

Newborn Screening Reference Manual for Medical Providers 2010

# Alabama Newborn Screening Program Staff

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# The 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 Program establishes protocol to ensure early identification and follow-up of infants affected with certain genetic or metabolic conditions. Early diagnosis may reduce morbidity, premature death, mental retardation and other developmental disabilities. The program works in partnership with pediatric specialists throughout the state to ensure all babies identified with abnormal results receive appropriate follow-up.

The program also seeks to expand relationships with other health professionals including hospitals and pediatricians in the state to enhance existing services and assure objectives are met. Additionally, there are seven community-based Sickle Cell Organizations who provide counseling and follow up for children identified with sickle cell disease or sickle cell trait, as well as two certified Cystic Fibrosis (CF) Care Centers that provide CF care.

The Alabama Newborn Screening Hearing 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 the Alabama Early Intervention System(AEIS) to ensure all infants are identified with hearing loss by three months of age and enrolled in AEIS before six months of age.

The Alabama Bureau of Clinical Laboratories (BCL) is the sole provider for blood analysis for the initial newborn screen. The BCL screens approximately 60,000 babies each year. The BCL also provides filter paper forms for screening to medical providers.

# HIPAA

The Alabama Newborn Screening Program contacts health providers daily, and sometimes providers are unsure if information may be shared due to HIPAA regulations. Please read the notice provided by the ADPH General Counsel regarding HIPAA guidelines related to newborn screening.

### MEMORANDUM

TO: ALABAMA NEWBORN SCREENING PROVIDERS

FROM: John R. Wible General Counsel HIPAA Privacy Officer

In light of HIPAA, concerns have been raised regarding sharing information with the Alabama Department of Public Health regarding newborn screenings. <u>Exchange of information</u> regarding newborn screenings 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 screenings 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. <u>Ala. Admin. Code</u> 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.

# Alabama NBS Panel of Disorders

There are twenty-eight disorders currently part of the Alabama Newborn Screening Panel of Primary Disorders and over fifty total disorders including secondary conditions. Please see appendix for a brief description and timeline of each disorder.

CURRENT: (As of Nov 23, 2009) 3-Methylcrotonyl-CoA Carboxylase Deficiency 3-OH 3-CH3 Glutaric Aciduria Argininosuccinic Acidemia Beta-ketothiolase Deficiency **Biotinidase Deficiency Carnitine Uptake Defect** Citrullinemia **Classical Galactosemia Congenital Adrenal Hyperplasia Congenital Hypothyroidism** Cystic Fibrosis (IRT/DNA) **Glutaric Acidemia** Hearing Loss Hemoglobin S/beta-thalassemia Hemoglobin SC Disease Hemoglobin SS Disease Homocystinuria Isovaleric Acidemia Long-chain L-3-OH Acyl-CoA Dehydrogenase Deficiency Maple Syrup Urine Disease Medium-chain Acyl-CoA Dehydrogenase Deficiency Methylmalonic Acidemia Methylmalonic Acidemia due to mutase deficiency Multiple Carboxylase Deficiency Phenylketonuria **Propionic Acidemia Trifunctional Protein Deficiency** Tyrosinemia Type 1 Very Long-chain Acyl-CoA Dehydrogenase Deficiency

# Medical Provider Responsibilities in Newborn Screening



- > mail as long as the provider is identified on the specimen collection form
- > immediate phone call and mail for potential positives and/or abnormal results

### Ex: **TSH≥60** and **CAH≥150**

- 1. <u>Medical providers are responsible for verifying newborn screening results and should not</u> <u>assume the newborn screen is normal if they are not notified</u>. Please utilize Alabama's Voice Response System (AVRS) to obtain newborn screening results.
  - Provider information may be missing or inaccurate on form
  - Specimens may be lost in the mail
  - Hospitals may fail to collect a newborn screen prior to hospital discharge or transfer
- 2. <u>Medical providers are responsible for ensuring that the infant receives an initial newborn screen</u> including a hearing screen immediately.
  - Please mark the filter form *First Test* only after assuring that no first test was collected by the birthing facility
  - Please use the pink sheet attached to filter form for recording hearing results
- 3. <u>Medical providers are encouraged to consult with an appropriate specialist if needed in order to</u> <u>develop a plan of action for necessary testing and evaluation</u>.
- 4. <u>Medical providers are encouraged to collect a repeat newborn screen as soon as possible if the first test is unsatisfactory</u>.
- 5. <u>Medical providers are responsible for ensuring that the recommended hearing screening</u> <u>method is used for rescreening of infants who fail an initial screen</u> (see page 36).
- 6. <u>Medical providers are responsible for obtaining a signed statement for parent refusal of</u> <u>newborn screening</u>. A newborn screening collection form should be filled out completely with a statement as to the refusal and mailed to the State Laboratory.
- 7. Medical providers are encouraged to collect a second newborn screen at two-six weeks of age.

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The Newborn Screening Program encourages consultation with the following medical specialists for recommendations regarding follow-up or if there are questions about abnormal test results.

Disorders:	Specialists:						
<ul> <li>Endocrine</li> <li>Congenital Adrenal Hyperplasia (CAH)</li> </ul>	<ol> <li>USA Medical Center, Endocrinology Anne Marie Kaulfers, MD 251-405-5147</li> </ol>						
<ul> <li>Congenital Hypothyroidism (CH)</li> </ul>	Christina Hair, RN <b>251-434-3723</b>						
	2. Children's Hospital, Endocrinology Gail Mick, MD <b>205-939-9107</b>						
	Leslie Pitts, CRNP 205-996-9166						
Hemoglobinopathies	1. USA Sickle Cell Center						
• Sickle cell disease, trait conditions and	Felicia Wilson, MD 251-405-5147	3)					
other hemoglobinopathies	Stephanie Durgin, RN 251-415-5172						
	2. Children's Hospital, Pediatric Hematolog	ξγ					
	Thomas Howard, MD <b>205-939-9285</b>						
	Sharon Carlton, RN 205-558-2390						
Cystic Fibrosis	1. USA CF Care Center						
	Lawrence Sindel, MD 251-343-6848						
	2. UAB CF Care Center						
	Hector Gutierrez, MD 205-939-9583						
	Staci Self, LGSW <b>205-939-5494</b>						
Metabolic	1. UAB Genetics						
<ul> <li>Phenylketonuria (PKU)</li> </ul>	S. Lane Rutledge, MD <b>205-975-6867</b>						
Galactosemia	Maria Descartes, MD 205-934-1154						
Biotinidase	Alicia Roberts, RD <b>205-996-6983</b>						
Amino, Fatty and Organic Disorders							
Metabolic Disorders screened by	ADPH NBS Program:						
Amino Acid Disorders:							
argininosuccinic acidemia							
citrullinemia							
homocystinemia							
maple syrup urine disease							
<ul> <li>phenylketonuria (PKU)</li> </ul>							
Fatty Acid Oxidation Disorders:							
carnitine uptake defect							
long chain 3-hydroxyacyl-CoA dehydrog	•						
medium chain acyl-CoA dehydrogenase	deficiency						
trifunctional protein deficiency							
<ul> <li>very long chain acyl-CoA dehydrogenase</li> </ul>	aeticiency						
Organic Acid Disorders:							
<ul> <li>beta-ketothiolase deficiency</li> <li>glutaric acidemia</li> </ul>							
<ul> <li>glutaric acidemia</li> <li>isovaleric acidemia</li> </ul>							
<ul> <li>proprionic acidemia</li> </ul>	methylmalmonic acidemia     proprionic acidemia						
<ul> <li>armsthylcrotonyl-CoA carboxylase defic</li> </ul>	ency						
	ency						

# Alabama Voice Response System



The AVRS provides 24-hour, 7 days a week telephone reporting of newborn screening results in 30 seconds or less directly through a toll free number, **1-800-566-1556**, and has the capability of providing you with a faxed copy of the results.

