES
P.O. BOX 1000
PRATTVILLE, AL 36067-9901

Infant's Last Name: DOE	Infant's First Name: BAMBI	Medical Record #: 345-2	Infant's Medicaid #: 500001234567

Date of Birth: 01 / 15 / 21	Time of Birth (Military): 0 3 2 0	(Current WT. if > 1 mth.) Birth Weight: 2250 (gms)	Multiple Birth Order: check appropriate box — Twin: [X] A [ ] B Triplet: [ ] A [ ] B [ ] C	Weeks Gestation: 38 WKS
Date of Collection: 02 / 15 / 21	Time of Collection (Military): 0 3 0 0	[ ] Male [X] Female [ ] TPN	Last Transfusion: MM / DD / YY TIME 01/16 /21 01:50
[ ] Home Birth	Infant's Age: 4 WKS	[ ] White [ ] Black [ ] Other [X] Asian [ ] Hispanic	[ ] First Test [X] Routine Second Test [ ] Retest - Prior Unsat [ ] Retest - Prior Abnormal (Requested by State)

Mother's Last Name: DOE	Mother's First Name: JANE	Mother's Social Security Number: 4 9 9 9 9 9 9 9 9
Mailing Address: 123 New Baby Dr.	Mother's Phone Number: 3 3 3 2 9 5 3 3 3 3	Mother's Medicaid Number: 5 0 0 0 0 9 9 9 9 9 9 9
City: Huntsville	County: Madison	State: AL / Zip: 35801

Ordering Physician (Last): McStuffins (First): Doc (MI):

NPI #: 1 0 1 0 1 0 1 0 1 0

Referral Physician: McStuffins, Doc

SUBMITTER ADDRESS: Pediatric Peds
1001 Peds Dr.
Huntsville AL 35801 ZIP

Notes

-Laboratory use only-
Do not write on or affix labels in this area

FORMS MUST BE FILLED OUT COMPLETELY IN BLUE OR BLACK INK - PRINT LEGIBLY

SN 475001

INSURANCE INFORMATION - Complete Form (Instructions on Back) - DO NOT REMOVE

SPECIMEN SHOULD BE COMPLETELY DRY BEFORE COVERING

BIOHAZARD

NO BLOOD ON FLAP

FLAP MUST REMAIN INTACT

SICK INFANT BLOOD COLLECTION GUIDELINES

Sick Infant and Well Baby Newborn Screening Blood Collection Algorithm, February 22, 2016

The following newborn screening algorithm has been developed by a task force of professional medical providers and consultants and has been approved by the Alabama Newborn Screening Advisory Committee. These recommedations are in keeping with the recommendations of the Clinical Laboratory Standards Institute (CLSI) as well as the standards required by the Alabama Department of Publich Health Laboratory.

BIRTH OF PRETERM, LBW OR SICK NEWBORN

Serial screening, with the collection of three specimens, is proposed as the most expedient and efficient paradigm for this population (CLSI Preterm, LBW, and Sick Newborns, page 19)

Transfer/Arrival NICU NBS Specimen

Collect the **"arrival NICU"** NBS specimen on admission to the NICU (if not already collected) **regardless of age*** before any other treatments are begun (transfusions, TPN or antibiotics). If transferred, **the transfer hospital** should collect a specimen on Form A before transported unless infant is unstable. **The receiving hospital,** on admission, should collect a specimen on a second test form (Form B) and mark the "First Test" box.

***For most preterm and LBW newborns, admission to the NICU occurs immediately after birth, usually 1 to 2 hours of age, or up to 24 hours of age. If an infant is 24 hours of age or older on admission to the NICU, repeat screening should be done according to local program recommendations for normal infants unless there were abnormalities on the initial specimen (CLSI, page 20).**

Acute NICU NBS Specimen

Collect the **"acute NICU" NBS specimen at 48-72 hours of life on infants initially tested at <24 hours of age at first screen.**

- **If receiving blood** - wait and collect 72 hours after the last transfusion.
- **If on TPN** - collect acute screen plus an additional screen when TPN is discontinued.

Final NICU NBS Specimen

Collect the **"final routine NICU"** NBS specimen at **28 days of age** or at discharge, whichever comes first, for any infant in the NICU > 2 weeks of age. All NICU infants discharged before 2 weeks of age should have the recommended routine NBS specimen collected by their pediatrician at 2-6 weeks of age.

BIRTH OF FULL-TERM OR WELL NEWBORN

Initial NBS Specimen

Collect an initial NBS specimen at **24-48 hours of age** (mail within 24 hours).

- Collect the first sample on a First Test Form (A Form) and any subsequent samples on a second test form (B Form).
- If the infant is discharged prior to 24 hours of age, a specimen must be obtained before discharge, and the parent or guardian must be informed of the importance of obtaining a second test before one week of age.

Routine Repeat NBS Specimen

Collect a recommended routine second NBS specimen at **2-6 weeks of age.**

- This specimen is not routinely tested for Hemoglobinopathies or Severe Combined Immunodeficiencies.
- Collect on a Second Test Form (B Form)

Note: If results from the first or second newborn screens place infant at high suspicion for a condition, appropriate confirmatory or diagnostic tests should be done, being alert to the effects that treatments and the infant's condition may have on the screening test results.

If a well infant has had 2 newborn screens collected or a sick infant has had 4 screens collected (check Secure Remote Viewer to determine), please contact the NBS Lab at 334-290-3097, or the NBS Follow-up Program at 334-206-5556 for follow-up issues.

NEWBORN SCREENING COLLECTION GUIDELINES

Alabama Department of Public Health
Bureau of Clinical Laboratories
Newborn Screening Blood Collection Guidelines

These guidelines have been provided for newborn screening providers in order to inform and instruct on the proper techniques of collecting a high-quality specimen, for handling it after it has been collected, and for transporting it to the testing facility. These guidelines are in keeping with the recommendations of the Clinical Laboratory Standards Institute® (CLSI) as well as the standards required by the Alabama Department of Public Health, Bureau of Clinical Laboratories.

For further guidance please refer to the *CLSI® Blood Collection on Filter Paper for Newborn Screening Programs; Approved Standard,* which addresses the issues associated with specimen collection, the filter paper collection device, the application of blood to the filter paper, and uniform techniques for collecting the best possible specimen for use in newborn screening programs.

Sharon P. Massingale

1/24/2025

Sharon Massingale, Ph.D., HCLD/CC (ABB) — Date
Public Health Laboratory Director
Bureau of Clinical Laboratories

1/24/2025

Aretha M. Williams, PhD — Date
Assistant Public Health Laboratory Director
Bureau of Clinical Laboratories

Stacey Hall

1/24/2025

Stacey Hall — Date
Newborn Screening Laboratory Manager
Bureau of Clinical Laboratories

NBS SPECIMEN COLLECTION TIPS

Newborn screens can have a dramatic impact on the welfare of the infant and the family. It is important to understand the significance of screening both from a medical outcome and a legal liability standpoint.

1. Storage of the filter paper both pre-use and post-use is very important. If the paper is stored in a dry, hot environment such as an unventilated warehouse it will affect the performance of the paper. Always try to store filter paper at room temperature and room humidity. Post-use storage should be in keeping with NBS lab guidance (©ID Biological Systems Report).
2. The type of lancet used can have a definite effect on the specimen collected. The "switch blade" type lancet achieves better blood flow than the puncture type. This could make a difference in your blood collection (©ID Biological Systems Report).
3. Only allow **well-trained** individuals to collect newborn screening blood in order to reduce unsatisfactory specimens.
4. Track the performance of these collectors and re-train or substitute as necessary if unsatisfactory or invalid results occur.
5. **Perform a quality control inspection** of all specimens before mailing them to the State Laboratory. At a minimum check for the following:
   - Complete and correct demographic information. **Any corrections should be legible and initialed.**
   - Record the name of the person that collected the sample.
   - Inspect the blood spots for specimen quality and quantity before mailing.
   - Allow specimens to dry first and then review a second time prior to mailing. A specimen may appear uniform when wet but when dry may reveal uneven saturation (dark spots).
   - Confirm results are received on each specimen submitted.

If you believe you are having issues with specimen collection, please contact the NBS Nurse Educator at 334-358-2081 or the NBS State Health Laboratory at 334-290-3097. You may also refer to the Clinical and Laboratory Standards Institute® (CLSI) Screening Collection Manual (copies provided to all birthing centers).

Remember: *Collection technique will not improve overnight. It takes practice to become proficient with newborn screening specimen collection.*

Whatman®
Part of GE Healthcare

Neonatal Screening

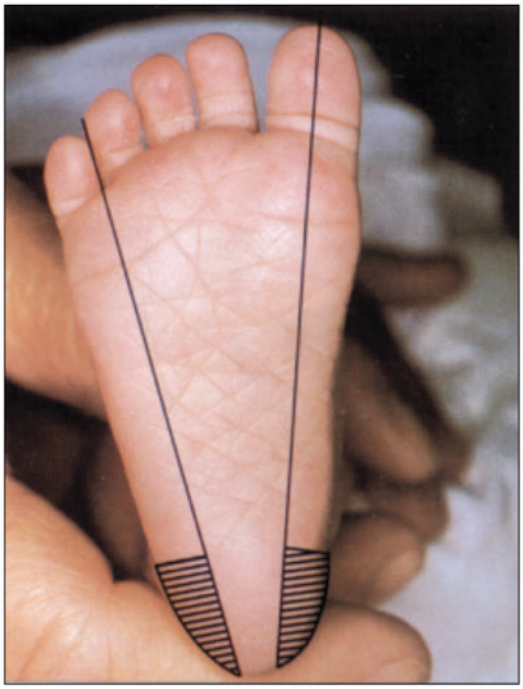
Blood Specimen Collection and Handling Procedure



1 Necessary equipment: sterile lancet with tip approximately 2.0 mm, sterile alcohol prep, sterile gauze pads, soft cloth, blood collection form, gloves.



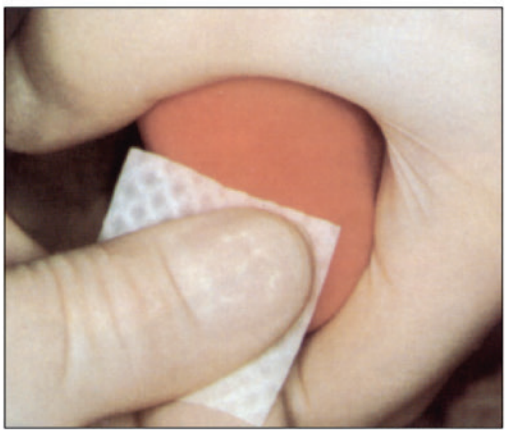
2 Complete ALL information. Do not contaminate filter paper circles by allowing the circles to come into contact with spillage or by touching before or after blood collection. Keep "SUBMITTER COPY" if applicable.



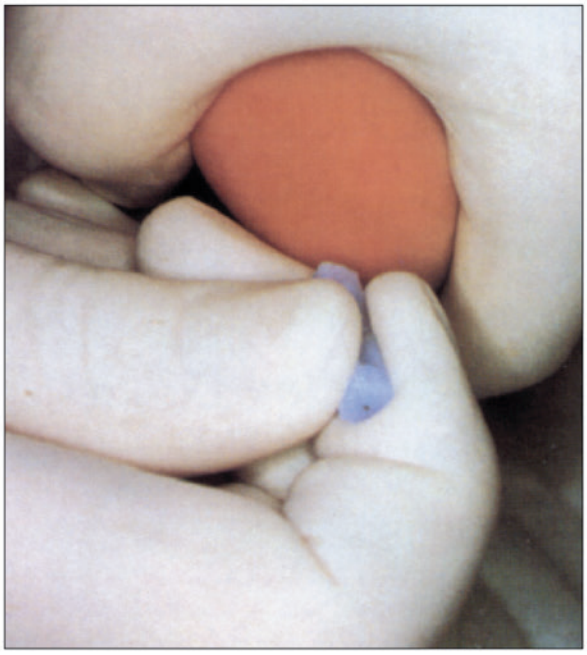
3 Hatched area ( ) indicates safe areas for puncture site.



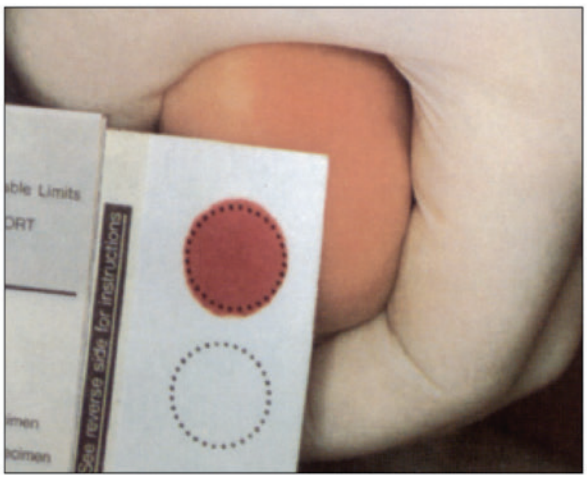
4 Warm site with soft cloth, moistened with warm water up to 41° C, for three to five minutes.



5 Cleanse site with alcohol prep. Wipe DRY with sterile gauze pad.



6 Puncture heel. Wipe away first blood drop with sterile gauze pad. Allow another LARGE blood drop to form.



7 Lightly touch filter paper to LARGE blood drop. Allow blood to soak through and completely fill circle with SINGLE application of LARGE blood drop. (To enhance blood flow, VERY GENTLE intermittent pressure may be applied to the area surrounding the puncture site). Apply blood to one side of filter paper only.



8 Fill remaining circles in the same manner as step 7, with successive blood drops. If blood flow is diminished, repeat steps 5 through 7. Care of skin puncture site should be consistent with your institution's procedures.



9 Dry blood spots on a dry, clean, flat, non-absorbent surface for a minimum of four hours.



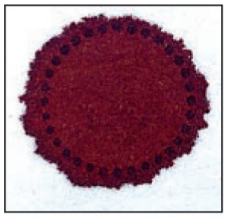
10 Mail completed form to testing laboratory within 24 hours of collection.

