

Mississippi Newborn Screening



Guide for Healthcare Providers

Mississippi State Department of Health
Office of Child & Adolescent Health
Bureau of Genetic Services

March 2012

Table of Contents

What Is Newborn Screening?	1
Who Should Be Screened?.....	1
Newborn Screening Panel.....	1
Mississippi Genetic Newborn Screening Panel	2
Birth Hospitals	3
Instructions For Dried Blood Spot Filter Paper (DBS) Completion.....	3
Specimen Collection.....	7
Supplies For Specimen Collection	7
Specimen Collection Procedure	7
Problems With Specimen Collection.....	9
Specimen Collection/Transfusions	9
Dried Blood Spot Card	10
How To Order Dried Blood Spot Cards	10
Newborn Screening Results	11
Unacceptable Or Inconclusive Results	11
Immediate Short Term Follow-Up Of Abnormal Or Presumptive Positive Result.....	11
Immediate Short Term Follow-Up Of Abnormal Or Presumptive Positive Result After Hours/Weekends	12
Appendices.....	13

Introduction

The purpose of this newborn screening guide is to provide information to healthcare professionals to assist in improving the newborn screening process in Mississippi. We hope that you find the information in this guide helpful. Contact the Newborn Screening Program at 601-576-7619 with questions or comments regarding newborn screening.

What is Newborn Screening?

Newborn Screening is a public health service performed before a newborn is discharged from the delivering facility to identify serious or life threatening conditions. This screening provides early detection of numerous diseases and disorders so that timely treatment can be initiated and long term sequelae minimized. Long term sequelae may include organ damage, stroke, or death if left undiagnosed and untreated.

Who should be screened?

Sections 41-21-201 and 41-21-203 of the Mississippi Code of 1972 requires all newborns born in Mississippi to be screened prior to discharge from the hospital regardless of the age of the newborn or the feeding status. Parents of newborns who object on the grounds that the screening conflicts with their religious practices are exempt from screening but are required to sign a refusal form stating their understanding of this process.

Newborn Screening Panel

The Mississippi State Department of Health (MSDH) contracts with an outside laboratory to perform newborn screen testing and when indicated second tier DNA testing for some disorders. Evaluation and confirmatory testing are performed at a tertiary care center. Confirmatory testing is completed by separate reference laboratories, as determined by tertiary treatment medical subspecialties. Following on page two is a listing of the diseases/disorders screened for in Mississippi.

Mississippi Genetic Newborn Screening Panel

Core Condition

Propionic acidemia
Methylmalonic acidemia (methylmalonyl-CoA mutase)
Methylmalonic acidemia (cobalamin disorders)
Isovaleric acidemia
3-Methylcrotonyl-CoA carboxylase deficiency
3-Hydroxy-3-methylglutaric aciduria
Holocarboxylase synthase deficiency
β-Ketothiolase deficiency
Glutaric acidemia type I
Carnitine uptake defect/carnitine transport defect
Medium-chain acyl-CoA dehydrogenase deficiency
Very long-chain acyl-CoA dehydrogenase deficiency
Long-chain L-3 hydroxyacyl-CoA dehydrogenase deficiency
Trifunctional protein deficiency
Argininosuccinic aciduria
Citrullinemia, type I
Maple syrup urine disease
Homocystinuria
Classic phenylketonuria
Tyrosinemia, type I
Primary congenital hypothyroidism
Congenital adrenal hyperplasia
S,S disease (Sickle cell anemia)
S, β-thalassemia
S,C disease
Biotinidase deficiency
Cystic fibrosis
Classic galactosemia
Severe Combined Immunodeficiencies