The Alabama Voice Response System (AVRS) requires pre-registration with the Alabama Newborn Screening Program and positive identification of the caller through two security checks. Physicians are prompted by the system to enter their state license number (preceded by zeros, if needed, in order to make a seven-digit number) and a four-digit personal identification number or PIN.

### **HOW DO I REGISTER?**

Physicians may register with the system by completing the registration form found on the Alabama Department of Public Health website, <u>http://www.adph.org/newbornscreening/</u>, or the following page and returning it to the following address:

Alabama Department of Public Health Attention: Wendy Caraway P.O. Box 303017 RSA Tower - Suite 1350 Montgomery, Alabama 36130-3017 wendy.caraway@adph.state.al.us

### HOW DO PHYSICIANS GET A PIN?

Each physician chooses his/her individual four-digit PIN and records the number on the pre-registration form. The PIN must be four numeric characters. It is the responsibility of each physician to safeguard his/her PIN. Do not allow unauthorized access to your confidential number. If a PIN is ever lost, stolen, forgotten, or if a physician suspects someone has gained access to it, immediately call the Newborn Screening Program at **334-206-7065** and a new PIN will be assigned.

### HOW DOES THE SYSTEM WORK?

Physicians must have available the mother's social security number <u>or</u> specimen kit number found on the filter paper collection form preceded by the year of the infant's birth. Information is provided by recorded voice messages. The infant's name and date of birth are spelled and verified by user response before any results are given. Information is provided concerning the need for repeat testing or medical follow-up along with the test result.

# Alabama Voice Response System Registration Form

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Participating physicians must complete and return this form in order to register for the automated Alabama Newborn Screening Voice Response System (AVRS).

(PLEASE PRINT)
Name of Physician
Name of Facility
Mailing Address
Area Code/Telephone Number
Area Code/Fax Number
E-Mail Address
Physician's State License Number
Personal Identification Number(PIN)
Signature of Physician
Please fax or mail to:
Wendy Caraway Alabama Department of Public Health P.O. Box 303017 201 Monroe Street RSA Tower, Suite 1350 Montgomery, Alabama 36130-3017 Fax: 334-206-3063
If you have any questions please call 334-206-7065 or 1-866-928-6755

# Newborn Screening Brochure Order Form

. . .

Hospital/Practice Name: _						
			mplete name)			
Mailing Address:						
Mailing Address:	(No	P.O. Boxes	please)			
City/Zip Code:						
Telephone:						
Contact Person:						
Brochure Number: *Please see below for Englis www.adph.org/newbornscr	sh versions of the I	NBS Brochu	ires or visit our			
Name of Brochure:						_
Quantity Requested (com	es in packets of 2	100):				_
*Please use a sepa	rate order fo	orm for	each brocl	hure or	dered*	
Please call, fax or e-m 334-206-7065 (phone 334-206-3063 (fax) wendy.caraway@adp	)	orm to W	/endy Caraw	vay at:		
FHS-223	FHS-534		FHS-536		FHS-533	
NEWBORN geneening	NEWBORN geneening Contenting		Newborn Horac Jackson De weit bestellt Heren Bestellt Heren Bestellt Heren Bestellt		NEWBORN screening	
ABRICO	ADPI I®		ADPH		ADPH®	

# Newborn Screening Refusal Form

The American Academy of Pediatrics and the Alabama Department of Public Health strongly recommend Newborn Screening for all infants

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 have been provided information about newborn screening in my state and the importance of early identification of the disorders. I have 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.
The risks and benefits of newborn screening.
<ul> <li>If my child does not participate in newborn screening, the consequences of a late diagnosis</li> </ul>
may include <u>delayed development</u> , <u>mental retardation</u> , or <u>death</u> .
<ul> <li>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.</li> <li>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.</li> </ul>
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 have had the opportunity to re-discuss my decision not to participate in my state's newborn screening program and still decline the recommended participation.

# Alabama Birthing Hospitals

### As of 2010, Alabama has 54 birthing hospitals listed below in birth rank order.

	<u>2010 Birth #</u>		<u>2010 Birth #</u>
Huntsville Hospital	5159	Helen Keller Memorial Hospital	737
UAB Hospital	3810	DeKalb Regional Medical Center	721
St. Vincent's Hospital	3589	South Baldwin Regional Medical Center	640
Brookwood Medical Center	3479	Springhill Memorial Hospital	637
Baptist Medical Center East	3432	UAB Medical West	628
USA Children & Women's Hospital	2808	Trinity Medical Center	619
Providence Hospital	1858	Russellville Hospital	556
DCH Regional Medical Center	1700	Decatur General Hospital	534
East Alabama Medical Center	1676	Athens Limestone Hospital	489
Northport Hospital	1581	Russell Hospital	457
Southeast Alabama Medical Center	1574	Coosa Valley Medical Center	440
Flowers Hospital	1343	Andalusia Regional Hospital	432
Jackson Hospital	1324	Princeton Baptist Medical Center	423
Northeast AL Regional Medical Center	1272	Parkway Medical Center	415
Mobile Infirmary Medical Center	1178	Cooper Green Hospital	361
St. Vincent's East	1165	Jacksonville Regional Medical Center	360
Gadsden Regional Medical Center	1160	Citizens Baptist Medical Center	359
Shebly Baptist Medical Center	1156	Highlands Medical Center	353
Thomas Hospital	1114	George H. Lanier Memorial Hospital	337
Eliza Coffee Memorial Hospital	1017	D.W. McMillan Memorial Hospital	316
Medical Center Enterprise	909	Marshall Medical Center North	306
Cullman Regional Medical Center	895	Bryan W. Whitfield Memorial Hospital	258
Marshall Medical Center South	869	Monroe County Hospital	245
Crestwood Medical Center	851	North Baldwin Infirmary	231
Baptist Medical Center South	849	Jackson Medical Center	165
Walker Baptist Medical Center	780	Crenshaw Community Hospital	153
Vaughan Regional Medical Center	771	Grove Hill Memorial Hospital	102

# Newborn Screening Specimen Collection

# The following pages provide information regarding specimen collection

Alabama Bureau of Clinical Laboratory Notice Please see this notice of changes made to the protocol for testing specimens received by the Newborn Screening Laboratory. Hemoglobinopathy Instructions for "B" Filter Forms Please see the instructions for completing the "B" filter form when hemoglobinopathy testing is needed. Lessons Learned: NBS Collection Please see these helpful tips for improving specimen collection that were noted at the NBS Coordinator Conference held August 2009. Alabama Bureau of Clinical Laboratory NBS Collection Guidelines Please see the Newborn Screening Collection Guidelines for the approved method of blood collection by the Alabama Bureau of Clinical Laboratories. Sick Infant Blood Collection Protocol Changes (March 25, 2010) The Newborn Screening protocol for premature or sick infants has been recently updated by the Alabama Newborn Screening Advisory Committee. Please see the protocol for recent changes. Whatman<sup>®</sup> Neonatal Screening Reference Form Please see this reference form to review steps for blood collection and handling procedure. Whatman<sup>®</sup> Simple Spot Check Reference Form Please see this reference form to review examples and possible causes of invalid or unsatisfactory results. Newborn Screening Provider Update Form Please see the Provider Update Form if your contact information has changed. Filter Paper Reorder Form Please see the Filter Paper Reorder Form to order newborn screening specimen kits.