Information provided by The New York State Department of Health.

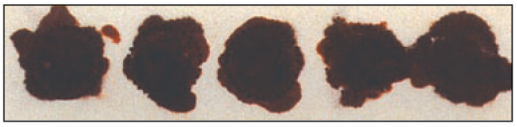
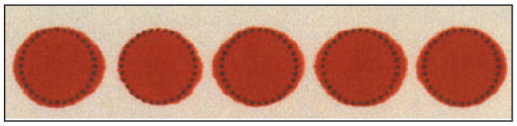
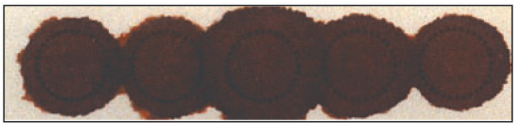
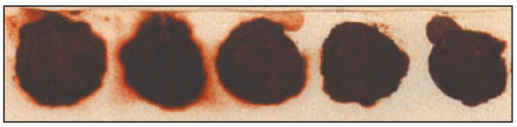
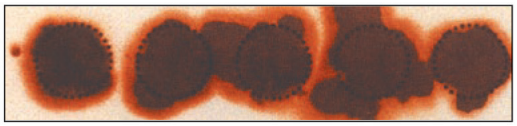
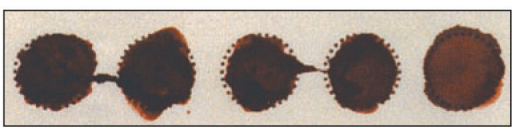
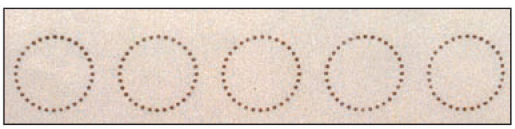
North America – Whatman Inc. • Tel: 1-800-WHATMAN • Tel: 1-973-245-8300 • Fax: 1-973-245-8329 • E-mail: info@whatman.com
Europe – Whatman International Ltd • Tel: +44 (0) 1622 676670 • Fax: +44 (0) 1622 691425 • E-mail: information@whatman.com
Japan – Whatman Japan KK • Tel: +81 (0) 3 5215 1240 • Fax: +81 (0) 3 5215 1245 • E-mail: japaninfo@whatman.com
Asia Pacific – Whatman Asia Pacific Pte Ltd • Tel: +65 6534 0138 • Fax: +65 6534 2166 • E-mail: wap@whatman.com

51684 3/08

SIMPLE SPOT CHECK



Valid specimen:
Allow a sufficient quantity of blood to soak through to completely fill the preprinted circle on the filter paper. Fill all required circles with blood. Do not layer successive drops of blood or apply blood more than once in the same collection circle. Avoid touching or smearing spots.

Invalid Specimen	Possible Causes
1. Specimen quantity insufficient for testing. 	· Removing filter paper before blood has completely filled circle of before blood has soaked through to second side. · Applying blood to filter paper with a capillary tube. · Allowing filter paper to come into contact with gloved or ungloved hands or substances such as hand lotion or powder, either before or after blood specimen collection.
2. Specimen appears scratched or abraded. 	· Applying blood with a capillary tube or other device.
3. Specimen not dry before mailing. 	· Mailing specimen before drying for a minimum of four hours.
4. Specimen appears supersaturated. 	· Applying excess blood to filter paper, usually with a device. · Applying blood to both sides of filter paper.
5. Specimen appears diluted, discolored or contaminated. 	· Squeezing or "milking" of area surrounding the puncture site. · Allowing filter paper to come into contact with gloved or ungloved hands or substances such as alcohol, formula, antiseptic solutions, water, hand lotion or powder, etc., either before or after blood specimen collection. · Exposing blood spots to direct heat.
6. Specimen exhibits serum rings. 	· Not wiping alcohol from puncture site before making skin puncture. · Allowing filter paper to come into contact with alcohol, hand lotion, etc. · Squeezing area surrounding puncture site excessively. · Drying specimen improperly. · Applying blood to filter paper with a capillary tube.
7. Specimen appears clotted or layered. 	· Touching the same circle on filter paper to blood drop several times. · Filling circle on both sides of filter paper.
8. No blood. 	· Failure to obtain blood specimen.

DEPARTMENT OF PUBLIC HEALTH
SCOTT HARRIS, M.D., M.P.H.
STATE HEALTH OFFICER

BUREAU OF CLINICAL LABORATORIES
DONALD E. WILLIAMSON, M.D. STATE HEALTH LABORATORY
Sharon P. Massingale, Ph.D., HCLD/CC(ABB)
Laboratory Director

Alabama Newborn Screening Program

Reorder Form

In order to assure that you have an adequate supply of newborn screening materials available, complete this form and mail or fax it to the State Health Laboratory at the address below when your stock has reached a **2-4 week** supply.

ALABAMA DEPARTMENT OF PUBLIC HEALTH
Bureau of Clinical Laboratories
Newborn Screening Division
204 Legends Court, Zip 36066-7893
P.O. Box 1000, Zip 36067-9901
Prattville, AL

FAX: (334) 206-3780

Name of Hospital, Practice, or Physician: _____

Street/Shipping Address **ONLY (No P.O. Box)**: _____

City, State, and Zip Code: _____

Telephone Number: _____

Name and Title: _____
(*Please Print)*

Please indicate the number of newborn infants that you screen per month: _____

Number of "**A**" (first test) Newborn Screening Forms Requested: _____
**Note "A" forms are sent to hospitals and birthing centers only.*

Number of "**B**" (second test) Newborn Screening Forms Requested: _____

NOTE: All orders will be shipped within 5 working days of receipt. Please plan your orders accordingly. We cannot make emergency shipments.

NBS Lab Phone: (334) 290-3097

MAILING ADDRESS: POST OFFICE BOX 1000 | PRATTVILLE, AL 36067-9901
PHYSICAL ADDRESS: 204 LEGENDS COURT | PRATTVILLE, AL 36066-7893
EMAIL ADDRESS: clab@adph.state.al.us

PHAB
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10/30/2024

DEPARTMENT OF PUBLIC HEALTH
SCOTT HARRIS, M.D., M.P.H.
STATE HEALTH OFFICER

BUREAU OF CLINICAL LABORATORIES
DONALD E. WILLIAMSON, M.D. STATE HEALTH LABORATORY
Sharon P. Massingale, Ph.D., HCLD/CC(ABB)
Laboratory Director

Alabama Newborn Screening Program

Provider Update Form

In order to offer more efficient service in providing Newborn Screening forms and patient reports, we are updating our provider list. It would be of great assistance to us if you would fill out the following information and return it to:

ALABAMA DEPARTMENT OF PUBLIC HEALTH
Bureau of Clinical Laboratories
Newborn Screening Division
204 Legends Court, Zip 36066-7893
P.O. Box 1000, Zip 36067-9901
Prattville, AL
Phone: Laboratory (334) 290-3097
Newborn Screening IT (334) 290-6702
Fax:(334) 206-3780

Name of Hospital or Practice: _____

Street/Shipping Address: (Physical address): _____

City, State, and Zip Code: _____

Provide P.O. Box/ P.O. Zip if applicable: _____

Telephone Number: _____

Contact Name / Office Manager: _____

Names of **ALL** physicians or nurse practitioners who currently submit NBS specimens:

- Name: _____ NPI# _____

  Email address:_____

- Name: _____ NPI# _____

  Email address:_____

- Name: _____ NPI# _____

  Email address:_____

- Name: _____ NPI# _____

  Email address:_____

MAILING ADDRESS: POST OFFICE BOX 1000 | PRATTVILLE, AL 36067-9901
PHYSICAL ADDRESS: 204 LEGENDS COURT | PRATTVILLE, AL 36066-7893
EMAIL ADDRESS: clab@adph.state.al.us

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DONALD E. WILLIAMSON, M.D. STATE HEALTH LABORATORY
Sharon P. Massingale, Ph.D., HCLD/CC(ABB)
Laboratory Director

Alabama Newborn Screening Program

Provider Lab Result Request Form

To offer efficient service in providing Newborn Screening patient reports to requesting providers, the Alabama Department of Public Health Bureau of Clinical Laboratories Newborn Screening Division requires the completion of the following information:

Name of Requesting Facility: _____

Facility Mailing Address: _____

City, State, Zip: _____

Facility Telephone Number: _____ Facility Fax Number: _____

Infant's Last Name: _____ Infant's First Name: _____

Infant's Date of Birth: _____ Infant's Gender: _____

Hospital of Birth: _____

Mother's Last Name: _____ Mother's First Name: _____

Mother's Address (at the time of the infant's birth): _____

_____

_____

Fax Request(s) to BCL Newborn Screening Division (334)206-3780.

For assistance, please call the Newborn Screening Division at (334)290-3097.

Newborn Screening patient results will be mailed to the requesting facility's address above.

MAILING ADDRESS: POST OFFICE BOX 1000 | PRATTVILLE, AL 36067-9901
PHYSICAL ADDRESS: 204 LEGENDS COURT | PRATTVILLE, AL 36066-7893
EMAIL ADDRESS: clab@adph.state.al.us

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Revised
10/30/2024

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Alabama's Listening!
UNIVERSAL NEWBORN HEARING SCREENING

NEWBORN HEARING SCREENING PROGRAM OVERVIEW

The Alabama Universal Newborn Hearing Screening Program, also known as *"Alabama's Listening!" or the Early Hearing Detection and Intervention (EHDI) Program*, is administered through the Alabama Department of Public Health and was established in February 2001 to address the hearing health care needs of Alabama's babies. The health care needs of infants with hearing loss include timely screening, diagnosis, and referral to Early Intervention (EI) services. The program follows the Joint Committee on Infant Hearing 1-3-6 guidelines: screening before **one** month of age, diagnostic evaluation by an audiology professional before **three** months of age, and referral to EI services before **six** months of age.

The Alabama EHDI Program collaborates with many partners to include state birthing hospitals, pediatric health care providers, Alabama Department of Rehabilitation Services, the National Center for Hearing Assessment and Management (NCHAM), Early Head Start Programs, the Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration (HRSA). The goal of the Alabama EHDI Program is to ensure all infants with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention in order to improve a child's speech and language development, as well as thinking, learning, and social skills.

INPATIENT NEWBORN HEARING SCREENING PROTOCOL

Each birthing hospital is responsible for creating and implementing policies and procedures that are in line with state and national recommendations. These policies and procedures should follow state law and include, but not be limited to the following: 1) screening procedure, 2) reporting procedure, 3) guidelines for training personnel, 4) performance maintenance, 5) quality improvement indicators, and 6) data management.

The Alabama State Law, Section 22-20-3, provides legal authority for institutions caring for infants 28 days or less of age to administer a reliable test for newborn screening to include the newborn hearing screening. The law allows for parents to refuse testing on the grounds that such tests conflict with their religious tenets and practices. A written refusal should be obtained if a parent objects to newborn screening (page 14). In addition, the Alabama State Board of Health Administrative Code, Chapter 420-10-1, *Care and Treatment of Infants Identified Through the Newborn Screening Program*, mandates reporting of any hearing tests performed on the newborns to the Alabama Department of Public Health and use of forms and guidelines as determined by the State Health Officer.

Inpatient Screening Protocol Recommendations:

- Identify staff responsible for screening, reporting, and training personnel.
- Document all job descriptions, qualifications, and roles, as well as orientation, minimum length of training, and competency validation.
- It is recommended that the discharge planner be responsible for notifying parents of the newborn's hearing results, and responsible for scheduling outpatient hearing screening as necessary.
- Identify the name, model, and type of testing equipment being used for screening purposes. Care, use, trouble-shooting, maintenance and servicing of the testing equipment should be included.
- A copy of the policy and procedure manual for newborn hearing screening should be located in close proximity to the screening site.
- Birthing hospitals should also perform in-house quality assurance/improvement on a quarterly basis.
- Hospitals should use a general consent to perform hearing screening. It is advised that each facility consult with their legal representation to ensure that the consent is appropriate to cover this service.
- Identify the optimal testing environment as well as the desired condition or state of the newborn during testing.
- Identify risk indicators associated with hearing loss if known.

Resources:

- An Audiology Provider Directory is available at www.ehdipals.org
- Training may be provided by:
    - State Newborn Hearing Screening Coordinator at 334-358-2082
    - Video training is also available on the website: www.alabamapublichealth.gov/newbornscreening/newborn-hearing-screening.html
    - Interactive Web Based Newborn Hearing Screening Training Curriculum strongly recommended for all hospital staff performing the newborn hearing screening: www.infanthearing.org/nhstc/index.html

JOINT COMMITTEE ON INFANT HEARING

The Joint Committee on Infant Hearing (JCIH) 2007 Position Statement serves as the national standard for Early Hearing Detection and Intervention Programs. JCIH endorses early detection and intervention for infants with hearing loss to ensure opportunities to maximize linguistic competence and literacy development so that infants and children do not fall behind their peers in communication, cognition, reading, and social-emotional development. According to JCIH, such delays may result in lower educational and employment levels in adulthood.

Included is a link to the 2007 JCIH Position Statement along with an outline of important points: www.jcih.org/posstatemts.htm

- Separate protocols are recommended for NICU and well-baby nurseries.
- NICU babies greater than five days are to have Automated Brainstem Response (ABR) included as part of their screen so that neural hearing loss will not be missed.
- For infants who do not pass automated ABR testing in the NICU, referral should be made directly to an audiologist for rescreening.
- All infants who do not pass the initial hearing screening and the subsequent rescreening should have appropriate audiological and medical evaluations to confirm the presence of hearing loss no later than 3 months of age.
- Screening results should be conveyed immediately to families so they understand the outcome and importance of follow-up when indicated.
- A complete evaluation of both ears is recommended for each rescreening, even if only one ear did not pass the initial screen.
- For readmissions of infants in the first month of life, if there are conditions present which are associated with potential hearing loss (e.g. hyperbilirubinemia requiring exchange transfusion or culture + sepsis), a repeat hearing screen is recommended prior to discharge.
- Audiologists with skills and expertise in evaluating infants with hearing loss should provide diagnostic evaluation before three months of age.