Secondary Condition

Methylmalonic acidemia with homocystinuria
Malonic acidemia
Isobutyrylglycinuria
2-Methylbutyrylglycinuria
3-Methylglutaconic aciduria
2-Methyl-3-hydroxybutyric aciduria
Short-chain acyl-CoA dehydrogenase deficiency
Medium/short-chain L-3-hydroxyacyl-CoA dehydrogenase deficiency
Glutaric acidemia type II
Medium-chain ketoacyl-CoA thiolase deficiency
2,4 Dienoyl-CoA reductase deficiency
Carnitine palmitoyltransferase type I deficiency
Carnitine palmitoyltransferase type II deficiency
Carnitine acylcarnitine translocase deficiency
Argininemia
Citrullinemia, type II
Hypermethioninemia
Benign hyperphenylalaninemia
Biopterin defect in cofactor biosynthesis
Biopterin defect in cofactor regeneration
Tyrosinemia, type II
Tyrosinemia, type III
Various other hemoglobinopathies
Galactoepimerase deficiency
Galactokinase deficiency
T-cell related lymphocyte deficiencies

Birthing Hospitals

All birthing hospitals are required to collect a newborn screening specimen on each newborn before discharge from the hospital or transfer to a facility for higher level care, regardless of age or feeding status. In order to expedite screen results, always follow the steps below:

- Fill out the specimen card completely
- Collect the specimen correctly (see Appendix A)
- Ship the specimen to the screening laboratory in a timely manner using the overnight courier service
- The Screening Laboratory has arranged courier services with UPS.
Note: The Complete View Solution (ICVS) is a secure Web-based shipping application that has been customized to accommodate your facility's unique business requirements. Please see [UPS - ICVS Training User Guide](#) for instructions.
- Mississippi law requires all newborns born in Mississippi to be screened prior to discharge from the hospital regardless of the age of the newborn or the feeding status. Parents of newborns who object on the grounds that the screening conflicts with their religious practices are exempt from screening but are required to sign a refusal form stating their understanding of this process (see Appendix B).

Instructions for Dried Blood Spot Filter Paper (DBS) Completion

Results may be delayed for screening specimens submitted with incomplete information.

ALWAYS check the specimen card expiration date located on the far left side of the filter paper, next to the hour glass, noted by the year and date. Expired cards are not acceptable. All information must be legible.

TOP LINE

First Specimen All tests – If it is the first newborn screening specimen collected on the infant, place an “X” in the blank provided.

Home Birth – If the newborn was born at home, place an “X” in the blank provided.

Repeat Specimen – If the test is a repeat newborn screening specimen collected on the infant, place an “X” in the blank provided.

Repeat Specimen Reason – Put an “X” by the appropriate reason for a Repeat Specimen; < 24 hr, Unsatisfactory, Abnormal, Transfused, Inconclusive.

INFANT'S INFORMATION

Infant's Last/First Name – Write infant's name in order as shown, last name, first name, previous last name, making sure the name is spelled correctly. If the infant's first name is not available, put last name, followed by Boy/Girl. (Example: Smith, Baby Boy).

Previous Last Name – If the infant's last name is different from the name given at birth, indicate the previous/original name in the blank provided. (Smith, John; Brown, Boy).

Birth Date – Write the date of birth using numbers only in the blank provided. (Example: December 25, 2002 will appear as 12-25-02).

Time of Birth – Write the time of birth using **MILITARY TIME ONLY** in the blank provided. (Example: 2:30 p.m. will appear as 1430).

Date Collected – Write the date the specimen was collected using numbers only in the blank provided. (Example: December 2, 2003 will appear as 12-02-03).

Time Collected – Write the time the specimen was collected using **MILITARY TIME ONLY** in the blank provided. (Example: 8:00 p.m. will appear as 2000).

Birth – Write an “X” in the blank provided. (EXAMPLE: in the case of twins/triplets, write an “X” to indicate the birth order of the infant to indicate A or B). For triplets or more use #3 blank and indicate C, D, or E etc.

Hospital of Birth Code/Hospital or Health Department Collected Code – Write the hospital code/health department code in the appropriate blank provided. **NOTE:** If the infant is born in the same hospital in which the specimen is collected, then both the hospital of birth code and hospital collected code will be the same. If the infant is born in one hospital, but transferred to another hospital prior to the specimen being collected, the hospital collection code will be different from that of the hospital of birth. **When the specimen is collected or repeated by the health department, the health department county code is entered into the health department collected blank.**

Medical Record Number – Write the infant's medical record number in the blank provided.