# **ONE DROP** ONE CIRCLE **ONE TIME**



STATE OF ALABAMA DEPARTMENT OF PUBLIC HEALTH Donald E. Williamson, M.D.+ State Health Officer

BUREAU OF CLINICAL LABORATORIES Sharon P. Massingale, Ph.D., HCLD(ABB) + Director

November 4, 2009

Dear Health Care Providers:

Effective November 9, 2009, the protocol for testing specimens received in the Newborn Screening (NBS) Laboratory at the Bureau of Clinical Laboratories will be as follows:

1. The "initial" or "first test" specimen will have the following test panel performed:

T4, TSH, CAH, Galactosemia, IRT (CF), Biotinidase, Amino Acid Profile, Fatty Acid Profile, Organic Acid Profile, and Hemoglobinopathy.

2. The "repeat" or "second test" specimen will have the following test panel performed:

T4, TSH, CAH, Galactosemia, IRT (CF), Biotinidase, Amino Acid Profile, Fatty Acid Profile, and Organic Acid Profile.

Note: Hemoglobinopathy testing <u>will not</u> be routinely performed on the "repeat" or "second test" specimen unless a repeat test is requested by the Newborn Screening (NBS) Laboratory.

Proper collection techniques are imperative to ensure that every specimen that is received in the NBS laboratory can be tested for all disorders. NBS forms should be completed and legible. Accuracy of testing and evaluation of results are dependent on the sample and information that is received.

Please call Danita Rollin, Deannie Morris, or Lynn Green with any questions at 334-260-3400.

Sincerely,

Sharon P. Massingale, Ph.D., HCLĎ(ABB) Laboratory Director Bureau of Clinical Laboratories

SPM/VL

# Alabama Newborn Screening Premature or Sick Infant Blood Collection Protocol

# November 2, 2010

The following Newborn Screening protocol for premature or sick infants 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 recommendations 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 Laboratory.

It is recommended that when collecting Newborn Screening blood samples involving premature or sick infants, who have been admitted to the NICU for five days or longer, the following protocol be used:

# Premature or Sick Infants-

- The first Newborn Screen Specimen is to be collected when infant is admitted to the NICU. \* (Prior to transfusions)
- The second (B form sample) Newborn Screen Specimen is to be collected between 5-7 days of age or prior to discharge if discharge is to be at less than 5 days of age. (At least 72 hours post transfusions)
- If on TPN at time of second NBS, collect the third NBS specimen 2 days after TPN is discontinued or upon discharge from NICU, whichever comes first.
- In very low birth-weight infants (less than 2000 grams), hypothalamic immaturity could obscure meaningful TSH elevations so T4/TSH levels are recommended between 4-12 weeks.

\*(Note: If the infant is admitted to the NICU and the expected stay is **less than 5 days**, the specimen should be collected according the well baby collection protocol.)

Alabama Department of Public Health Bureau of Clinical Laboratories 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, Hypothyroidism, CAH, Galactosemia, Abnormal Hemoglobin's, Biotinidase, Amino Acid Disorders, Fatty Acid Disorders and Organic Acid Disorders 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, Hemoglobinopathies, Biotinidase Deficiency, Amino Acid Disorders, Fatty Acid Disorders, and Organic Acid Disorders.

Full Term	A newborn screening test should be collected when the infant is 24-48
Infants	hours of age and on adequate protein feeding for > 24 hours. If the infant is discharged
	prior to 24 hours of age or feeding < 24 hours, 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 is collected at 24-48 hours of age.
Extended	It is recommended that a specimen be collected upon admission to the NICU if the infant
Hospital Stay	is expected to receive TPN or transfusions unless the infant is so unstable that it cannot
(low birth	be done safely. For further information, a copy of the Alabama Newborn Screening
weight/sick infants)	collection is attached.
Transitioning	Infants admitted to NICU for short term observation but are not receiving TPN or
Infants	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	A specimen should be collected prior to transfusion regardless of age or treatments
Infants	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, and Galactosemia. If a Galactosemia condition is suspected and the
	specimen was not collected prior to transfusion, place the infant on a lactose-free diet
	until a definitive diagnosis can be made.
Transferred	The transferring facility must collect a specimen prior to transfer regardless of age or
Infants	treatments unless the baby is so unstable that is 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.
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Parents         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.           Second Test ("g" form) – This specimen is tested for Hemoglobinopathies. If no valid test has been done for this disorder, please see instructions below for collection of requested repeat specimens.           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 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 usatifactory for testing, a repeat test should be collected as soon as possible. The "Retest-Prior Abnormal" box must be marked on the collection form.           3. Ory sterile gauze pads           3. Dry sterile gauze pads           4. Sterile sticking device with a point not greater than 2.4 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 sits		
<ul> <li>as to the refusal and malled to the State Laboratory.</li> <li>Second Test ("B" form) – This specimen is tested for Hypothyroidism, CAH, Amino Acid Disorders, Forty Acid Disorders, Organic Acid Disorders, Cystic Fibrosis, Biotridase, and Galactosemia.</li> <li>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.</li> <li>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.</li> <li>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.</li> <li>If the first test specimen was collected after two weeks of age, a second ("B") specimen need NOT be collected.</li> <li>Requested Repeat ("B" form)</li> <li>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.</li> <li>If the first test specimes hould be collected in the time frame indicated by the report. The "Retest-Prior Unsat" box must be marked on the collection form.</li> <li>If diversite a subatisfactory for testing, a repeat test should be collected as soon as possible. The "Retest-Prior Unsat" box must be marked on the collection form.</li> <li>Gloves</li> <li>Dry sterile gauze pads</li> <li>Sterile sixing device with a point not greater than 2.4 mm in depth (the most effective method is the use of scalpel bladed lancets)</li> <li>Newborn Screening filter paper collection form (CL-89) with protective envelope</li> <li>Bleeding Procedure:</li> <li>The preferred puncture site is indicated by the shaded areas on the heel. The leas</li></ul>		under this condition should sign a statement that is placed in the infant's medical record.
<ul> <li>Fatty Acid Disorders, Organic Acid Disorders, Cystic Fibrosis, Biotinidase, and Galactosemia.</li> <li>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.</li> <li>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.</li> <li>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.</li> <li>If the first test specimen was collected after two weeks of age, a second ("B") specimen need NOT be collected.</li> </ul> Requested Repeat ("B" form) <ol> <li>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. 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: <ul> <li>Gloves</li> <li>Sterile sticking device with a point not greater than 2.4 mm in depth (the most effective method is the use of scalpel bladed lancets)</li> <li>Newborn Screening filter paper collection form (CL-89) with protective envelope</li> </ul> Bleeding Procedure: <ul> <li>Warm the infant's foot if necessary using warm water, towel, or chemical pack. Heat sources should not exceed 42" cand should not be left in contact with the skin for a prolonged period. </li> <li>Disinfect the skin with alcohol pads and allow to air dry. Vigorous rubbing during this step stimulates blood flow to the area.</li> <li>Wipe away and discard the first drop</li></ul></li></ol>		
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fluid.	4.	
6. Allow the second drop of blood to form by the spontaneous free flow of blood.	5.	
	6.	Allow the second drop of blood to form by the spontaneous free flow of blood.