NEWBORN HEARING SCREENING HOSPITAL ALGORITHM

Based on the Joint Committee on Infant Hearing (JCIH) Guidelines

Initial newborn hearing screening is performed 24-48 hours of age or before the baby leaves the hospital

Before you start the initial newborn hearing screening, is the baby's...

- ❑ Information entered exactly as entered on the blood spot form? (Refer to the instructions for entering demographic information into the hearing device)
- ❑ Testing method appropriate and all supplies gathered for testing both ears?

It is recommended to perform **only** two inpatient hearing screens, one initial and one rescreen if needed.

Otoacoustic Emissions (OAE)

- Measures hair cells of the outer ear
- Does not detect neural hearing loss
- Should only be used for well babies

Automated Auditory Brainstem Response (AABR)

- Measures inner ear and brain response to sound
- Detects neural hearing loss
- May be used for all infants, must be used for all NICU.

DID NOT PASS IN ONE OR BOTH EARS

Re-screen both ears with OAE and/or AABR, even if only one ear did not pass.

PASS BOTH EARS

No further testing required

DID NOT PASS IN ONE OR BOTH EARS

Re-screen both ears with AABR **only,** even if only one ear did not pass. **A referral should be made directly to an audiologist for rescreening on infants who do not pass AABR.**

DID NOT PASS RE-SCREEN IN ONE OR BOTH EARS

Schedule follow-up testing with a hearing professional within 2-3 weeks after discharge.

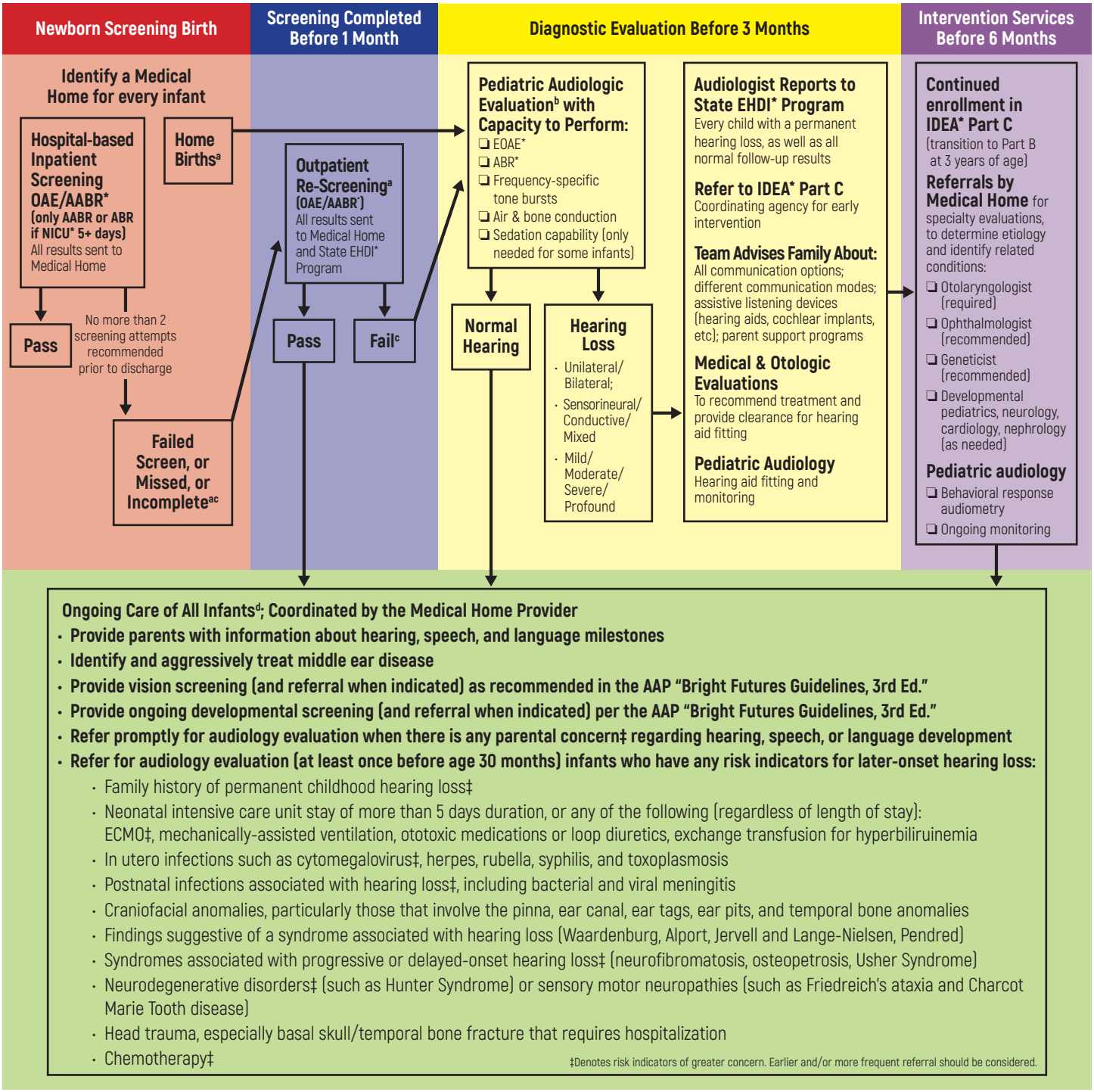
PASS WITH RISK FACTORS

Further testing recommended between 24-36 months of age.

NICU admission > 5 days is considered a risk factor.

Hearing Results should be sent electronically to the Alabama Newborn Screening Program each day. See the instructions for *Reporting Hearing Results Electronically.*

AMERICAN ACADEMY OF PEDIATRICS EARLY HEARING DETECTION & INTERVENTION (EHDI) GUIDELINES FOR PEDIATRIC PROVIDERS



February 2010 - American Academy of Pediatrics Task Force for Improving Newborn Hearing Screening, Diagnosis and Intervention (www.medicalhomeinfo.org)

***OAE =** Otoacoustic Emissions, **AABR =** Automated Auditory Brainstem Response, ABR = Auditory Brainstem Response, **EHDI =** Early Hearing Detection and Intervention, **IDEA =** Individuals with Disabilities Education Act, **NICU =** Newborn Intensive Care Unit, **AAP =** American Academy of Pediatrics

Notes:

(a) In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiologic Evaluation. Likewise, infants at higher risk for hearing loss (or loss to follow-up) also may be referred directly to Pediatric Audiology.

(b) Part C of IDEA* may provide diagnostic audiologic evaluation services as part of Child Find activities.

(c) Even infants who fail screening in only one ear should be referred for further testing of both ears

(d) Includes infants whose parents refused initial or follow-up hearing screening.

Re-screen Newborn Hearing Results Form

ALABAMA NEWBORN HEARING PROGRAM
PHONE 334.206.2944 FAX 334.206.3791

Hearing re-screen should be completed before one month of age

Alabama's Listening!
UNIVERSAL NEWBORN HEARING SCREENING

NEWBORN'S NAME	DATE OF BIRTH
HOSPITAL OF BIRTH	HOSPITAL ID NUMBER
MOTHER'S OR GUARDIAN'S NAME (as noted per hospital records)	HOME PHONE NUMBER
HOME ADDRESS	
PRIMARY CARE PHYSICIAN	PHYSICIAN PHONE NUMBER
ADDRESS	

BIRTH	HEARING SCREEN PERFORMED AT BIRTH FACILITY OR HOME BIRTH	Inpatient Screen Date: _____ Right Ear: ☐Pass ☐ Refer ☐ Not Tested Left Ear: ☐ Pass ☐ Refer ☐Not Tested Method: ☐ AABR ☐ OAE ☐ TEOAE ☐DPOAE	Infants who fail initial OAE screen may have an OAE or AABR re-screen. Infants who fail initial AABR screen **must** have an AABR re-screen.
BEFORE 1 MONTH	REPEAT SCREENING RESULTS Inpatient ☐ Outpatient ☐	DATE SCREENED: _____ **Both ears should be tested even if only one ear did not pass the initial screen.** Right Ear: ☐Pass ☐Refer ☐Not Tested Left Ear: ☐Pass ☐Refer ☐Not Tested Method: ☐AABR ☐OAE ☐TEOAE ☐DPOAE *Date referred for diagnostic evaluation:_____	RISK FACTORS FOR DELAYED HEARING LOSS: ☐ NICU admission ☐ Received ototoxic medications ☐Transfused ☐Other_____ _____ If any risk factors present, refer for an audiology assessment by 24 to 30 months of age.

TEST SITE NAME	PHONE	FAX
ADDRESS		

COMMENTS/FOLLOW-UP PLAN :

_____

_____

_____

The completed form should be returned as soon as the hearing re-screen/initial diagnostic audiological evaluation is completed. Fax to the Newborn Hearing Screening Program at 334-206-3791 .

*If refer, infant should have diagnostic testing by three months of age per the Joint Committee on Infant Hearing.

NBS.Hearing Re-Screen Reporting Form.2018

Diagnostic Hearing Evaluation Form

ALABAMA NEWBORN HEARING PROGRAM
PHONE 334.206.2944 FAX 334.206.3791
Diagnostic testing should be completed before three months of age

Alabama's Listening!
UNIVERSAL NEWBORN HEARING SCREENING

NEWBORN'S NAME	DATE OF BIRTH
HOSPITAL OF BIRTH	HOSPITAL ID NUMBER
MOTHER'S OR GUARDIAN'S NAME (as noted per hospital records)	HOME PHONE NUMBER
ADDRESS	

TEST SITE

Audiology Provider Name	Phone	Fax
Address		

Before 3 Months	**Pediatric Diagnostic Audiology Evaluation**	**DIAGNOSTIC TEST DATE**_____ **METHOD:** ☐ABR ☐AABR ☐OAE ☐ TEOAE ☐DPOAE ☐ Normal Hearing ☐ Hearing Loss Confirmed (Please Complete Section Below)	Please select all that apply. **Both ears should be tested at each visit.**
Before 6 Months	**Enrollment in Early Intervention**	Date of Referral to EI_____ Enrollment Date_____ Medical Referral: ☐Otolaryngologist ☐Geneticist ☐Ophthalmologist ☐Pediatrician ☐ Other (specify)_____ Additional Audiology Services_____	

		dB HL	SEVERITY/TYPE	Sensorineural	Conductive*	Mixed	Unspecified	Auditory Neuropathy
___UNILATERAL LOSS	RIGHT EAR	16 to 25	Slight					
		26 to 40	Mild					
		41 to 55	Moderate					
		56 to 70	Moderately Severe					
		71 to 90	Severe					
		91+	Profound					
			Unknown Severity					
___BILATERAL LOSS	LEFT EAR	dB HL	SEVERITY/TYPE	Sensorineural	Conductive*	Mixed	Unspecified	Auditory Neuropathy
		16 to 25	Slight					
		26 to 40	Mild					
		41 to 55	Moderate					
		56 to 70	Moderately Severe					
		71 to 90	Severe					
		91 +	Profound					
			Unknown Severity					

*Includes fluid in the middle ear, ear infection, poor eustachian tube function, hole in eardrum, earwax, swimmer's ear, foreign body in the ear canal, and malformation of the outer ear, ear canal, or middle ear per the American Speech-Language Hearing Association.

COMMENTS/FOLLOW UP (please add other descriptors associated with hearing loss):

_____

_____

_____

The completed form should be returned as soon as the hearing re-screen/initial diagnostic audiological evaluation is completed. Fax to the Newborn Hearing Screening Program at 334-206-3791.

NBS.Hearing Diagnostic Reporting Form.2018

CRS NEWBORN HEARING ASSESSMENT CLINICS

CHILDREN'S REHABILITATION SERVICE HEARING SERVICES

Communication is a critical skill that connects people. Through its Hearing Services, CRS gives children and youth a chance for success at home, at school, and in the community.

Newborn Hearing Screening

for follow-up to hearing screening done at the birthing center

Early detection of hearing loss is vital because it can help assure that your baby acquires the skills that are essential to success throughout life.

Testing is the only way to know if an infant has a hearing loss. If your child is referred to CRS for a follow-up newborn hearing screening, a CRS hearing specialist (called an audiologist) will test your child, explain the results, and tell you if more tests are necessary.

Hearing Aid Clinic

- Hearing aid evaluation and prescription
- Hearing aid and ear mold ordering
- Hearing aid orientation and fitting
- Hearing aid follow-up checks
- Hearing aid maintenance and repairs
- Ear mold replacement
- Explanation of educational options
- Consultation or technical assistance for local schools
- Referral for speech-language therapy
- Education and support for the child and family

Hearing Assessment Clinic

- Evaluation by a pediatric audiologist
- Referral to Hearing Clinic and/or Hearing Aid Clinic as necessary

Hearing Clinic

- Evaluation by a pediatric audiologist
- Examination by an ear, nose, and throat (ENT) physician
- Referral for specialized testing or services (i.e., CT scans, MRI, lab work, hearing impaired education, etc.)

If you think your child might benefit from CRS Hearing Services, contact the CRS office in your area.