Transferred – If the infant has been transferred to another facility; check yes and write the name of the facility in the space provided.

Physician's Name – Write the name of the provider and contact information who will be providing local medical care for the infant in the blank provided. In the event of a homebirth, **provide the name of the midwife or person attending the homebirth, with contact information.**

Additional Information – Use these lines to give the following information when:

- PRE TRANSFUSION specimen
- Infant is **ADOPTED** (give the name and address of the adoption agency, attorney or physician handling the adoption)
- Infant **left hospital prior to newborn screening being done.**
- **INCARCERATION** – if mother will return to an incarceration facility, write INMATE and to whom the infant has been discharged and the contact information.

Submitter Name/Address – Write the name and address of the hospital/health department (submitter) in the blank provided.

Specimen Collected By – Write name or initials of person collecting specimen in the blank provided.

INFANT'S INFORMATION

Sex – Write an “X” in the appropriate blank provided.

Race – Write an “X” in the appropriate blank provided.

Ethnicity – Write an “X” in the appropriate blank provided.

Transfused – **Collect specimen PRIOR to transfusion** if at all possible. Provide the **date and time of the last transfusion** in the space provided and in using six numbers in the blank. (Example: December 15, 2002 at 10:00 a.m. will appear as 12-15-02/1000.)

NOTE:

- **Ideal collection time: 24-48 hours of age**
- **Transfusion required > 24 hours of age: collect specimen prior to transfusion**
- **Transfusion required < 24 hours of age: collect specimen prior to transfusion and 2-4 days after the transfusion**
- **Transfusion required but no specimen collected prior to transfusion: collect specimen 2-4 days, 2-4 weeks and > 90 days after transfusion**

Gestation/Infant's Age – Write the gestational age of the infant at the time of birth or the age of the infant at the time of collection in the blank provided.

Birth Weight – Write the infant's weight in grams, **AT THE TIME OF BIRTH** in the blank provided. If specimen is collected > 14 days of age, write current weight in grams.

Feeding – Write an “X” in the appropriate blank provided, indicating the infant's feeding status at the time of collection. More than one blank may be marked if appropriate.

Meconium Ileus – Check the blank if appropriate, to indicate the presence of a meconium ileus.

MOTHER’S INFORMATION

Mother’s Current Last/First Name – Write mother’s full name, as specified at time of delivery in the blank provided (Example: Smith, Caroline). **(NOTE: If the infant is ADOPTED, do not give the birth mother’s information. In the case of ADOPTION, this area should reflect the name of the agency, physician or attorney handling the adoption.)**

Mother’s Date of Birth – Write Mother’s date of birth.

Address/Phone Number – Write the physical street address, **(DO NOT GIVE P.O. BOX)**, or apartment number, as well as the city, state, and zip code in the blanks provided. Write the telephone number or emergency contact number where a voicemail/message can be accepted, in the blanks provided. **(NOTE: In the case of ADOPTION, give the agency, physician or attorney name, address and phone number handling the adoption in the blanks provided.)**

Medicaid Number/Mother’s Social Security Number – Write Mother’s Medicaid Number, if applies, and Social Security Number in the blanks provided.

County of Residence – Write the county two digit code where the infant resides in the space provided (Example Hinds County/25).

NOTE: In the event an infant is a “Drop Off Baby”, assign the baby a name. The date the baby is left at the hospital should be used as the date of birth, and the approximate time the baby was left should be used as the time of birth, unless other information is known to the hospital. The hospital code should be entered in the space provided for the hospital of birth and hospital collected. In the box provided for Physician’s Name, note the emergency medical services provider. This will allow for adequate follow-up/tracking in the event of an abnormal or positive newborn screen.

HEARING SCREENING

This section of the newborn screening form should be completed by the hospital of birth prior to discharge. Check the appropriate test performed, i.e. ABR/OAE, and the appropriate result for each ear, i.e., pass/refer. If the hearing screening is not performed, leave this section blank.