### **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 and place them 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 <u>unsatisfactory</u> specimens or erroneous test results.

1. Do not touch any part of the filter paper circles before, during, or after collection.

Improperly prepared blood spots and failure to complete the information form accurately constitute a major problem for the testing laboratory. Good blood spot preparation will assure prompt and accurate testing.

- 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 indicate any medications that may affect test results.
  - b) Mark the proper feeding status.
  - c) Always note any transfusions of red blood cells.
- 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 or 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.

# Completing the Demographic Data

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.



### Newborn Screening "B" form

	(First	() Me	dical Record #	Infant's Medicaid #		1-
Birthdate Time of Birt		lbs oz. [	Single Birth		1001	1
		east TPN Date	nsfused R White Asian Me (Military) First Tes	Black Hispanic Other t Routine Second Test	NS SCRE	/-
Mother (Last)	Infant's	Age (First)	(M) Retest - Prior Ur	nsat Prior Abnormal (Requested by State)	ENING INF	
Mother's Social Security Number	r Mother's Medica	id Number	Mother's Pl	hone Number Mother's Age	1072 IS 2012-04	1-
City	County		State	Zip	INSTRU	١.
Physician (Last) Physician's Phone Number	(First)	(M) Notes Birth			CIONS ON	1
			The Rec (1977 - Double)	A BREED A SHIPPING A CON	BACKO	`-
MD					FTHIS	1
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		-	
1	Name field – enter the patient's last name and first	2	Medical Record field – enter the patient's medical record
	name (if applicable)		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	4	Birth date field – enter the birth date in the format
	applicable		MM/DD/YY (required field)
5	Time of Birth field – enter in military format, failure to	6	Birth Weight field – enter the infant's birth weight in pounds
	use military format may result in erroneous test results		and ounces. If the infant is more than one month of age, enter the
	since many lab tests are based on the age of the infant		current weight. The laboratory sets standards and cutoffs for some
	at the time of collection.		tests using weight. Indicating the weight helps to ensure accurate test results and eliminate the need for unnecessary repeat
			specimens.
7	Multiple Births field – if this birth is a multiple birth	8	Gestational Age field – enter the gestational age as
	(twins, triplets, etc.), check the multiple		number of completed weeks
9	<b>Sex field</b> – Mark the check box M for male or F for	10	Date of 1 <sup>st</sup> Feeding field – enter the date of the first
	female		protein feeding. This includes TPN feeding.
11	Time of Feeding field – enter the time of the first	12	Type feeding field – mark the box beside the appropriate
	protein feeding in military format.		feeding type. Feeding type refers to the type of nutrition that the
			infant is receiving. If the infant is receiving more than one type of
			feeding, mark all that apply.
13	Infant's age field – enter the infant's age at the time of	14	Transfused field – mark the box if the infant has ever received a
	specimen collection.		transfusion of red blood cells. Enter the date of the last transfusion
			prior to specimen collection in the format MM/DD/YY and the time of the last transfusion prior to specimen collection in military
			format. The date and time of transfusion are important for the
			laboratory to determine whether the test results are valid. Failure
			to indicate transfusions can result in an infant with a detectable
			disorder being missed due to the presence of donor cells in the
	<b>• • • • • • • • • •</b>		newborn screening specimen.
15	Race field – mark the appropriate box for the infant's	16	<b>Type of test fields</b> – mark the "First Test" box if the
	race		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. Including
			the lab number of the previous test will help to ensure that
			the appropriate tests are ordered.
17	Mother's information fields – enter the mother's	18	Physician fields – enter the full name and phone number
	information in the appropriate fields. <i>Mother's social</i>		of the physician who will be providing direct care after
	security number should be entered accurately. This will		discharge. There are many physicians with the same last
	allow the submitting facility to access test results more		name and therefore cannot always be identified by last
	readily and ensures that infants needing immediate		name only. The physician listed on the collection form
	follow-up can be located quickly.		becomes the physician-of-record and will be contacted by
			the laboratory in the event of an abnormal test result.
			Responsibility for follow-up remains with the physician of
			record until another practitioner actively accepts it. All
			physicians should be registered in the State Laboratory data base to ensure timely receipt of test reports.
19	<b>Home birth field</b> – check the home birth box if the	20	<b>Hearing field</b> – On the "A" form enter the date that the
19	infant was born outside of the birthing facility with a	20	hearing screen was performed in the format MM/DD/YY and
	birthing attendant present.		check the appropriate boxes to indicate the results of the
	Shanny attendant present.		hearing screen and the testing method used. On the "B"
			form the hearing data will be entered on the pink form.
21	Submitter field – enter the name and address of the	22	Lab use field - Do not write or place labels in this area. This
	facility submitting the specimen. Do not use		space is used by the laboratory to attach a unique
	abbreviations as there are facilities with similar names.		identification number to the specimen for use in the
	An address label may be attached in this area as long as		laboratory.
	it does not obscure any other fields or hang off of the		
	edge of the form.		
		L	

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13.02

# Hemoglobinopathy Repeats

If a repeat Hemoglobinopathy (Hgb) is needed, please complete the "B" filter form by:

- 1. Marking Retest-Prior Abnormal (Requested by State)
- 2. Writing Hgb as shown below

Note: Hgb testing will not be routinely performed on the "repeat" or "second test" specimen unless a repeat test is requested by the Alabama Newborn Screening Laboratory.

\*Regarding home births: If you are aware that an infant was born outside of a hospital setting for any reason, it is your responsibility to ensure that the infant receives an initial newborn screen and newborn hearing screen immediately. If you use the B filter paper, please mark the box indicating a first test, and you may use the pink sheet to record hearing screen results.

Personal sector and the sector and t		ENING PROGRAM	Monigoniery, AL 50124-401	8 STATE LAB	(334) 260-3400	
Patient	(Last)	(First)	Medical Record #	Infant's Medicaid #	긑	12. 100
Birthdate Date of 1 <sup>st</sup> Feeding Date of Collection	Time of Birth (Military) Time of 1 <sup>st</sup> Feeding (Military Time of Collection (Military) Time of Collection	Birth Weight (Current WT. if >         Ibs.         Type Feeding       Soy         Breast       TPN         Regular       Other         Infant's Age	oz.   Multiple Birth:   A		Other	SPECIME SHOULD E COMPLETELY BEFORE COVI
Mother	(Last)	(First)	(M)	Reest - Prior Unsat	bnormal	$\square \bigcirc$
Mother's Social Se	curity Number Moth	er's Medicaid Number			er's Age	BIOHAZA
City		County	State	Zip	STR	NO BLOO
City					and the second se	ON FLAP
City Physician (Last) Physician's Phone Nun	(First)	(M) Home Birth E	Notes:		2	ON FLAF FLAP MUS REMAIN INT.
Physician (Last)	ber	Home -		DO NOT WRITE IN THIS B	ON BAC	FLAP MUS

# Lessons Learned: NBS Collection



Newborn Screens can have dramatic impact to the welfare of the infant and the family, and it is important to understand the significance of screening both from a medical outcome and a legal liability standpoint. Here is a summary of best practices that Alabama hospital staff found helpful in improving specimen collection at their facility.