CRS OFFICE LOCATIONS

STATE OFFICE
602 S. Lawrence St., Montgomery, 36104
334-293-7500, 1-800-846-3697

ANDALUSIA
1082 Village Square Drive, Suite 2, 36420
334-222-5558,1-800-723-8064

ANNISTON
1910 Coleman Road, 36207
256-240-8801, 1-800-289-9533

BIRMINGHAM
Homewood CRS
234 Goodwin Crest Drive, 35209
Community Office: 205-290-4550,
1-888-430-7423

Birmingham TCH (The Children's Hospital)
1600 Seventh Ave. South, 35233
205-939-5900, 1-800-285-9318

DOTHAN
795 Ross Clark Circle NE, 36303
334-699-6600,1-800-677-9123

GADSDEN
1100 George Wallace Drive, 35903
256-547-8653, 1-800-289-1353

HUNTSVILLE
3000 Johnson Road, 35805
256-650-1701, 1-800-283-9352

JACKSON
1506 College Ave., 36545
251-246-4025, 1-800-283-8140

MOBILE
1610 Center St., Suite A, 36604
251-432-4560, 1-800-879-8163

MONTGOMERY
602 S. Lawrence St., 36104
334-293-7500, 1-800-568-9034

MUSCLE SHOALS
1450 E. Avalon Ave., 35661
256-381-1212, 1-800-285-9924

OPELIKA
516 W. Thomason Circle, 36801
334-749-8339, 1-800-568-8428

SELMA
2906 Citizens Parkway, 36701
334-872-8422, 1-800-967-6876

TUSCALOOSA
1110 Dr. Edward Hilliard Drive, 35401
205-759-1279, 1-800-723-0490

EHDI Program Update
CDC's Progress in Detecting Infant Hearing Loss

CDC's Early Hearing Detection and Intervention (EHDI) has made clear progress in supporting the early identification of deaf and hard of hearing (DHH) infants.
The earlier children with hearing loss are identified and start getting intervention, the more likely they will reach their full potential.



Hearing Professionals use These Important 1-3-6 Benchmarks

1 **Before one month of age: *Hearing Screening***

3 **Before three months of age: *Hearing evaluation***

6 **Before six months of age: *Early Intervention***

Hearing screening is the first hearing service to determine if a baby has hearing loss.

Hearing evaluation is a comprehensive test to determine the severity of hearing loss.

Identifying hearing loss early is important

- Hearing loss is one of the most common birth defects.
- Each year 12,000 infants are born deaf or hard of hearing (DHH).
- When left undetected, a hearing loss can delay a child's speech and language development, as well as his or her thinking, learning, and social skills.
- Newborn hearing screening and intervention programs can save nearly $200 million in additional education costs annually[1].

How CDC is helping to make progress

- CDC is responsible for collecting and analyzing EHDI data from across the United States.
- The CDC EHDI program provides technical assistance to all states and territories to help support the early identification of DHH infants.
- CDC funds the development and use of systems and data tools that help states and territories ensure DHH children receive essential services:
  - Hearing screening
  - Hearing evaluation
  - Early intervention
- Nearly all newborns are screened for hearing loss, usually before leaving the hospital.

National Center on Birth Defects and Developmental Disabilities
Division of Human Development and Disability

CS262933

ALABAMA NEWBORN HEARING PROVIDER DIRECTORY



The Early Hearing Detection & Intervention – Pediatric Audiology Links to Services (EHDI-PALS) is a web-based link to information, resources, and services for children with hearing loss. It includes a directory of facilities that offer pediatric audiology services to young children who are younger than five years of age.

For an updated list of Alabama audiology providers please visit the EHDIPALS site at the following link: www.ehdipals.org.

Are you a provider interested in listing your facility in the EHDI-PALS directory?
If so, enter your information at: www.ehdipals.org/EP_AudiologicalServiceProviders.aspx

1-3-6 NEWBORN HEARING SCREENING CHECKLIST

Patient Name: _____ **Patient DOB:** _____ **Date of Visit:** _____

1 INITIAL SCREENING *(by no later than 1 month of age)*		
Has the child had a newborn hearing screening?	**Yes**	**No ⇨** Schedule initial screening
Did you obtain the test results from the screening hospital or state EHDI program?	**Yes**	**No ⇨** Contact the hospital or state EHDI program
Are the results recorded in the patient's chart?	**Yes**	**No ⇨** Record test results in patient chart
Did the child pass the newborn hearing screening?	**Yes**	**No ⇨** Schedule rescreening appointment
Have the results been reported to the state EHDI program?	**Yes**	**No ⇨** Confirm results have been reported to state EHDI program within 48 hours of receiving them
Have results been discussed with family?	**Yes**	**No ⇨** ❑ For a child who passed, stress the importance of ongoing surveillance and risk factors* ❑ For a child who did not pass, discuss the need for follow-up and assist in arranging a rescreening
Has a rescreening occurred (if the initial screen resulted in "did not pass" or if otherwise necessary)?	**Yes**	**No ⇨** Schedule rescreening appointment
RESCREENING *(by no later than 1 month of age)*		
Where will the rescreening be performed? ✓ If hospital/outpatient center, when is the rescreening appointment? ✓ If conducted in office: • Determine what screening equipment was used at the hospital. • Follow the AAP office rescreening guidelines.	❑ Hospital: _____ ❑ Office ❑ Other (specify): _____ Location: _____ Date: _____	
Did the child pass the rescreening?	**Yes**	**No ⇨** Send child to audiologist with pediatric expertise for diagnostic evaluation.
Are the results recorded in the patient chart?	**Yes**	**No ⇨** Record results in patient chart.
Have the results been discussed with the family?	**Yes**	**No ⇨** ❑ For a child who passed, stress the importance of ongoing surveillance and risk factors* ❑ For a child who did not pass, discuss the need for follow-up and assist in arranging an audiologic evaluation
Have the results been reported?	**Yes**	**No ⇨** Confirm results have been reported to state EHDI program within 48 hours of receipt
3 DIAGNOSTIC EVALUATION *(by no later than 3 months of age)*		
If the child did not pass the rescreening, was he/she referred to an audiologist with expertise in pediatrics?	**Yes** Provider: _____ Date of Visit: _____	**No ⇨** Refer to audiologist with expertise in pediatrics
Were the results of the diagnostic test normal?	**Yes**	**No ⇨** Discuss early intervention (EI) and need for comprehensive plan
Have the results been discussed with the family?	**Yes**	**No ⇨** ❑ For a child who passed, stress the importance of ongoing surveillance and risk factors* ❑ For a child who did not pass, discuss EI and need for comprehensive plan
Have the results been reported?	**Yes**	**No ⇨** Confirm results have been reported back to state EHDI program within 48 hours of receipt
6 EARLY INTERVENTION *(by no later than 6 months of age)*		
If the child was diagnosed with a hearing loss, was he/she referred for early intervention and multidisciplinary evaluation?	**Yes** Date of visit: _____	**No ⇨** Provide referral for EI, ophthalmology, and otolaryngology and offer referral for genetics
ONGOING SURVEILLANCE AND SCREENING		
Continue to perform ongoing surveillance and screening for late-onset hearing loss, particularly children with risk factors.		

*JCIH Risk Factors

Early Hearing Detection & Intervention Program

GLOSSARY OF TERMS FOR NEWBORN HEARING SCREENING

The American Academy of Pediatrics (AAP) Early Hearing Detection and Intervention (EHDI) Loss to Follow-up/ Documentation (LTF/D) Workgroup has compiled a glossary of terms important to newborn hearing screening and resources related to LTF/D.

TERM	DEFINITION
Newborn hearing screening (NBHS)	Hearing screening performed shortly after birth, typically performed in hospitals prior to discharge involving the use of OAEs or AABR.
Otoacoustic emissions (OAEs)	This test measures a response produced by the cochlea (outer hair cells) when a sound is presented to the ear. To conduct the test, a tiny probe is placed just inside the baby's ear canal and a soft click is presented, a tiny microphone measures the response produced by the baby's ear. The test is quick (about 5 to 10 minutes) and painless and may be performed while the baby is sleeping or lying still. Thus, OAEs reflect the status of the peripheral auditory system extending to the cochlear outer hair cells.
Automated auditory brainstem response (AABR)	This screening test measures how the hearing nerve responds to sound. Clicks are presented to the ear through a probe or soft earphones, and the neural response is measured through 3 electrodes placed on the baby's head. AABR measurements reflect the status of the peripheral auditory system, the eighth nerve, and the brainstem auditory pathway.
Outpatient rescreening	Hospital screening protocols vary and often include an outpatient screening stage. The specific technology used to conduct the outpatient screening should be based on the knowledge of how the inpatient screening was conducted. For example, when a baby fails an inpatient AABR screening, the outpatient screening must be conducted using AABR; if an OAE screening is used, auditory neuropathy will be missed. The outpatient screening may be completed at the birth hospital or by another provider, such as an audiologist, or physician.
Lost to follow-up	For infant who did not pass newborn hearing screening, "lost to follow-up" refers to a failure to receive the next step of treatment, be it rescreening or comprehensive audiologic evaluation.
Lost to documentation	Failure to report the results from hearing screening, rescreening, diagnostic services, and/or treatment services that are needed for comprehensive surveillance and monitoring by EHDI and the medical home
Lost to treatment	Failure for a child with an identified hearing loss to receive needed therapeutic services and failure for families to receive needed information to support decisions regarding treatment options.
Medical home	A model for providing high-quality primary care that addresses and integrates health promotion, acute care, and chronic condition management in a planned, coordinated, and family-centered manner.
Late-onset hearing loss	A hearing loss that is not present at birth and the newborn hearing screening, which would result in a "pass."
Auditory neuropathy	Children with auditory neuropathy have evidence of normal cochlear function but show impairment in the function of the auditory nerve. Functional hearing can often be quite impaired, and diagnosis and treatment can be confusing and complicated.
Risk factors	Risk factors are indicators used (1) for the identification of infants who should receive audiologic evaluation but who live in geographic locations (eg, developing nations, remote areas) where universal hearing screening is not yet available; (2) to help identify infants who pass the neonatal screening but are at risk of developing delayed-onset hearing loss and, therefore, should receive ongoing medical, speech and language, and audiologic surveillance; and (3) to identify infants who may have passed neonatal screening but have mild forms of permanent hearing loss.



JCIH 11 risk indicators	The Joint Commission on Infant Hearing (JCIH) lists 11 risk indicators associated with permanent congenital, delayed-onset, or progressive hearing loss in childhood (risk indicators that are marked with a "*" are of greater concern for delayed-onset hearing loss.) 1. Caregiver concern* regarding hearing, speech, language, or developmental delay. 2. Family history* of permanent childhood hearing loss. 3. Neonatal intensive care of more than 5 days or any of the following regardless of length of stay: ECMO,* assisted ventilation, exposure to ototoxic medications (gentamicin and tobramycin) or loop diuretics (furosemide/Lasix), and hyperbilirubinemia that requires exchange transfusion. 4. In utero infections, such as cytomegalovirus,* herpes, rubella, syphilis, and toxoplasmosis. 5. Craniofacial anomalies, including those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies. 6. Physical findings, such as white forelock, that are associated with a syndrome known to include a sensorineural or permanent conductive hearing loss. 7. Syndromes associated with hearing loss or progressive or late-onset hearing loss, such as neurofibromatosis, osteopetrosis, and Usher syndrome; other frequently identified syndromes include Waardenburg, Alport, Pendred, and Jervell and Lange-Nielson syndrome. 8. Neurodegenerative disorders,* such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome. 9. Culture-positive postnatal infections associated with sensorineural hearing loss,* including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis. 10. Head trauma, especially basal skull/temporal bone fracture* that requires hospitalization. 11. Chemotherapy*

NEWBORN HEARING SCREENING FAQ

What is hearing loss?

There are two main types of hearing loss:

1. Conductive hearing loss – occurs when sound cannot enter into the inner ear. This may be caused by wax buildup, fluid in the ear, or structural abnormalities. It can usually be corrected with medical or surgical intervention. **This is also a reportable diagnosis of hearing loss.**
2. Sensorineural hearing loss – occurs when there is damage to the inner ear. This may be caused by disease, birth injury, toxic drugs, or genetic syndromes.

In addition, there are various degrees of hearing loss. They include:

- slight hearing loss
- mild hearing loss
- moderate hearing loss
- moderately severe hearing loss
- severe hearing loss
- profound hearing loss

It is important to note that milder hearing losses or hearing losses that affect only one ear may not be apparent.

Why should a baby's hearing be screened?

The first two years of a baby's life are critical for learning speech and language. Thus, it is important to diagnose hearing problems early because a hearing loss could affect a baby's speech and language development. In addition, early detection makes talking, learning, and adjusting to hearing devices easier.

How is the hearing screen performed?

There are two types of screening methods that may be used. Both tests are very safe, take only minutes to perform, and are non-invasive. Most babies sleep through the hearing screening.

1. Automated Auditory Brainstem Response (AABR) – determines the infant's ability to hear soft sounds normally by inserting miniature earphones and attaching electrodes to measure brain-wave responses to the sound. **This screening method is recommended by the Joint Committee on Infant Hearing (JCIH) for high risk newborns admitted to the NICU greater than five days and should be completed as a second test method if an infant is initially tested with AABR.**
2. Otoacoustic emissions (OAE) – measures inner ear function by inserting a miniature microphone in the ear canal via a soft probe tip and measuring tones from the ear by sending responses to a special computer.

What if a baby does not pass the hearing screen?

If a baby does not pass the initial hearing screening at birth, then no more than one other attempt to re-screen should be completed on the day of discharge. If the baby does not pass on discharge, an appointment should be made with an audiologist for a re-screen (second tier screen) and notify the primary care physician of appointment so he or she can send a referral.

PARENT INFORMATION

Newborn Hearing Screening: What do the results mean?