Office Mechanics/Filing/Retention:

The yellow copy should be kept by the hospital of birth /county health department. Once the newborn screen result is received, the yellow copy can be destroyed. The hard copy of the newborn screen result should be filed in the infant’s medical record and retained according to hospital/county health department policy.

SPECIMEN COLLECTION

SUPPLIES FOR SPECIMEN COLLECTION

Dried Blood Spot Filter Paper

Soap and water

Cotton balls soaked with 70% isopropyl alcohol

Dry, cotton balls

Heel Warmer (if available); Lancet

SPECIMEN COLLECTION PROCEDURE

- A. Recommended site: The least hazardous sites for heel puncture are medial to a line drawn posteriorly from the middle of the big toe to the heel or a similar line drawn on the other side extending from between the 4th and 5th toe to the heel. Refer to [Blood Specimen Collection and Handling Procedure](#) for the shaded areas for preferred puncture sites (see Appendix A).
- B. Thoroughly wash the puncture site with soap and water.
- C. Disinfect the skin with 70% isopropyl alcohol and allow to air dry. Vigorous rubbing during this step stimulates blood flow in the area.
- D. Puncture the skin in one continuous motion using the Lancet. (Avoid the use of long tip lancets which may damage the heel bone.)
- E. Wipe away and discard the first drop of blood since it may be contaminated by disinfectant or tissue fluid.
- F. Allow a second drop to form a spontaneous free flow of blood.
- G. Expose the filter paper end of the DBS card. Touch the filter paper to the drop of blood, as close to the center of the circle as possible. Observing from the opposite side, allow the blood spot to enlarge until the circle is completely filled. There should only be a single application of the filter paper to the blood spot for each circle. (No dabbling of filter paper to the heel; this will cause an overlay of blood, which may cause inaccurate results.)
- H. Once the blood collection is completed, press a sterile gauze pad to the puncture site until the bleeding has stopped.
- I. Dry the blood spots on a level, nonabsorptive surface, away from the direct sunlight, and at room temperature for at least four hours. DBS cards should not be stacked while the filter paper specimen are exposed. After drying, rewrap the filter paper with the cover sheet to its original position to protect the specimen.

- J. All information requested on the DBS card should be completed. Failure to complete such critical information as the infant's last name, the date and time of birth, and the date and time of collection will cause the specimen to be rejected by the screening laboratory and necessitate a repeat specimen collection on the infant by the originator of the specimen.

- K. The DBS card should be mailed within 24 hours to the screening laboratory utilizing the overnight courier service.

PROBLEMS WITH SPECIMEN COLLECTION

- I. Dilution or contamination of the blood spot may occur due to the following errors:
 - a. Failure to wipe off the alcohol residue.
 - b. Failure to discard the first drop of blood that forms, since it may be contaminated with alcohol or tissue fluids.
 - c. “Milking” the puncture site to stimulate bleeding which can dilute the blood with tissue fluid.
 - d. Touching the blood spot circles before or after filling which can contaminate the spots with perspiration and/or oil from fingertips.
 - e. Allowing blood spots to be contaminated by contact with water, feeding formulas, antiseptics, etc.

- II. The blood may be unevenly distributed on the filter paper due to the following errors:
 - a. The repeated touching of the filter paper to small drops of blood in an attempt to fill a circle. This will result in areas overfilled due to layering one drop over a partially dried drop and some areas contain no blood at all.
 - a. A mottled appearance will occur if the filter paper is not soaked through, front to back.
 - b. Overfilling the circles causes the center of the circle to be supersaturated. This may cause inaccurate test results.
 - c. Blood collected in capillary tubes and used to fill the circles. There is a chance of the capillary tube scratching the surface of the filter paper, which may alter the thickness in that area.

SPECIMEN COLLECTION/TRANSFUSIONS

Optimal time for specimen collection is 24 – 48 hours after birth. If an infant is discharged before 24 hours of age or transferred to another facility for higher level of care, the specimen must be collected before discharge to assure that the infant is in the system. It is also recommended that the specimen is collected before a blood transfusion, if possible.