- Storage of the filter paper both pre-use and post-use can be 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 paper at room temperature and room humidity. Post-use storage should be in keeping with NBS lab guidance (©ID Biological Systems Report).
- 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).
- Limit the number of people allowed to actually draw NBS blood to a very few, <u>well</u> <u>trained</u> individuals to reduce unsatisfactory specimens (AlabamaNBS Coordinator Conference 2009).
- 4. Track the performance of these collectors and re-train or substitute as necessary if unsatisfactory or invalid results occur (Alabama NBS Coordinator Conference 2009).
- 5. Perform a quality control inspection of all specimens before mailing them to the NBS lab. At a minimum check for the following:
  - Complete and correct demographic information
  - Complete and correct NBS hearing test information
  - Record who collected the sample
  - Confirm results are received on each specimen submitted

If you believe you are having issues with specimen collection, please contact the NBS State Health Laboratory at 334-260-3400.



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



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.



areas for puncture site.

# Whatman® Part of GE Healthcare

# Neonatal Screening

Blood Specimen Collection and Handling Procedure



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





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



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



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.

Information provided by The New York State Department of Health.



B 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.

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REGERT GUTARIE, MD	DOG, JANE
BURFALO	



Dry blood spots on a dry, clean, flat, nonabsorbent surface for a minimum of four hours.



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

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

# Simple Spot Check

Invalid specimen:

# 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.

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### Possible causes:

I. Specimen quantity insufficient for testing.	<ul> <li>Removing filter paper before blood has completely filled circle or before blood has soaked through to second side.</li> <li>Applying blood to filter paper with a capillary tube.</li> <li>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.</li> </ul>
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.	<ul><li>Applying excess blood to filter paper, usually with a device.</li><li>Applying blood to both sides of filter paper.</li></ul>
5. Specimen appears diluted, discolored or contaminated.	<ul> <li>Squeezing or "milking" of area surrounding the puncture site.</li> <li>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.</li> <li>Exposing blood spots to direct heat.</li> </ul>
6. Specimen exhibits serum rings.	<ul> <li>Not wiping alcohol from puncture site before making skin puncture.</li> <li>Allowing filter paper to come into contact with alcohol, hand lotion, etc.</li> <li>Squeezing area surrounding puncture site excessively.</li> <li>Drying specimen improperly.</li> <li>Applying blood to filter paper with a capillary tube.</li> </ul>
<b>0-0 0-0 0</b> 7. Specimen appears clotted or layered.	<ul><li>Touching the same circle on filter paper to blood drop several times.</li><li>Filling circle on both sides of filter paper.</li></ul>
	Failure to obtain blood specimen.

8. No blood.

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 677011 • 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 Information provided by The New York State Department of Health.

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BUREAU OF CLINICAL LABORATORIES SHARON P. MASSINGALE, PH.D., HCLD(ABB) • 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 8140 AUM Drive, Zip 36117-7001 P.O. Box 244018, Zip 36124-4018 Montgomery, AL

FAX (334) 260-3439

Name of Hospital or Doctor:

Street/Shipping Address ONLY No P.O. Box:

City, State, and Zip Code:

Telephone Number:

Signature and Title:

Number of "A" (first test) Newborn Screening Kits Requested:

\*Note "A" forms are sent to Hospitals and Birthing Centers only.

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

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

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

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### STATE OF ALABAMA DEPARTMENT OF PUBLIC HEALTH Donald E. Williamson, M.D.+ State Health Officer

BUREAU OF CLINICAL LABORATORIES SHARON P. MASSINGALE, PH.D., HCLD(ABB) • DIRECTOR

### <u>M E M O R A N D U M</u>

TO: Health Care Providers

**FROM:** Newborn Screening Division Bureau of Clinical Laboratories

SUBJECT: Newborn Screening Provider Update

In order to provide more efficient service in providing newborn screening forms we are updating our provider list. It would be of a great assistance to us if you would fill out the following information and return it as soon as possible to:

> ALABAMA DEPARTMENT OF PUBLIC HEALTH Bureau of Clinical Laboratories Newborn Screening Division P.O. Box 244018 Montgomery, AL 36124-4018 FAX (334) 260-3439

Thank you for your prompt attention to this matter.

Group or Name of Practice:

Street/Shipping Address ONLY No P.O. Box:

City, State, and Zip Code:

Telephone Number:

Approximate Number of Specimens per Month:

NAMES OF ALL PHYSICIANS THAT SEND NEWBORN SCREENING SPECIMENS:
# Newborn Hearing

# The following pages provide information regarding newborn hearing

#### Newborn Hearing Screening

Please see the Newborn Hearing Screening information if there are questions regarding hearing loss and testing methods.

#### Guidelines for Pediatric Medical Home Providers

Please see the hearing screen algorithm for appropriate referral and follow up.

### Audiological Evaluation Form

Please see the audiological evaluation form to report newborn hearing results for outpatient/diagnostic testing.

### Children's Rehabilitation Service (CRS) Hearing Clinics

Please see the directory for CRS Hearing Clinics in Alabama to obtain an appointment for newborns who fail the initial hearing screen in the hospital.

# Newborn Hearing Screening

#### What is hearing loss?

There are two main types of hearing loss:

- 1. <u>Conductive hearing loss</u> 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.
- 2. <u>Sensorineural hearing loss</u> occurs when there is damage to the inner ear. This may be caused by diseases, birth injury, toxic drugs, viruses, or genetic syndromes.

In addition, there are various degrees of hearing loss. They include mild, moderate, severe, and profound hearing loss. It is important to note that milder hearing losses or hearing losses that affect only one ear may not be apparent. Thus, it is important to follow up even though a baby may appear to hear normally.

#### Why should a baby's hearing be screened?

Statistics show that between one to three newborns per 1000 have some degree of hearing loss. Although these statistics indicate that it is unlikely that a baby will have a hearing loss, if there is one, it is important that you know about it as soon as possible. The first two years of a baby's life are critical for learning speech and language. It is important to diagnose hearing problems early because a hearing loss could affect a baby's speech and language development.

#### 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.

- <u>Auditory Brainstem Response</u> (ABR) determines the infant's ability to hear soft sounds by inserting miniature earphones and attaching electrodes to measure brain-wave responses to the sound in order to determine if the sounds are heard normally. This diagnostic testing is recommended for high risk newborns admitted to the NICU greater than five days by the Joint Committee on Infant Hearing (JCIH) and should be completed as a second test method if an infant is initially tested with ABR.
- 2. <u>Otoacoustic emissions</u> (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 screening?

If a baby does not pass the first screening an attempt may be made to repeat the screening before a baby goes home, or it may be scheduled after going home. Different types of hearing tests will be recommended if a baby does not pass the second screening. It is recommended that all testing be completed by 3 months of age, and infants with hearing loss be enrolled in appropriate intervention services as early as possible, but no later than 6 months of age.