Baby is born



Hearing screening is performed at 24-48 hours of age or before the baby leaves the hospital

Ask for your baby's hearing results before leaving the hospital:

PASS
no further testing required (always monitor for speech and language milestones)

PASS WITH RISK FACTORS
further testing recommended between 9-12 months of age

DID NOT PASS
The hospital should re-screen your baby one more time or make you an appointment for a hearing re-screen (does not mean your baby has hearing loss)

Did Not Pass:

- Schedule follow-up testing with an audiologist (hearing professional) within 2-3 weeks after you go home from the hospital.
- Ask your baby's doctor to help you find an audiologist or you can visit www.ehdi-pals.org
- Remember that just because a baby may respond to noise does not mean he or she can hear properly

Alabama's Listening!
UNIVERSAL NEWBORN HEARING SCREENING

ALABAMA PUBLIC HEALTH

WANT TO KNOW MORE?
Call us: 1-866-928-6755

SECTION 4 – PULSE OXIMETRY SCREENING

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CRITICAL CONGENITAL HEART DISEASE (CCHD)

INTRODUCTION

In September 2011, U.S. Department of Health and Human Services (HHS) Secretary Kathleen Sebelius approved adding Critical Congenital Heart Disease (CCHD) to the Recommended Uniform Screening Panel (RUSP). This recommendation was endorsed by the Alabama Chapter of the American Academy of Pediatrics. Donald E. Williamson, M.D., Alabama's State Health Officer, supported implementation of screening for CCHD in Alabama's birthing facilities. The Newborn Screening Program convened a CCHD Work Group that met on November 30, 2011, and again on December 13, 2011, to create a protocol for pulse oximetry screening on well infants in Alabama's fifty-three birthing facilities with a goal to implement by April 2012.

According to the Centers for Disease Control and Prevention (CDC), congenital heart defects account for 24% of infant deaths due to birth defects. In the United States, about 4,800 (or 11.6 per 10,000) babies born every year have CCHDs. In Alabama, approximately seventy infants are expected to be diagnosed with a CCHD each year. Babies with a CCHD are at significant risk for death or disability if their CCHD is not diagnosed and treated soon after birth. Pulse oximetry, which is a test to determine the amount of oxygen in the blood, is the recommended screening method to detect CCHDs in newborns.

There are seven defects classified as CCHD:

- Hypoplastic left heart syndrome
- Pulmonary atresia (with intact septum)
- Tetralogy of Fallot
- Total anomalous pulmonary venous return
- Transposition of the great arteries
- Tricuspid atresia
- Truncus arteriosus

This manual serves as a guide to assist each birthing facility to establish its own policy and procedures to implement a Critical Congenital Heart Disease Screening Program (CHDSP). These policies and procedures should establish clear, complete, and concise evidence-based policy and address the components listed below:

- Equipment
- Training
- Screening
- Education

It is recommended that each facility designate a program coordinator to facilitate the planning and implementation of the screening program, including the establishment of an interdisciplinary team. Members of this team should participate in the planning process and should represent hospital executives, physicians, nurses, and ancillary staff.

PULSE OX SCREENING TRAINING

SECTION 1 - EQUIPMENT



Each birthing facility will be responsible for selecting and securing pulse oximeter equipment for screening newborns for CCHD, if appropriate equipment is not already available. Such equipment must be compliant with national standards and adhere to the following:

- Must be motion-tolerant and report functional oxygen saturation.
- Must be validated in low-perfusion conditions.
- Must have been cleared by the FDA for use in newborns.
- Must have 2% root, mean-square accuracy.
- Must be calibrated regularly based on manufacturer guidelines.

PULSE OX SCREENING TRAINING

SECTION 2 - TRAINING

Training should be performed by qualified personnel who have participated in the planning process (e.g., unit nurse manager or assistant nurse manager, nurse educator, the program coordinator, or a registered nurse). This training should be hands-on and competency based. The training of personnel should include:

- Overview of screening protocol
- Education on the use, care, maintenance, and trouble-shooting of screening equipment
- A review of general nursery policies and procedures
- Education on the differences between adult and pediatric oximeter probes
- An explanation on the importance of adequate circulation
- The effects of hypothermia and phototherapy on pulse oximetry screening
- Facility resources for pediatric echocardiogram and referral sources when not available in house

PULSE OX SCREENING TRAINING

IN-SERVICE EDUCATION PROGRAM COMPONENTS

The following is an overview of educational tools and components that may be used to educate staff who will be directly involved in screening implementation. Educational tools discussed are included.

1. **PowerPoint Presentation:**
   a. Provides attendees with education on background, significance, and need for screening.
   b. Provides attendees with education on Congenital Heart Disease Screening Program (CHDSP) screening methods and guidelines.

2. **Education for Providers:**
   a. Provides attendees with educational tool, "Congenital Heart Disease Screening Program: Education for Providers," which includes an overview of pulse oximetry, congenital heart disease, and pulse oximetry screening for critical congenital heart disease.

3. **Pulse Oximetry Demonstration:**
   a. Provide attendees with a demonstration of correct and safe use of pulse oximetry equipment in obtaining an accurate infant reading by in-service facilitator or representative from pulse oximeter manufacturer.
   b. Provide attendees with an opportunity to practice performing pulse ox screening on a doll.
   c. Provide attendees with the opportunity to ask questions regarding correct and safe methods for performing pulse ox screening.
   d. Provide attendees with the "Performing Pulse Oximetry (Pulse Ox) with the Infant Patient: Education for Providers" and "Pulse Ox Placement" educational tools.

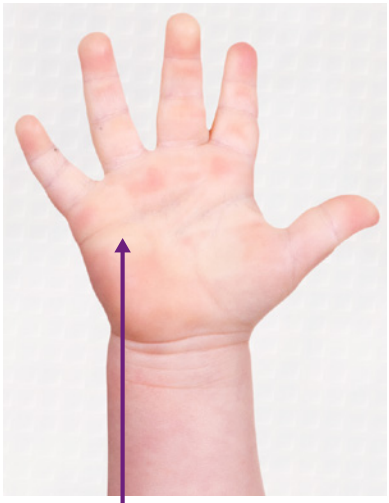
4. **Knowledge Assessment Quiz:**
   a. Allow time for attendees to complete the "Knowledge Assessment Quiz."
   b. Review the correct answer for each question.
   c. Allow time for remediation of questions answered incorrectly.
   d. Allow time for attendees to re-take quiz, if necessary.

5. **Competency Checklist:**
   a. Allow adequate time for completion of competency checklist.
   b. Provide each attendee with a copy of the complete competency checklist to forward to his or her manager.

PULSE OX SCREENING TRAINING

PULSE OX PROBE PLACEMENT EDUCATION

1. Select application site on the outside, fleshy area of the infant's hand or foot.



RH Application Site



Foot Application Site

2. Place the photodetector portion of the probe on the fleshy portion of the outside of the infant's hand or foot.
3. Place the light emitter portion of the probe on the top of the hand or foot. Place the photodetector directly opposite of light emitter, on the bottom of the hand or foot.
4. Remember: The photodetector and emitter must be directly opposite each other in order to obtain an accurate reading.
5. Secure the probe to the infant's hand or foot using the adhesive or foam tape recommended by the vendor. It is not recommended to use tape to secure probe placement.
6. Some vendors use visual images such as a star or bar to specify which side of the probe should be placed on top of the hand or foot. You may choose to use a helpful statement such as, "Raise the bar" to help you to remember proper probe placement.





PULSE OX SCREENING TRAINING

PERFORMING PULSE OXIMETRY (PULSE OX) WITH THE INFANT PATIENT: EDUCATION FOR PROVIDERS

Pulse Ox – Dos

1. If you are using disposable pulse ox probes, use a new, clean probe for each infant. If you are using reusable pulse ox probes, clean the probe with recommended disinfectant solution between each infant. Dirty probes can decrease the accuracy of your reading and can transmit infection. A disposable wrap should be used to secure the probe to the site.
2. The best sites for performing pulse ox on infants are around the palm and the foot. An infant pulse ox probe (not an adult pulse ox clip) should always be used for infants.
3. When placing the sensor on the infant's skin, there should not be gaps between the sensor and the infant's skin. The sides of the probe should be directly opposite of each other.
4. Nail polish dyes and substances with dark pigmentation (such as dried blood) can affect the pulse ox reading. Assure that the skin is clean and dry before placing the probe on the infant. Skin color and jaundice do not affect the pulse ox reading.
5. Movement, shivering and crying can affect the accuracy of the pulse ox reading. Ensure that the infant is calm and warm during the reading. Swaddle the infant and encourage family involvement to promote comfort while obtaining the reading. If possible conduct screening while the infant is awake.
6. Pulse oximeters have different confidence indicators to ensure that the pulse ox reading is accurate. Determine the confidence indicators for the pulse oximetry equipment that you are using.
7. If an infant requires pulse ox monitoring for an extended amount of time, assess the site where the probe is placed at least every two hours. Monitor for signs of irritation and burning of the skin.

Pulse Ox – Don'ts

1. Never use an adult pulse ox clip when obtaining a pulse ox reading for an infant. Using an adult clip on an infant will give you an inaccurate reading.
2. Blood flow is needed to obtain an accurate pulse ox reading. Never attempt to obtain a pulse ox reading on the same extremity that you have an automatic blood pressure cuff.
3. Bright or infrared light, including bilirubin lamps and surgical lights, can affect the accuracy of the reading. Ensure that the infant is not placed in bright or infrared light while pulse ox is being performed. You may cover the pulse ox probe with a blanket to ensure that extraneous light does not affect the accuracy of your reading.
4. Do not use tape to apply the pulse ox probe to the infant's skin.

Pulse Ox - Caution!

1. The pulse is needed to determine the oximetry reading. Pulse ox is not accurate if the patient is coding or is having a cardiac arrhythmia. Remember: No pulse, no oximetry!
2. Pulse ox readings are not instantaneous. The oximetry reading that is displayed on the monitor is an average of readings over the past few seconds.

PULSE OX SCREENING TRAINING

KNOWLEDGE ASSESSMENT

1. The following can affect the accuracy of the pulse oximetry (pulse ox) reading:
   a. Movement
   b. Cold extremities or shivering
   c. Crying
   d. Bilirubin lamps and surgical lights
   e. All of the above

2. One clean, disposable pulse ox probe can be used on up to five patients.
   a. True
   b. False

3. All of the following can affect the accuracy of the pulse ox reading except:
   a. Placing the pulse ox probe on the same extremity that you are taking the blood pressure
   b. Performing the pulse ox test while the infant is crying
   c. Using a clip on the finger of an infant
   d. Infant skin color or jaundice

4. Pulse ox screening will detect all forms of CHD
   a. True
   b. False

5. The screening guidelines state that pulse ox should be performed on:
   a. The right hand
   b. One foot
   c. Both a and b
   d. Neither a or b

6. Pulse ox screening should be performed when the infant is what age?:
   a. Less than 8 hours
   b. Between 8 hours and 18 hours
   c. Greater than 24 hours
   d. Less than 24 hours

7. An infant's pulse ox readings should be reported to the physician or nurse practitioner caring for the infant if:
   a. Pulse ox readings are greater than 94% for both right hand and one foot and there is a difference of 4 or more between the two on three measures each separated by one hour
   b. Pulse ox readings are less than 95% for both right hand and one foot or there is a difference of 4 between the two on three measures each separated by one hour
   c. Pulse ox reading is less than 90% for either or both the right hand and one foot
   d. All of the above

8. Pulse ox screening results can be shared with individuals that are not directly involved in the patient's care:
   a. True
   b. False

PULSE OX SCREENING TRAINING

KNOWLEDGE ASSESSMENT ANSWERS

1. The following can affect the accuracy of the pulse oximetry (pulse ox) reading:
   a. Movement
   b. Cold extremities or shivering
   c. Crying
   d. Bilirubin lamps and surgical lights
   e. All of the above

2. One clean, disposable pulse ox probe can be used on up to five patients.
   a. True
   b. False

3. All of the following can affect the accuracy of the pulse ox reading except:
   a. Placing the pulse ox probe on the same extremity that you are taking the blood pressure
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   b. Pulse ox readings are less than 95% for both right hand and one foot or there is a difference of 4 between the two on three measures each separated by one hour
   c. Pulse ox reading is less than 90% for either or both the right hand and one foot
   d. All of the above

8. Pulse ox screening results can be shared with individuals that are not directly involved in the patient's care:
   a. True
   b. False

PULSE OX SCREENING TRAINING

COMPETENCY CHECKLIST

- **Competency Title: Congenital Heart Disease Screening Process**

- **Competency Criteria includes the following:**
  1. Completion of the in-service education.
  2. Accomplishment of 90 percent or more on the knowledge assessment quiz with remediation as necessary.
  3. Appropriate application of pulse oximetry.
  4. Accurate reading and documentation of the pulse oximetry readings.

- **Competency Statement: Proficiently perform the required activities defined in research protocol.**

  Validation Criteria: A. Discussion (D) C. Written Test (T)
  B. Verbal Feedback (VF) D. Return Demonstration (RD)

Directions for completing evaluation form: Evaluator, please circle the appropriate method of validation, initial each line and place signature in the appropriate place at the end of the document.

Name:_____ Job Title:_____

Competency	Date	Method of Validation	Supervisor Initials	Comments
Explains screening eligibility guidelines for pulse oximetry screening		D VF T		
Identifies safe and correct methods for performing pulse oximetry		D VF T RD		
Describes methods to ensure that pulse oximetry reading is accurate		D VF T RD		
Explains screening methods and guidelines for pulse oximetry screening		D VF T		
Discuss HIPAA confidentiality standards		D VF T		

Name:_____ Date: _____

Supervisor Name (Printed): _____

Supervisor Signature: _____

PULSE OX SCREENING TRAINING

TRAINING LOG *(For the records of unit managers or nursing educators)*

Employee Name and Title	Date	Completion of Competency Checklist		Manager Initials
		Yes	No	

**Each employee responsible for performing pulse oximetry screening methods should complete the competency checklist prior to participation.*

Unit:_____

Supervisor Name (Printed):_____

Manager Signature: _____

PULSE OX SCREENING SCREENING

SECTION 3 - SCREENING

Supplies for screening

- Pulse Oximeters
  1. At least one motion-tolerant pulse oximeter to be used for screening
  2. One motion-tolerant pulse oximeter for back-up

- Infant Disposable or Reusable Pulse Ox Sensors
  1. If using disposable sensors, one disposable sensor for every infant screened
  2. If using reusable sensors, one reusable sensor for each pulse oximeter. Also consider additional reusable sensors for back-up
     a. Disinfecting agent recommended by pulse oximetry equipment manufacturer
  3. One disposable wrap per infant screened to secure sensor to hand or foot

- Rolling Cart for Supplies

- Data Collection Forms
  1. One for every infant screened

- Dedicated individual to perform screening

- Red Heart-Shaped Stickers
  1. One red heart-shaped sticker for every infant who has been screened (optional)

- Blankets for warming the infant and blocking extraneous light

- A parent for comforting infant during screening (optional)

CRITICAL CONGENITAL HEART DISEASE SCREEN (CCHD)

ALABAMA Newborn Screening PROGRAM

ALABAMA PUBLIC HEALTH

CCHD Screen at Birth Off Supplemental Oxygen
Obtain pulse oximetry reading on right hand and either foot (in parallel or direct sequence) at 24 hours or later (infant should be on room air, warm and quiet, with screening sites clean and dry)

Immediate Fail
Pulse ox reading less than 90% in right hand or foot

Fail
Pulse Ox less than 95% in both the right hand and foot and a saturation difference of 4% or greater

Pass
Pulse ox reading of 95% or higher in right hand or foot AND Saturation Difference of 3% or less between the right hand and foot readings

Repeat screen in 1 hour

PASS

Provide Routine Newborn Care

FAIL - Do NOT repeat Pulse Ox AND proceed with immediate clinical assessment.

FAIL - Do NOT repeat Pulse Ox AND proceed with immediate clinical assessment.

Immediate Fail
Pulse ox less than 90

- Notify physician and proceed with immediate clinical assessment.
- If no etiology is found, immediate echocardiogram interpreted by a pediatric cardiologist is indicated. **This may require transfer to a NICU with pediatric cardiology services.**
- Report failed pulse ox screen reporting form to the Alabama Department of Public Health. You may fax the form to (334) 206-3791 or electronically submit via the web portal as required by state law.

Failed Screen

- Perform comprehensive evaluation for causes of hypoxemia including infectious and pulmonary pathology.
- If no other etiology is found, consultation with pediatric cardiology or neonatology is indicated to arrange for a diagnostic echocardiogram to be interpreted by a pediatric cardiologist. This may require telemedicine, transfer to a NICU with pediatric cardiology services, or discussion with cardiology services to schedule a timely outpatient echocardiogram. Physician to physician communication recommended.
- Report failed pulse ox screen reporting form to the Alabama Department of Public Health. You may fax the form to (334) 206-3791 or electronically submit via the web portal as required by state law.

- This screening algorithm should not take the place of clinical judgment or customary clinical practice.
- A negative screen does not rule out heart disease.
- Optimal results are obtained using a motion-tolerant pulse oximeter that reports functional oxygen saturation, has been validated in low perfusion conditions, has been cleared by the FDA for use in newborns, has a 2% root mean-square accuracy, and is calibrated regularly.
- For more information see: Kemper, AR, Mahle, WT, Martin, GR et al; Strategies for Implementing Screening for Congenital Heart Disease. Pediatrics.2011. available at: http://pediatrics.aappublications.org/content/early/2011/10/06/peds.2011-1317

FAILED PULSE OX SCREEN REPORTING FORM

ALABAMA Newborn Screening PROGRAM

ALABAMA PUBLIC HEALTH

PLACE LABEL OR WRITE-IN INFORMATION

Medical Record # _____

Patient Name: Last _____ First _____

Mother's Name: _____ Date of Birth ____/____/____

Hospital: _____ Medical Provider: _____

Alabama Newborn Screening Program

Fax failed screens to **334-206-3791**

Age at Initial Screening: _____ hours

Initial Screening	
Time	
Pulse Ox Saturation of Right Hand	
Pulse Ox Saturation of Foot	
Difference between right hand and foot	
	❑ **FAIL***

Second Screening *(1 hour following initial screen if fail initial screen)*	
Time	
Pulse Ox Saturation of Right Hand	
Pulse Ox Saturation of Foot	
Difference between right hand and foot	
	❑ **FAIL*** *DO NOT repeat and proceed with immediate assessment*

Immediate Fail = Pulse ox less than 90% in the right hand or foot

Fail = Pulse ox less than 95% in both the right hand and foot and a saturation difference of 4% or greater

*Fail may require transfer to a NICU with pediatric cardiology services

Other etiology identified: ❑ Pulmonary ❑ Infection ❑ Unknown ❑ Other: _____

Transferred: _____

Provider referred to: _____

Screener's First Initial/Last Name: _____ Date: ____/____/____

Revised 2/10/2025

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PUBLIC HEALTH DISTRICTS

EAST CENTRAL DISTRICT
Richard Burleson, District Administrator
3060 Mobile Highway
Montgomery, AL 36108
(334) 293-6400
Connie King, Assistant District Administrator
1850 Crawford Rd.
Phenix City, AL 36867
(334) 297-0251

JEFFERSON COUNTY
Mark E. Wilson, M.D., County Health Officer
David Hicks, D.O., M.P.H., Deputy Health Officer
1400 Sixth Ave. S.
Birmingham, AL 35233
(205) 933-9110

MOBILE COUNTY
Bernard H. Eichold, II, M.D.
County Health Officer
Susan Stiegler, Assistant Health Officer
251 N. Bayou St.
Mobile, AL 36603
(251) 690-8827

NORTHEASTERN DISTRICT
Karen Landers, M.D., District Medical Officer
Mary Gomillion, District Administrator
Mark Johnson, Assistant District Administrator
709 E. Broad St.
Gadsden, AL 35903
(256) 547-6311

NORTHERN DISTRICT
Karen Landers, M.D., District Medical Officer
1000 S. Jackson Hwy.
Sheffield, AL 35660
(256) 383-1231
Judy Smith, District Administrator
Michael Glenn, Assistant District Administrator
3821 Highway 31 South
Decatur, AL 35603
(256) 340-2113

SOUTHEASTERN DISTRICT
Corey Kirkland, District Administrator
1781 E. Cottonwood Rd.
Dothan, AL 36301
(334) 792-9070

SOUTHWESTERN DISTRICT
Chad Kent, District Administrator
Suzanne Terrell, Assistant District Administrator
1115 Azalea Place
Brewton, AL 36426
(251) 947-1645
303 Industrial Drive
Linden, AL 36748
(334) 295-1000

WEST CENTRAL DISTRICT
Stacey Adams, District Administrator
2350 Hargrove Rd., E.
Tuscaloosa, AL 35405
(205) 554-4500



ALABAMA COUNTY HEALTH DEPARTMENTS

East Central District	
Autauga	334-361-3743
Bullock	334-738-3030
Chambers	334-756-0758
Elmore	334-567-1171
Lee	334-745-5765
Lowndes	334-548-2564
Macon	334-727-1800
Montgomery	334-293-6400
Russell	334-297-0251
Tallapoosa	256-329-0531

Jefferson	
Central Health	205-933-9110
Eastern Health	205-591-5180
Morris Health	205-933-4242
Western Health	205-715-6121

Mobile County	
Keeler Clinic	251-690-8158
Semmes Clinic	251-445-0582
Citronelle Clinic	251-866-9126
Eight Mile Clinic	251-456-1399
Dauphin Island	251-445-3450
Newburn Clinic	251-405-4524
North Mobile	251-829-9884
Southwest Mobile	251-666-7413

Northeastern District	
Blount	205-274-2120
Calhoun	256-237-7523
Cherokee	256-927-3132
Clay	256-396-6421
Cleburne	256-463-2296
DeKalb	256-845-1931
Etowah	256-547-6311
Randolph	334-863-8981
St. Clair	205-338-3357
Shelby	205-664-2470
Talladega	256-362-2593

Northern District	
Colbert	256-383-1231
Cullman	256-734-1030
Franklin	256-332-2700
Jackson	256-259-4161
Lauderdale	256-764-7453
Lawrence	256-974-1141
Limestone	256-232-3200
Madison	256-539-3711
Marion	205-921-3118
Marshall	256-582-3174
Morgan	256-353-7021
Winston	205-489-2101

Southeastern District	
Barbour	334-687-4808
Butler	334-382-3154
Coffee	334-347-9574
Covington	334-222-1175
Crenshaw	334-335-2471
Dale	334-774-5146
Geneva	334-684-2256
Henry	334-585-2660
Houston	334-678-2800
Pike	334-566-2860

Southwestern District	
Baldwin	251-947-1910
Choctaw	205-459-4026
Clarke	251-275-3772
Conecuh	251-578-1952
Dallas	334-874-2550
Escambia	251-867-5765
Marengo	334-295-4205
Monroe	251-575-3109
Washington	251-847-2245
Wilcox	334-682-4515

West Central District	
Bibb	205-926-9702
Chilton	205-755-1287
Fayette	205-932-5260
Greene	205-372-9361
Hale	334-624-3018
Lamar	205-695-9195
Perry	334-683-6153
Pickens	205-367-8157
Sumter	205-652-7972
Tuscaloosa	205-562-6900
Walker	205-221-9775

ALABAMA'S EARLY INTERVENTION SYSTEM FOR INFANTS AND TODDLERS WITH DISABILITIES

Child Find is the process used in Alabama for *identifying* all children who may be eligible for services and *referring* them to Alabama's Early Intervention System. It is an important step that provides families with the guidance and support they need to make it on their own behalf.

There are three steps in the Child Find process:

1. Identification - Children who may be in need of special help are identified by parents or by individuals within the community. These individuals, agencies, or organizations may include:

- parents
- well-baby clinics
- hospital follow-up clinics
- physicians
- pediatricians' offices
- community health services
- developmental disabilities programs
- prenatal/postnatal facilities
- child day care centers
- home child day care programs
- Head Start programs
- local educational agencies
- outpatient clinics
- public health facilities
- Medicaid programs
- hospitals
- social service agencies
- other healthcare providers

Children are identified *when parents or other family* members express concern about their child's development. Children are also identified when a *service provider* suspects that there is delay in a child's development and discusses this concern with the parents. Any infant or toddler age birth to 3 years with a delay of 25 percent or more in any of the major areas of development - cognitive, physical, communication, social, emotional, or adaptive development - who lives in Alabama is eligible to receive supports and appropriate services through the state's early intervention system. Children may be identified if a child has a *diagnosed physical or mental condition* that may contribute to a developmental delay.

Once potentially eligible infants and toddlers have been identified as having a suspected or diagnosed delay, the service provider or family may make a referral to Child Find. Families need to be made aware when a service provider is making the referral.

2. Making a Referral - making a referral to Alabama's Early Intervention System is as simple as making a phone call to **Early Intervention Child Find at 1-800-543-3098** (voice/TDD). Fax-back referral forms are also available for use by doctor's offices, social workers, hospitals, etc.

If parents ask a service provider to make the referring phone call, the referral must be made no more than *two working days* after the child has been identified. Information needed to make a referral includes the child's name, sex, ethnic origin, birth date, and Social Security number, if available. Additional information needed to process the referral includes the name of the parents or guardian; the language spoken by the family; the areas of development that are of concern to the parents and professional; the name of the child's primary care physician; and acceptance/refusal of the referral to AEIS, from the family.

3. Processing of a Referral - When a call is received by Child Find, the child's name and other identifying information will be entered into the data base for follow-up by Alabama's Early Intervention System. The referral will be passed on to the local contact (known as the District Early Intervention Coordinator or DEIC) within the child's community. The coordinator will contact the child's family within a two week period to discuss Alabama's Early Intervention System and explain the evaluation process. The child and family's progress through Alabama's Early Intervention System will be monitored under the lead agency, the Alabama Department of Rehabilitation Services.

ALABAMA'S EARLY INTERVENTION SYSTEM FOR INFANTS AND TODDLERS WITH DISABILITIES

Any individual who works with young children and their families is in a unique position to help identify, at an early stage, those infants and toddlers who may need intervention. It is important that any child under the age of 3 that may have a delay in development be referred to Alabama's Early Intervention System as quickly as possible. The evaluation and assessment process for the state's early intervention system for infants and toddlers with disabilities, and their families, is free to the family. Families are also not required to pay for appropriate services for their eligible child.

If you work with young children and families, you can help them in the following ways:

- Display information about Alabama's Early Intervention System in offices, libraries, faith-based facilities and clinics. Free materials are available by simply calling **Early Intervention Child Find at 1-800-543-3098** and making a request for free AEIS materials.
- Help families monitor their children's development by helping them to understand developmental milestones.
- Act on any concerns that you have or that are expressed by parents by discussing the early intervention Child Find process with the family and helping them to make the contact if they are interested.
- Monitor the progress of an infant or toddler that may have a delay if a family is not ready to make a referral or a decision and talk to the parents at a later date if necessary.
- Nurture families who have infants and young children and understand the stress they are enduring. Provide information, guidance and support that parents may need to make informed choices during the early stages of accessing services for an eligible child.

To learn more about Alabama's Early Intervention System, contact the Early Intervention Office, located within the Alabama Department of Rehabilitation Services, at 1-800-441-7607 or visit the web site at www.rehab.state.al.us.