# Early Hearing Detection and Intervention (EHDI) Guidelines for Pediatric Medical Home Providers



Tudiologica	l Evaluation
Baby's Name:	Date of Birth:
Birthing Hospital:	Medical ID#:
Parent or Guardian Contact Information:	Baby's Primary Care Physician
Name:	Name:
Address:	Address:
Phone:	Phone:
Outpatient Screening Facility:	
Name:	Date of Referral:
Address:	
	Phone:
Hearing Screening Results Attached:	Yes No
Results: Right Ear Pass	Refer
Left Ear Pass	Refer
Date of Screening:	Technology Used:
To the Screening Facility: Please complete the reve	erse side of this form and return to:
Alabama Department of Public Health Newborn Hearing Screening Program	
P.O. Box 303017 Montgomery, Alabama 36130-3017	
Phone: (334) 206-2944 Fax: (334) 206-3063	

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## Results of Diagnostic Audiological Evaluation

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		Name of Child
	Right Ear	Left Ear
Normal Hearing		
Conductive Loss		
Sensorineural Loss Mild		
Moderate		
Severe		
Profound		
Date of evaluation		
Diagnostic Evaluation Donort	Attachod. Vo	No
Diagnostic Evaluation Report	Attached: Ye	s No
Diagnostic Evaluation Report . Comments:	Attached: Ye	s No
	Attached: Ye	s No
Comments:	Attached: Ye	Please return form when initial diagnos
Comments:	Attached: Ye	Please return form when initial diagnos audiological evaluation is completed to Alabama Department of Public Health Newborn Hearing Screening Program
Comments:	Attached: Ye	Please return form when initial diagnos audiological evaluation is completed to Alabama Department of Public Health

## Children's Rehabilitation Service (CRS) Office Locations

CRS is part of the Alabama Department of Rehabilitation Services (ADRS). There are multiple sites across the state offering the preferred follow up screening method of AABR. Parents may choose the site that is most convenient for them. **Please see the list below to obtain an appointment for the <u>CRS Hearing Assessment Clinic</u>**. This clinic is for newborns who fail the initial hearing screen. For other hearing providers in Alabama that offer this method of hearing screening or OAE hearing screening, please see our website at <u>www.adph.org/newbornscreening</u>.

Calhoun County – Anniston CRS	Jefferson County - Homewood CRS
1010 Christine Avenue, Suite 250	234 Goodwin Crest Drive
Anniston, AL 36207	Birmingham, AL 35209
Phone: 256-235-3050 or 1-800-289-9533	Phone: 205-290-4550 or 1-888-430-7423
Clarke County – Jackson CRS	Lee County – Opelika CRS
1506 College Avenue	516 W. Thomason Circle
Jackson, AL 36545	Opelika, AL 36801
Phone: 251-246-4025 or 1-800-283-8140	Phone: 334-749-8339 or 1-800-568-8428
Colbert County – Muscle Shoals CRS	Madison County – Huntsville CRS
1450 E. Avalon Avenue	3000 Johnson Road
Muscle Shoals, AL 35661	Huntsville, AL 35805
Phone: 256-381-1212 or 1-800-285-9924	Phone: 256-650-1701 or 1-800-283-8140
Covington County – Andalusia CRS	Montgomery County – Montgomery CRS
1082 Village Square Drive, Suite 2	602 South Lawrence Street
Andalusia, AL 36420	Montgomery, AL 36104
Phone: 334-222-5558 or 1-800-723-8064	Phone: 334-293-7500 or 1-800-568-9034
Dallas County – Selma CRS	Mobile County – Mobile CRS
2906 Citizens Parkway	1610 Center Street, Suite A
Selma, AL 36701	Mobile, AL 36604
Phone: 334-872-8422 or 1-800-967-6876	Phone: 251-432-4560 or 1-800-879-8163
Etowah County – Gadsden CRS	Talladega County – Talladega CRS
1100 George Wallace Drive	7 Bemiston Avenue
Gadsden, AL 35903	Talladega, AL 35160
Phone: 256-547-8653 or 1-800-289-1353	Phone: 256-362-9254 or 1-800-947-7140
Houston County – Dothan CRS	Tuscaloosa County – Tuscaloosa CRS
795 Ross Clark Circle NE	1110 Sixth Avenue East
Dothan, AL 36303	Tuscaloosa, AL 35401
Phone: 334-699-6600 or 1-800-677-9123	Phone: 205-759-1279 or 1-800-723-0490

# Resources

# The following pages provide local resources to help you in choosing appropriate follow-up services

### Alabama County Health Departments

Not all county health departments perform newborn screens. Please see the Alabama County Health Department Clinic Directory for a list of health department clinics that offer newborn screening.

#### Alabama Early Intervention System (AEIS)

AEIS Child Find is Alabama's statewide effort to locate, identify and evaluate children 0-3 years of age that may have special needs and may benefit from supports and services. Please see the information provided on AEIS to make a referral if needed.

### Children's Rehabilitation Service (CRS)

CRS offers specialty clinics such as hearing clinics to anyone younger than 21 years of age who is a resident of Alabama and has a special health care need. CRS staff members also work closely with local school systems to enable children with special health care needs to participate fully in school.

### Community-Based Sickle Cell Organizations (CBSCO)

CBSCO offer additional testing and counseling services aimed at educating sickle cell patients and their families about sickle cell disease. Please see the directory of local sickle cell organizations to make a referral if needed.

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# Public Health Area Map



# Alabama County Health Department Clinic Directory

PHA 1	Winston County*	205-489-2101	PHA 7	Wilcox County*	334-682-4515
	Franklin County*	205-332-2700		Choctaw County	205-459-4026
	Walker County*	205-221-9775		Dallas County	334-874-2550
	Colbert County	256-383-1231		Hale County	334-624-3018
	Lauderdale County	256-764-7453		Lowndes County	334-548-2564
	Marion County	205-921-3118		Marengo County	334-295-4205
	-			Perry County	334-683-6153
				Sumter County	205-652-7972
PHA 2	Madison County*	256-539-3711	PHA 8	Chilton County*	205-755-1287
	Cullman County**	256-734-1030		Autauga County	334-361-3743
	Marshall County**	256-582-3174		Bullock County	334-738-3030
	Jackson County	256-259-4161		Elmore County	334-567-1171
	Lawrence County	256-974-1141		Lee County	334-745-5765
	Limestone County	256-232-3200		Macon County	334-727-1800
	Morgan County	256-353-7021		Montgomery County	334-293-6400
				Russell County	334-297-0251
PHA 3	Lamar County**	205-695-9195	PHA 9	Butler County*	334-382-3154
11110	Greene County**	205-372-9361		Baldwin County	251-947-1910
	Bibb County	205-926-9702		Clarke County	251-275-3772
	Fayette County	205-932-5260		Conecuh County	251-578-1952
	Pickens County	205-367-8157		Covington County	334-222-1175
	Tuscaloosa County	205-562-6900		Escambia County	251-867-5765
	Tuscaloosa county	203 302 0700		Monroe County	251-575-3109
				Washington County	251-847-2245
PHA 4	Jefferson County*:		PHA 10	Henry County*	334-585-2660
1 1111 1	Bessemer Health Center	205-497-9300	111110	Geneva County*	334-684-2259
	Central Health Center	205-933-9110		Barbour County	334-687-4808
	West End Health Center	205-715-6121		Coffee County	334-347-9574
	Eastern Health Center	205-591-5180		Crenshaw County	334-335-2471
	Morris Health Center	205-933-4242		Dale County	334-774-5146
	Western Health Center	205-788-3321		Houston County	334-678-2800
	Western neurin Genter			Pike County	334-566-2860
PHA 5	Blount County	205-274-2120	PHA 11	Mobile County*:	551 500 2000
FIIAJ	Cherokee County	256-927-3132	FIIA II	Keeler, Main Site	251-690-8158
	Dekalb County	256-845-1931		Semmes Clinic	251-445-0582
	Etowah County	256-547-6311		Calcedeaver Clinic	251-829-9884
	St. Clair County	205-338-3357		Citronelle Clinic	251-866-9126
	Shelby County	205-664-2470			251-456-1399
	Shelby County	205-004-2470		Eight Mile Clinic Newburn Clinic	251-405-4525
				Mount Vernon Clinic	251-403-4323
	Class Cause <b>5</b> **	256 206 6421	4 C		251-025-4002
PHA 6	Clay County**	256-396-6421	-	s newborn screenings	
	Randolph County*	334-863-8981	performe occusionally		
	Calhoun County	256-237-7523			
	Chambers County	334-756-0758	Some HD	have EPSDT MOUs with loc	al
	Cleburne County	256-463-2296	physician	s to perform screens for the	m.
	Coosa County	256-377-4364		-	
	Talladega County	256-362-2593			
	Tallapoosa County	256-329-0531			