Alabama's Early Intervention System

Child Find Referral Form

To make a referral by phone: 1-800-543-3098
Mail to: ADRS/EI, 602 S. Lawrence St., Montgomery, AL 36104 or Fax to: Child Find Fax # (334) 293-7393
or send via email to: REHAB--Childfind@rehab.alabama.gov
For more info, please visit: http://rehab.alabama.gov/individuals-and-families/early-intervention

Please print clearly and complete all blanks - no stamps or labels

INFANT/TODDLER INFORMATION

1. SSN# (if available): _____ 2. Date of Birth: _____ 3. Sex: F ☐ M ☐

4. Last Name: _____ First Name: _____ MI/Name: _____

5. Is your child of Hispanic or Latino origin? Y ☐ N ☐ 6. Child's Primary Race: _____

* **If Primary Race is Two or More Races:** ☐Hispanic/Latino ☐American Indian/Alaska Native ☐Asian

(Mark appropriate boxes) ☐Black/African American ☐Hawaiian/Pacific Islander ☐White

7. Home Language: _____ 8. Medicaid: Y ☐ N ☐ Medicaid # _____

9. Private Insurance: Y ☐ N ☐ 10. CHIP/All Kids Y ☐ N ☐

CHILD RELATION INFORMATION

11. First Name: _____ Last Name: _____ MI: _____

12. Relation Type: _____ 13. Is this Primary relation? Y ☐ N ☐ 14. Is address same as child? Y ☐ N ☐

15. Mailing Address: _____

City/State/Zip: _____ 16. County: _____

17. Physical Address (if different from above): _____

City/State/Zip: _____ 18. County: _____

19. Primary contact #: ( ) _____ 20. Alternate contact #: ( ) _____

Alternate contact #: ( ) _____ Work Phone #: ( ) _____ Ext #: _____

Primary Contact Email address: _____

REFERRAL SOURCE INFORMATION

21. Person making referral: _____ 22. Referral Source: _____

23. County: _____ 24. Phone: _____ 25. Fax: _____

26. Reason for referral: _____

27. How family became aware of Child Find: _____ Additional Information: _____

Refer to Service Coordinator/Caseload ID # (leave blank if unknown): _____

Date Mailed/Faxed to Child Find: _____ Sender's Name/Phone #: _____

PHYSICIAN/CRNP USE ONLY

28. I certify that the child named above has a confirmed diagnosis of _____

29. Printed Name of Physician/CRNP: _____ 30. Phone #: _____

31. Signature of Physician/CRNP: _____ Today's date: _____

STATE OFFICE USE ONLY

New Case ID#: _____ SS# or T#: _____

Referral taken by: _____ Date taken: _____ Received by: ☐ phone ☐ email ☐ fax Processed by: _____ Official referral/entry date: _____

☐ ATTACHMENT: _____ ☐ Signed release of information

Revised 01/2019

Alabama's Early Intervention System (AEIS) – Child Find Referral Info Sheet

IMPORTANT NOTE: Question #'s 2 through 7 and 11 through 27 are required information

INCOMPLETE REFERRALS WILL NOT BE ACCEPTED (FILL IN ALL REQUIRED BLANKS)

1. Please provide the SS# if available, however, if the number is unavailable we can assign a pseudo number in order to process the referral.

5. Please answer either yes or no. We cannot process the referral without this information.

6. Enter the primary race that the family identifies. If the child is of multiple races, check all boxes that apply.
American Indian or Alaska Native – A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment. (Does not include persons of Hispanic/Latino ethnicity)
Asian – A person having origins in any of the original peoples of the Far East, Southeast Asia, or Indian subcontinent. This includes for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam. (Does not include persons of Hispanic/Latino ethnicity)
Black or African American – A person having origins in any of the Black racial groups of Africa. (Does not include persons of Hispanic/Latino ethnicity)
Hispanic or Latino - A person Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race.
Native Hawaiian or Other Pacific Islander - A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands. (Does not include persons of Hispanic/Latino ethnicity)
White - A person having origins in any of the original peoples of Europe, the Middle East, or North Africa. (Does not include persons of Hispanic/Latino ethnicity)
Two or More Races – A person having origins in two or more of the six race categories listed immediately above. (Does not include persons of Hispanic/Latino ethnicity)

7. If the family is multi-lingual and English is one of the languages spoken, please enter English. If English is not spoken in the home, please enter the language spoken so that an interpreter can be obtained, if needed.

8. Not required, but please enter if available.

11. Enter the first and last name of the primary caregiver of which the child lives with.

12. How is this person that the child lives with related to the child? (mother, father, aunt, foster parent, etc.)

13. Is the person named the child's primary caregiver?

14. Does the child live with the person named?

15. Enter the address where correspondence for this child should be sent.

17. Where does the family live (if different from mailing address)? This determines which program will serve the child.

19. Provide all available contact information for the family.

21. The name of the person making this referral.

22. The organization affiliated with the person making the referral or description of who that person is (for example, Children's Hospital, ABC Therapy Company, DPS, grandfather).

23. -25. Demographic and contact information for the referral source.

27. Who told the family about Early Intervention? Please choose one of the following:
Agency, APC Parenting Kit, Audiologist, Certified Registered Nurse Practitioner, Child Care, Developmental Follow Up Clinic, Doctor, Early Head Start, EI Program, EI Recipient's family, Head Start, Healthy Child Care Alabama, High Risk Clinic, Hospital, Hurricane Katrina Evauee, Interpreter, Media, Military, Nurse-Family Partnership, Other, PA Materials, Parent Assistance Line (PAL), Parent (Previously Received EI Services), Receiving Service in Other State, Relative/Friend, School System, Self, Social Media (Facebook, Twitter, Etc.), Social Worker, SSA, Therapist, Web Site
In additional information, please enter any other information that may be useful in helping us serve this child. Please enter when this referral was sent to Child Find and who sent it along with their phone number so that we can call if there are any questions.

28. This section can only be completed by a physician or nurse practitioner who is making the referral. In order to expedite eligibility determination, a physician/nurse practitioner can provide documentation of any diagnoses the child may have. We must have the physician/nurse practitioner's name and signature along with the diagnosis.

Revised 11/2017

CHILDREN'S REHABILITATION SERVICE

Any child or adolescent younger than 21 years of age who is a resident of Alabama and has a special health care need is eligible for CRS. CRS provides specialty medical services to include medical clinics, evaluation clinics, medication, equipment, therapies, hospitalizations, and surgeries as well as support for families.

Calhoun County – Anniston CRS 1910 Coleman Road, Anniston, AL 36207 Phone: 256-240-8801 or 1-800-289-9533 Counties: Calhoun, Cherokee, Clay, Cleburne, St. Clair, Talladega	**Jefferson County - Homewood CRS** 234 Goodwin Crest Drive, Birmingham, AL 35209 Phone: 205-290-4550 or 1-888-430-7423 Counties: Cullman, Jefferson, Shelby, Walker
Clarke County – Jackson CRS 1506 College Avenue, Jackson, AL 36545 Phone: 251-246-4025 or 1-800-283-8140 Counties: Choctaw, Clarke, Monroe, Washington	**Lee County – Opelika CRS** 516 W. Thomason Circle, Opelika, AL 36801 Phone: 334-745-7579 or 1-800-568-8428 Counties: Chambers, Lee, Macon, Randolph, Russell, Tallapoosa
Colbert County – Muscle Shoals CRS 714 State Street, Muscle Shoals, AL 35661 Phone: 256-381-4047 or 1-800-285-9924 Counties: Colbert, Franklin, Lauderdale, Lawrence, Marion, Winston	**Madison County – Huntsville CRS** 3000 Johnson Road, Huntsville, AL 35805 Phone: 256-650-1701 or 1-800-283-8140 Counties: Jackson, Limestone, Madison, Marshall, Morgan
Covington County – Andalusia CRS 1082 Village Square Drive, Suite 2, Andalusia, AL 36420 Phone: 334-222-5558 or 1-800-723-8064 Counties: Butler, Conecuh, Covington, Crenshaw	**Montgomery County – Montgomery CRS** 602 South Lawrence Street, Montgomery, AL 36104 Phone: 334-293-7500 or 1-800-568-9034 Counties: Autauga, Bullock, Chilton, Coosa, Elmore, Lowndes, Montgomery, Pike
Dallas County – Selma CRS 720 Alabama Avenue, Selma, AL 36701 Phone: 334-877-2900 or 1-800-967-6876 Counties: Dallas, Marengo, Perry, Wilcox	**Mobile County – Mobile CRS** 1610 Center Street, Suite A, Mobile, AL 36604 Phone: 251-432-4560 or 1-800-879-8163 Counties: Baldwin, Escambia, Mobile
Etowah County – Gadsden CRS 1100 George Wallace Drive, Gadsden, AL 35903 Phone: 256-547-8653 or 1-800-289-1353 Counties: Blount, DeKalb, Etowah	**Talladega County – Talladega CRS** office closed – clients referred to Anniston
Houston County – Dothan CRS 795 Ross Clark Circle NE, Suite 3, Dothan, AL 36303 Phone: 334-699-6600 or 1-800-677-9123 Counties: Barbour, Coffee, Dale, Geneva, Henry, Houston	**Tuscaloosa County – Tuscaloosa CRS** 1400 James I. Harrison, Jr. Parkway East, Suite 100 Tuscaloosa, AL 35405 Phone: 205-562-1802 or 1-800-723-0490 Counties: Bibb, Fayette, Greene, Hale, Lamar, Pickens, Sumter, Tuscaloosa

CHILDREN'S REHABILITATION SERVICE MAP



ALABAMA COMMUNITY BASED SICKLE CELL ORGANIZATIONS

The Alabama NBS Program refers all infants identified with sickle cell trait and sickle cell disease to one of the local Community-Based Sickle Cell Organizations. Genetic counseling is offered to these families.

Organization	Address & Phone	Counties
Sickle Cell Disease Association of America Central Alabama Chapter Service Area I	3813 Avenue I Ensley Birmingham, AL 35218 205-780-2355 Fax: 205-780-2368 www.sicklecellbham.org	Blount, Calhoun, Cherokee, Clay, Cleburne, Cullman, Etowah, Jefferson, Randolph, Shelby, St. Clair, Talladega, Walker
Sickle Cell Disease Association of America West Alabama Chapter Service Area II	3011 5th Street Northport, AL 35476 205-758-1761 Fax: 205-758-1781	Bibb, Fayette, Green, Hale, Lamar, Marion, Pickens, Sumter, Tuscaloosa, Winston
Sickle Cell Foundation of Greater Montgomery, Inc. Service Area IV	3180 US Highway 80 West P.O. Box 9278 Montgomery, AL 36087 334-286-9122 Fax: 334-286-4804 www.riverregionsicklecell.com	Autauga, Butler, Chambers, Chilton, Coffee, Coosa, Crenshaw, Dallas, Elmore, Lowndes, Montgomery, Tallapoosa, Wilcox
Southeast Alabama Sickle Cell Association Service Area V	P.O. Box 1079 Tuskegee, AL 36087 334-727-6120 www.seasca.com	Barbour, Bullock, Dale, Geneva, Henry, Houston, Lee, Macon, Marengo, Perry, Pike, Russell
Sickle Cell Disease Association of America Mobile Chapter, Inc. Service Area VI	P.O. Box 40696 1453 Springhill Avenue Mobile, AL 36604 251-432-0301 www.scdaamobile.org	Baldwin, Choctaw, Clarke, Conecuh, Covington, Escambia, Mobile, Monroe, Washington
North Alabama Sickle Cell Foundation, Inc. Service Area VII	P.O. Box 813 Huntsville, AL 35804 256-536-2723 1-800-636-2723 Fax: 256-536-2714 www.sicklecellna.org	Colbert, DeKalb, Franklin, Jackson, Lauderdale, Lawrence, Limestone, Madison, Marshall, Morgan

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ALABAMA NEWBORN SCREENING TIMELINE

1964 PKU

1978 Congenital Hypothyroidism

1987 Hemoglobinopathies

1992 Galactosemia

1994 Congenital Adrenal Hyperplasia

1997 Voice Response System (VRS)

04/2004 Biotinidase Deficiency

10/2004 **Amino Acid Disorders:**
Citrullinemia (CIT)
Homocystinuria (HCY)
Maple Syrup Urine Disease (MSUD)
Tyrosinemia (TYR)
Argininosuccinate aciduria (ASA)

Organic Acid Disorders:
Propionic Acidemia (PROP)
Methylmalonic Acidemia
(Vitamin B12 Disorders) (CBL, A,B)
Methylmalonic Acidemia
(methylmalonyl-CoA mutase) (MUT)

Fatty Acid Disorders:
Medium chain acyl-CoA dehydrogenase deficiency (MCAD)
Carnitine Uptake Defect (CUD)

10/2006 **Organic Acid Disorders:**
Glutaric Acidemia (GA-1)
Isovaleric Acidemia (IVA)
Multiple carboxylase (MCD
3-Hydroxy 3-methylglutaric Aciduria (HMG)

04/2007 **Fatty Acid Disorders:**
Very long chain acyl-CoA dehydrogenase deficiency (VLCAD)
Long chain 3-hydroxyacyl-CoA dehydrogenase deficiency (LCHAD)
Trifunctional Protein Deficiency (TFP)

Organic Acid Disorders:
3-Methylcrotonyl-CoA carboxylase (3-MCC)
Beta ketothiolase (BKT)
Carnitine palymitoyltranferase II (CPT II)

2008 Voice Response System replaced with Secure Remote Viewer

01/2008 Universal Newborn Hearing Screening*

04/2008 Cystic Fibrosis (CF) (IRT/DNA)

2009 Cord Blood collection and testing discontinued

06/2013 Critical Congenital Heart Disease (CCHD)

10/2018 Severe Combined Immunodeficiency (SCID)

2/2022 Spinal Muscular Atrophy (SMA)

3/2023 X-linked Adrenoleukodystrophy (X-ALD)

7/2024 **Lysosomal Storage Disorders:**
Mucopolysaccharidosis Type I (MPS I)
Pompe

***started voluntarily in 2001/mandated 2008**

ALABAMA NBS CONFIRMED DISORDERS

Genetic Disorders	2018	2019	2020	2021	2022	2023*
Biotinidase Deficiency	2	2	1	1	2	1
Classical Galactosemia	1	2	2	1	1	1
Cystic Fibrosis	10	14	17	16	15	13
Hearing Loss	113	84	119	105	90	64
Critical Congenital Heart Disease	1	1	1	0	0	1
Severe Combined Immunodeficiencies (SCID)	--	0	0	0	0	0
X-Linked Adrenoleukodystrophy (X-ALD)	--	--	--	--	--	0
Spinal Muscular Atrophy	--	--	--	--	2	2
Endocrine Disorders						
Congenital Hypothyroidism	38	49	49	63	62	62
Congenital Adrenal Hyperplasia	6	6	5	0	4	1
Hemoglobinapathy						
Sickle Cell Disease	58	59	50	60	60	46
Sickle Cell Trait	1798	1992	1996	1885	1792	1375
Amino Acid Disorders						
Phenylketonuria	4	3	2	4	7	2
Homocystinuria	0	0	0	0	0	0
Maple Syrup Urine Disease (MSUD)	0	0	0	0	0	0
Citrullinemia	0	0	0	0	0	0
Tyrosinemia	0	0	0	0	0	0
Arginosuccinic Aciduria (ASA)	0	0	0	0	2	
Fatty Acid Disorders						
Carnitine Uptake Defect	1	0	1	1	0	2
Medium chain Acyl-CoA Dehydrogenase Deficiency (MCAD)	5	2	1	6	6	3
Long chain Acyl-CoA Dehydrogenase Deficiency (LCAD)	0	0	0	0	0	0
Very long chain Acyl-CoA Dehydrogenase Deficiency (VLCAD)	0	3	1	0	0	1
Trifunctional Protein Deficiency	0	0	0	0	0	1
Organic Acid Disorders						
Glutaric Acidemia	0	0	0	0	0	1
Isovaleric Acidemia	0	0	0	0	1	1
Propionic Acidemia	0	0	1	1	1	0
Methylmalonic Acidemia (MMA)	1	0	2	0	0	0
3-Methylcrotonyl-CoA Carboxylase Deficiency (3-MCC)	1	1	1	1	1	2

*data for 2023 approximate pending final diagnosis

PUBLIC HEALTH LAWS OF ALABAMA

Section 22-20-3

Neonatal testing for certain diseases; rules and regulations for treatment thereof.

(a) It shall be the duty of the administrative officer or other persons in charge of each institution caring for infants 28 days or less of age, or the physician attending a newborn child or the person attending a newborn child that was not attended by a physician to cause to have administered to every such infant or child in his care a reliable test for hypothyroidism and a reliable test for phenylketonuria (PKU), such as the Guthrie test, or any other test considered equally reliable by the State Board of Health and a reliable test for sickle cell anemia, sickle cell trait, and/or abnormal hemoglobin and such other tests relating to mental retardation or other heritable diseases and conditions as are designated by the Board of Health. Provided, however, that the Board of Health shall designate only conditions that are detectable by mass screening of newborn infants. Initial mass screening tests and the recording of results shall be performed by the Public Health Laboratory at such times and in such manner as may be prescribed by the State Board of Health; confirmatory tests shall be undertaken by such laboratory facilities as are designated by the attending physician or parent; provided, that no such initial screening or confirmatory tests shall be given to any child whose parents object thereto on the grounds that such tests conflict with their religious tenets and practices. In the event a test is not given to a child on account of such objections by the parents, then no physician, nurse, laboratory technician, person administering tests, hospital, institution or other health care provider shall be liable for failure to administer the test.

(b) The State Board of Health shall promulgate such rules and regulations as it considers necessary to provide for the care and treatment of those newborn infants whose tests are determined positive, including but not limited to, advising dietary treatment for such infants. The State Board of Health shall promulgate any other rules and regulations necessary to effectuate the provisions of this section including the collection of a reasonable fee for the newborn child screening program.

(Acts 1965, No. 885, p. 1664; Acts 1979, No. 79-437, p. 703; Acts 1987, No. 87-672, p. 1202; Acts 1991, 1st Ex. Sess., No. 91-793, p. 188, §1.)

ALABAMA STATE BOARD OF HEALTH ADMINISTRATIVE CODE

ALABAMA STATE BOARD OF HEALTH
ALABAMA DEPARTMENT OF PUBLIC HEALTH
BUREAU OF FAMILY HEALTH SERVICES
ADMINISTRATIVE CODE

CHAPTER 420-10-1
CARE AND TREATMENT OF INFANTS IDENTIFIED THROUGH THE NEWBORN SCREENING PROGRAM

TABLE OF CONTENTS

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420-10-1-.01 Purpose.

The purpose of these rules is to provide administrative details and procedures for the care and treatment of newborns identified with phenylketonuria, hypothyroidism, galactosemia, congenital adrenal hyperplasia, hearing loss, hemoglobinopathy, biotinidase deficiency, cystic fibrosis, aminoacidopathies, fatty acid oxidation disorders, organic acidurias and acidemias, critical congenital heart disease, severe combined immunodeficiency, spinal muscular atrophy, x-linked adrenoleukodystrophy, lysosomal storage disorders, and other heritable diseases.

Authors: P. Scott Harris, M.D., Thomas M. Miller, M.D., Lucinda G. Ashley, R.N.-B.C., Rachael N. Montgomery, B.S.N., R.N. **Statutory Authority:** Code of Ala. 1975, §§ 22-2-2, 22-20-3. **History:** Filed December 21, 1987. **Amended:** Filed September 18, 2002; effective October 23, 2002. **Repealed and New Rule:** Filed December 17, 2003; effective January 21, 2004. **Amended:** Filed December 17, 2007; effective January 21, 2008. **Amended:** Filed May 17, 2013; effective June 21, 2013. **Amended:** Filed January 19, 2017; effective March 5, 2017. **Amended:** December 15, 2021; effective February 13, 2022.

420-10-1-.02 Definitions.

(a) **Phenylketonuria** - A congenital disease due to a deficit in the metabolism of the amino acid phenylalanine.

(b) **Hypothyroidism** - A deficiency of thyroid gland activity with underproduction of thyroxin or the condition

resulting from it.

(c) **Hemoglobinopathy** - Any hemoglobin phenotype which is other than AA.

(d) **Physician of Record** - The physician who requests the test.

(e) **Galactosemia** - An inherited error in the metabolism of galactose.

(f) **Congenital Adrenal Hyperplasia** - an inherited error in steroid biosynthesis.

(g) **Hearing Loss** - the total or partial inability to hear sound in one or both ears.

(h) **Biotinidase Deficiency** - inherited deficiency caused by the lack of an enzyme involved in biotin synthesis.

(i) **Amino Acid Disorders** - inherited disorders in amino acid metabolism.

(j) **Fatty Acid Oxidation Disorders** - inherited disorders in fatty acid metabolism.

(k) **Organic Acid Disorders** - inherited disorders in organic acid metabolism.

(l) **Cystic Fibrosis** - inherited disorder caused by a defective protein (cystic fibrosis transmembrane regulator) involved in the salt balance of the body.

(m) **Critical Congenital Heart Disease (CCHD)** - a subset of congenital heart defects characterized by a diminished availability of oxygen to the body tissues that causes severe and life-threatening symptoms and requires intervention within the first days or first year of life.

(n) **Severe Combined Immunodeficiency (SCID) and Related T-cell Lymphocyte Deficiencies** - a group of rare inherited immune disorders in which T lymphocytes are either absent or compromised.

(o) **Licensed midwife** - a practitioner who holds a certified professional midwife credential and is licensed by the Alabama State Board of Midwifery to practice midwifery.

(p) **Spinal Muscular Atrophy (SMA)** - a rare genetic disorder caused by spinal motor neuron gene change.

(q) **X-Linked Adrenoleukodystrophy (X-ALD)** - a genetic_ disease that affects the nervous system and the adrenal glands.

(r) **Lysosomal Storage Disorders** - inherited metabolic diseases that are characterized by an abnormal build-up of various toxic materials in the body's cells as a result of enzyme deficiencies.

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Statutory Authority: Code of Ala. 1975, §§ 22-2-2, 22-20-3.
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420-10-1-.03 Designation of Additional Heritable Diseases.

The State Board of Health hereby designates the following as a heritable disease subject to testing, reporting, and notification requirements herein below specified. Phenylketonuria, hypothyroidism, galactosemia, congenital adrenal hyperplasia, hearing loss, hemoglobinopathy, biotinidase deficiency, cystic fibrosis, aminoacidopathies, fatty acid oxidation disorders and organic acidurias and acidemias, CCHD, SCID, SMA, X-ALD, lysosomal storage disorders, and other heritable disorders.

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Statutory Authority: Code of Ala. 1975, §§ 22-2-2, 22-20-3.
History: Filed December 21, 1987; **Amended:** Filed September 21, 1992; effective October 26, 1992. **Repealed and New Rule:** Filed December 17, 2003; effective January 21, 2004. **Amended:** December 17, 2007; effective January 21, 2008. **Amended:** Filed May 17, 2013; effective June 21, 2013. **Amended:** Filed January 19, 2017; effective March 5, 2017. **Amended:** December 15, 2021; effective February 13, 2022.

420-10-1-.04 Reporting and Notification.

(1) The Alabama Department of Public Health shall report all results of phenylketonuria, hypothyroidism, galactosemia, congenital adrenal hyperplasia, hearing loss, hemoglobinopathy, biotinidase deficiency, cystic fibrosis, aminoacidopathies, fatty acid oxidation disorders, organic acidurias and acidemias, CCHD, SCID, SMA, X-ALD, lysosomal storage disorders, and other

heritable disease testing to the submitting health care provider. Test results on transferred infants may be made available to both the transferring and receiving facilities.

(2) The submitting health care provider shall report all results, including positives, suspected positive results, and unsatisfactory specimens, to the physician of record (the physician indicated on the collection form) of the newborns tested and shall use such forms and follow such guidelines as shall be determined by the State Health Officer. The health care provider shall report the results of any hearing tests performed on the newborns to the Alabama Department of Public Health and shall use such forms and follow such guidelines as shall be determined by the State Health Officer.

(3) The Alabama Department of Public Health may release results of newborn screening tests, including hearing screening results, to any physician registered with the Secure Remote Viewer under the terms and conditions of the system without a signed release from the parent or guardian.

(4) The submitting health care provider shall screen all newborns in well baby nurseries for CCHD using pulse oximetry and shall use such forms and follow such guidelines as shall be determined by the State Health Officer.

(5) The submitting health care provider shall report the results of any failed pulse oximetry screening results to the Alabama Department of Public Health and shall use such forms and follow such guidelines as shall be determined by the State Health Officer.

(6) A licensed midwife must refer all newborns in his or her care to a licensed physician within 24 hours of age to perform Newborn Screening Tests which include: 1) bloodspot specimen tests; 2) newborn hearing screening tests; and 3) pulse oximetry screening tests. The licensed midwife must instruct the client regarding the requirements of the administration of these newborn health screening tests by the Alabama Department of Public Health.

Authors: P. Scott Harris, M.D., Thomas M. Miller, M.D., William J. Callan, Ph.D., Sharon P. Massingale,Ph.D., Aretha M. Williams,Ph.D., Lucinda G. Ashley, R.N.-B.C., Rachael N. Montgomery, B.S.N., R.N.
Statutory Authority: Code of Ala. 1975, §§ 22-2-2,22-20-3.
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2002; effective October 23, 2002. **Repealed and New Rule:** Filed December 17, 2003; effective January 21, 2004. **Amended:** December 17, 2007; effective January 21, 2008. **Amended:** Filed May 17, 2013; effective June 21, 2013. **Amended:** Filed January 19, 2017; effective March 5, 2017. **Amended:** Filed July 19, 2018; effective September 2, 2018. **Amended:** December 15, 2021; effective February 13, 2022.

420-10-1-.05 Counseling and Management.

(a) The Alabama Department of Public Health shall make contact with the physician of record and the parent/guardian of newborns who test positive for phenylketonuria, hypothyroidism, galactosemia, congenital adrenal hyperplasia, hearing loss, hemoglobinopathy, biotinidase deficiency, cystic fibrosis, aminoacidopathies, fatty acid oxidation disorders, organic acidurias and acidemias, CCHD, SCID, SMA, X-ALD, lysosomal storage disorders, and other heritable disorders to notify them of positive test results and ascertain whether or not these newborns are under the care of a private physician. Additionally, the Alabama Department of Public Health shall make contact with the physician of record and the parent/guardian to advise them of the services available through the Alabama Department of Public Health. Newborns who are under the care of a private physician may additionally utilize these same services. The Alabama Department of Public Health may make contact with the family to make their services available or may assist the family in obtaining the services of a private physician. Services include health assessments, treatment, and referrals to tertiary care centers.

(b) The Alabama Department of Public Health shall make contact with the submitting health care provider of newborns with failed pulse oximetry results to verify that appropriate screening, referral, and intervention services have been provided and if needed, may assist in obtaining the services. Services include health assessments, treatment, and referrals to tertiary care centers.

Authors: P. Scott Harris, M.D., Thomas M. Miller, M.D., William J. Callan, Ph.D., Sharon P. Massingale,Ph.D., Aretha M. Williams,Ph.D., Lucinda G. Ashley, R.N.-B.C., Rachael N. Montgomery, B.S.N., R.N.
Statutory Authority: Code of Ala. 1975, §§ 22-20-3.
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420-10-1-.06 Fees.

The Board shall assess and collect newborn screening fees from hospitals and birthing centers or third party payors. The newborn screening fee shall be set by the State Committee of Public Health based on the schedule of laboratory fees established by the Centers for Medicare and Medicaid Services (CMS) for use by Medicare and Medicaid. The Board shall bill the Medicaid Agency for Medicaid eligibles.

(1) Hospitals classified as "rural" by CMS or which have less than 105 beds and are located at least twenty (20) miles from the nearest acute care facility with obstetrical capabilities may have newborn screening fees waived for non-Medicaid eligible patients where there is no third party payor for such fees. The State Health Officer shall annually submit a list of hospitals to the Board which are eligible for waiver of fees.

(2) Additional reasonable and necessary fees may be charged to other payors by the hospital or physician in connection with this rule. The State Health Officer may waive fees deemed uncollectible because of a patient's inability to pay.

(3) There shall be only one (1) fee per birth collected from a hospital by the Board.

Authors: Lloyd Hofer, M.D., William J. Callan, Ph.D.
Statutory Authority: Code of Ala. 1975, §§ 22-20-3.
History: Filed February 19, 1992. **Amended:** Filed September 21, 1992; effective October 26, 1992. **Repealed and New Rule:** Filed December 17, 2003; effective January 21, 2004.

ACT SHEETS



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