What is Alabama's Early Intervention System for Infants and Toddlers With Disabilities and Their Families?

## What is Early Intervention?

Early intervention is a coordinated, family-focused system of resource access, supports and services for eligible infants and toddlers, ages birth to 3 years who have developmental delays. Alabama's Early Intervention System (AEIS) is a statewide system that offers eligible families the opportunity to receive appropriate services, including assistive technology, audiology, family therapy, nursing, nutrition, occupational therapy, psychological services, service coordination, special instruction, social work, speech language pathology, medical services, transportation, vision and health services, and physical therapy.

The Alabama Early Intervention System is supported by federal, state and private funding sources. Services for eligible children are provided in natural environments and in the family's community.

## What is Developmental Delay?

The term *developmental delay* means that a child is not growing as expected, physically and/or mentally. For example, infants and toddlers may be delayed in walking, talking, speaking, learning or understanding.

When a child has a developmental delay, it can affect the whole family, and parents may face uncertainty about their child's future. Alabama's Early Intervention System helps families learn about resources, supports and services that are available and how to care for the child who has special needs.

## How Does Alabama's Early Intervention System Work?

The Alabama Early Intervention System is a statewide effort of many parents and service providers. *Providers* may work in hospitals, daycare centers, state agencies, clinics or special programs. They may be nurses, doctors, social workers, nutritionists, teachers, service coordinators or others who are concerned about a child's development and want to help both the child and his or her family.

State agencies in Alabama that are directly involved in Alabama's Early Intervention System include Alabama Department of Public Health, Children's Rehabilitation Service, Alabama Headstart, Department of Mental Health/Mental Retardation, Alabama Institute for Deaf and Blind, Alabama Medicaid Agency, Alabama Insurance Department, Department of Transportation, Department of Human Resources, and the State Department of Education.

All of these agencies work together with the lead agency, the Alabama Department of Rehabilitation Services, and with other service providers and families to establish and coordinate the statewide system. The agency heads, their support personnel and others meet often to advise and assist the lead agency through the Governor's Interagency Coordinating Council. This council meets quarterly in Montgomery, and all who are interested are welcome to attend.

## How Does the Early Intervention System Work in Your Community?

In Alabama, parents and other family members of infants and toddlers with developmental delays are directly involved with the service providers in the care of their young child. Parents and family members may also become involved with groups called *district coordinating councils*, where interested individuals meet to get to know each other, to share information about resources and specific services within their own community, and to learn more about the statewide Early Intervention System. Coordination within the council and community can help families understand what resources are available for their family and meet other parents who may have similar interests.

Alabama's Early Intervention System provides evaluation and assessment to identify early intervention supports and services for a particular child and family. Once the child has been evaluated and is found to be eligible, service providers, including a service coordinator, help the family develop an Individualized Family Service Plan (IFSP) that describes what supports and services are appropriate. Services that are outlined on the IFSP can be provided to the child and family in the family's home, at a daycare center or in other natural environments within the family's community.

### What is AEIS Child Find?

Child Find is Alabama's statewide effort to locate, identify and evaluate children who may have special needs and may benefit from supports and services. Anyone may receive referral information or find out about available resources for infants and toddlers ages birth to 3 years by calling the toll-free AEIS Child Find number 1-800-543-3098. For children over 3, contact your local school system or the State Department of Education.

To begin the process, family members who contact AEIS Child Find will be asked a few simple questions:

- What is the child's name, birth date and social security number?
- What is the name, phone number and address of the parent or guardian?
- What is your name, phone number and address?
- What is the reason for calling Child Find?

Many parents call Child Find, but some choose to ask a service provider they already know to make the call.

How Can Families and Providers Learn More About Alabama's Early Intervention System?

Throughout Alabama, district early intervention coordinators and community organizations work to reach more parents, family members and service providers. For more information, call the toll-free number, 1-800-543-3098. Web access is also available at <u>www.rehab.state.al.us</u>.

For more information contact: Alabama's Early Intervention System Alabama Department of Rehabilitation Services 602 South Lawrence Street Montgomery, AL 36104 (334) 293-7500 • 1-800-543-3098 • TTY 1-800-499-1816 Fax: 334-293-7393



www.rehab.state.al.us

This information is available in alternate format upon request.

Date Mailed/Faxed to Child INCC		STATE OFFICE USE ON	•	
			e #: (FILL IN ALL REQUIRED B	BLANKS)
Refer to Service Coordinato	r/Caseload ID #:			
27. How family became awar	re of Child Find:	Addit	ional Information:	
26. Reason for referral:				
23. County:	24. Phone	e:	25. Fax:	
21. Person making referral:		22.	Referral Source:	
	REFERRAL	L SOURCE INFORMAT	ION	
		(	)	Ext #:
19. Home Phone: ( )	20	). Alternate Phones: (	)	
City/State/Zip:			18. County:	
17. Physical Address:				
City/State/Zip:			16. County:	
15. Mailing Address:				
12. Relation Type:	13. Is this Primar	ry relation? Y N	_ 14. Is address same as ch	ild'? Y N
11. First Name:		RELATION INFORMA Name:	TION	MI:
9. Insurance: YN				
7. Home Language:				
	_		lawaiian/Pacific Islander	U White
If Primary Race is Two or (Mark appropriate boxes)	More Races: 📋 Hispanio		merican Indian/Alaska Native	_
	_	_	Child's Primary Race:	_
			MI/Name:	
			n: 3	
	1-800 En Espan Child Fin www.r INFANT/	nd Referral Form 0-543-3098 101: 1-866-450-2838 d Fax # (334) 293-7: rehab.state.al.us/ei TODDLER INFORMAT	ION	

#### <u> Alabama Early Intervention System – Code Info Sheet</u>

#### REQUIRED

#### Question # 5 - Is your child of Hispanic/Latino origin? (Must answer Yes or No)

#### Question #6 - Child's Primary Race

- 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)

#### Question #7 - Child's Home Language

1 - American Sign Language 2 - Spanish 3 - Asian 4 - English 5 - Other

Question # 8 - Medicaid: If you know the Medicaid #, please insert in provided space.

Question # 12 - Relation Type - Refers to the person that the child is residing with. (Example: Mother)

#### Question #27 - How Family Became Aware of Child Find

- 1 Agency 2 APC Parenting Kit 3 Child Care 4 Therapist 5 Doctor 6 EI Programs
- 7 Web Site 8 Relative/Friend 9 High Risk 10 PA Materials 11 Media 12 Healthy Child Care
- AL 13 Hospital 14 SSA 15 EI in Other State 16 Parent (Child in EI before)
- 17 EI Recipient's Family 18- Dev. Follow-Up Clinic 19 Interpreter
- 20 Certified Registered Nurse Practioner 21 PAL (Parenting Assistance Line) 22 Other

#### Question #16, #18, and #23 - County Code

		<u> </u>		
01	Autauga	22 Cullman	43 Lowndes	64 Walker
02	Baldwin	23 Dale	44 Macon	65 Washington
03	Barbour	24 Dallas	45 Madison	66 Wilcox
04	Bibb	25 DeKalb	46 Marengo	67 Winston
05	Blount	26 Elmore	47 Marion	
06	Bullock	27 Escambia	48 Marshall	
07	Butler	28 Etowah	49 Mobile	
08	Calhoun	29 Fayette	50 Monroe	
09	Chambers	30 Franklin	51 Montgomery	
10	Cherokee	31 Geneva	52 Morgan	
11	Chilton	32 Greene	53 Perry	
12	Choctaw	33 Hale	54 Pickens	
13	Clarke	34 Henry	55 Pike	
14	Clay	35 Houston	56 Randolph	
15	Cleburne	36 Jackson	57 Russell	
16	Coffee	37 Jefferson	58 Saint Clair	
17	Colbert	38 Lamar	59 Shelby	
18	Conecuh	39 Lauderdale	60 Sumter	
19	Coosa	40 Lawrence	61 Talladega	
20	Covington	41 Lee	62 Tallapoosa	
21	Crenshaw	42 Limestone	63 Tuscaloosa	

YOU MAY <u>WRITE THE WORDS</u> INSTEAD OF CODE NUMBERS! Revised 04/09

# Children's Rehabilitation Service Office Locations



## Children's Rehabilitation Service (CRS) Office Locations

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	Jefferson County - Homewood CRS
1010 Christine Avenue, Suite 250	234 Goodwin Crest Drive
Anniston, AL 36207	Birmingham, AL 35209
Phone: 256-235-3050 or 1-800-289-9533	Phone: 205-290-4550 or 1-888-430-7423
Clarke County – Jackson CRS	Lee County – Opelika CRS
1506 College Avenue	516 W. Thomason Circle
Jackson, AL 36545	Opelika, AL 36801
Phone: 251-246-4025 or 1-800-283-8140	Phone: 334-749-8339 or 1-800-568-8428
Colbert County – Muscle Shoals CRS	Madison County – Huntsville CRS
1450 E. Avalon Avenue	3000 Johnson Road
Muscle Shoals, AL 35661	Huntsville, AL 35805
Phone: 256-381-1212 or 1-800-285-9924	Phone: 256-650-1701 or 1-800-283-8140
Covington County – Andalusia CRS	Montgomery County – Montgomery CRS
1082 Village Square Drive, Suite 2	602 South Lawrence Street
Andalusia, AL 36420	Montgomery, AL 36104
Phone: 334-222-5558 or 1-800-723-8064	Phone: 334-293-7500 or 1-800-568-9034
Dallas County – Selma CRS	Mobile County – Mobile CRS
2906 Citizens Parkway	1610 Center Street, Suite A
Selma, AL 36701	Mobile, AL 36604
Phone: 334-872-8422 or 1-800-967-6876	Phone: 251-432-4560 or 1-800-879-8163
Etowah County – Gadsden CRS	Talladega County – Talladega CRS
1100 George Wallace Drive	7 Bemiston Avenue
Gadsden, AL 35903	Talladega, AL 35160
Phone: 256-547-8653 or 1-800-289-1353	Phone: 256-362-9254 or 1-800-947-7140
Houston County – Dothan CRS	Tuscaloosa County – Tuscaloosa CRS
795 Ross Clark Circle NE	1110 Sixth Avenue East
Dothan, AL 36303	Tuscaloosa, AL 35401
Phone: 334-699-6600 or 1-800-677-9123	Phone: 205-759-1279 or 1-800-723-0490

## Alabama Community-Based Sickle Cell Organizations

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NBS encourages a referral to one of the local Community-Based Sickle Cell Organizations if an infant is identified with Sickle Cell Trait or Disease.

Organization	Contacts	Address & Phone	Counties
Sickle Cell Disease Association of America Central Alabama Chapter	Claudette Stallworth <u>Executive Director</u> Ms. Sharon Lewis	3813 Avenue I Ensley Birmingham, AL 35218 205-780-2355 Fax: 205-780-2368	Blount, Calhoun, Cherokee, Clay, Cleburne, Cullman, Etowah, Jefferson, Randolph, Shelby, St. Clair, Talladega, Walker
Service Area I			
Sickle Cell Disease Association of America West Alabama Chapter	Betty Bagby <u>Executive Director</u> Dr. B.L. Winston	P.O. Box 3151 Tuscaloosa, AL 35403 205-758-1761	Fayette, Green, Hale, Lamar,Marion, Pickens, Sumter, Tuscaloosa, Winston
Service Area II Tri-County Sickle Cell Anemia Association, Inc. Service Area III	Mamie Danzey <u>Executive Director</u> Ms. Margaret Bolling	Fax: 205-758-1781 P.O. Box 3151 Selma, AL 36701 334-872-9362	Bibb, Chilton, Coosa, Dallas, Marengo, Perry, Wilcox
Sickle Cell Foundation of Greater Montgomery, Inc. Service Area IV	Executive Director Mr. Willie Owens	Fax: 334-872-9383 3180 US Highway 80 West P.O. Box 9278 Montgomery, AL 36087 334-286-9122	Autauga, Butler, Chambers, Coffee, Crenshaw, Elmore, Lowndes, Montgomery, Tallapoosa
Southeast Alabama Sickle Cell Association Service Area V	Executive Director Wendy Morgan	P.O. Box 1079 Tuskegee, AL 36087 334-727-6120	Barbour, Bullock, Dale, Geneva, Henry, Houston, Lee, Macon, Pike, Russell
Sickle Cell Disease Association of America Mobile Chapter, Inc. Service Area VI	Pam Ware <u>Executive Director</u> Ms. Nichelle Williams	P.O. Box 40696 1453 Springhill Avenue Mobile, AL 36604 251-432-0301	Baldwin, Choctaw, Clarke, Conecuh, Covington, Escambia, Mobile, Monroe, Washington
North Alabama Sickle Cell Foundation, Inc.	McAuthor Johnson <u>Executive Director</u> Mr. E.C. Rentz	P.O. Box 813 Huntsville, AL 35804 256-536-2723	Colbert, Dekalb, Franklin, Jackson, Lauderdale, Lawrence, Limestone, Madison, Marshall, Morgan
Service Area VII			



Alabama Newborn Screening Program P.O. Box 303017 201 Monroe Street RSA Tower – Suite 1350 Montgomery, AL 36130-3017

www.adph.org/newbornscreening/