- Ideal collection time: 24 – 48 hours of age
- Transfusion required at > 24 hours of age: collect specimen prior to transfusion
- Transfusion required < 24 hours of age: collect specimen prior to transfusion and 2 – 4 days after the transfusion
- Transfusion required but no specimen collected prior to transfusion: collect specimen 2 – 4 days, 2 – 4 weeks and > 90 days after transfusion

APPENDIX D DRIED BLOOD SPOT CARD

NEWBORN SCREENING TO AVOID RECOLLECTION- Accurately complete the entire form

First Specimen All tests
 Home Birth
 Repeat Specimen
 Reason: <24 hr.
 Unsatisfactory
 Abnormal
 Transfused
 Inconclusive

<p>INFANT'S INFO</p> <p>Infant's Last Name: _____ First: _____ Previous Last Name: _____</p> <p>Birth Date: ____/____/____ Time of Birth: _____</p> <p>Date Collected: ____/____/____ Time Collected: _____</p> <p>Hospital of Birth Use Code: _____ Hospital of H.D. Use Code: _____</p> <p>Transfused: <input type="checkbox"/> Yes Where: _____</p> <p>Physician's Name: _____ Physician's Phone: _____</p> <p>Additional Information: _____</p> <p>Submitter's Name and Address: _____</p>	<p>MOTHER'S INFORMATION</p> <p>Mother's Current Last Name: _____ First: _____ Mother's Date of Birth: ____/____/____</p> <p>Address: _____</p> <p>City: _____ State: _____ Zip: _____</p> <p>Phone: _____ Medicaid Number: _____</p> <p>Mother's Social Security No. _____</p>
---	---

SEX: 1. Male 2. Female
 Transfused: Yes No
 Date of Last Transfusion: ____/____/____

RACE: 1. White 2. Black 3. Asian 4. Am. Ind. 5. Other

ETHNICITY: 1. Hispanic 2. Non-Hispanic

Gestation: _____ Weeks
 Birth Weight: _____ Infant's Age at Birth: _____

*Feeding: 1. Breast 2. Soy 3. I.V. 4. Lactose 5. TPN

Meconium Stool: Yes No

HEARING SCREEN: ABN OAD R Ear L Ear Pass Refer

SN **6525200** LABEL HERE

GALACTOSEMIA RESULTS ARE BASED ON THE ASSUMPTION THAT THE INFANT HAS HAD LACTOSE FEEDING AND HAS NOT BEEN TRANSFUSED

INSTRUCTIONS

1. Hold infant's limb in a dependent position to increase blood flow.
2. Clean heel thoroughly. Wipe with alcohol and dry before puncturing.
3. Puncture heel with sterile lancet deep enough to assure free flow of blood.
4. Wipe away first drop and discard.
5. Allow a large drop of blood to form on the infant's heel. Apply the back side of the filter paper directly to the puncture site where the drop of blood has formed. **The drop of blood should be large enough to approximately fill one circle.**
DO NOT: a) Apply more than one drop of blood per circle.
DO NOT: b) Apply blood to both front and back of filter paper.
6. Apply blood to all circles.
7. Allow blood spots to completely dry in a horizontal position at room temperature for a minimum of 4 hours (see diagram). Do not stack specimens while specimen is exposed. After drying, rewrap this cover sheet to its original position to protect specimen.
8. Send by Pre-Paid Overnight Courier within 24 hours of collection to:
 PerkinElmer Genetics, Inc.
 90 Emerson Lane
 Bridgeville, PA 15017
 (412) 220-2300
9. If you have questions please call the Mississippi State Department of Health Genetic Screening Program at (601) 576-7619.



HOW TO ORDER DRIED BLOOD SPOT CARDS

To order Newborn Screening Pamphlets and dried blood spot filter paper cards complete a [Newborn Screening Supply Form](#) and FAX to 601-576-7498 or call 601-576-7619. (See Appendix C)

NEWBORN SCREENING RESULTS

The screening laboratory provides results to the birthing hospitals to file in the infant's medical record. Birthing Hospitals can also obtain newborn screening results for specimens submitted by their facility by accessing Information@PerkinElmer.com. To request a User Access Form call PerkinElmer Genetics at 1-866-463-6436.

In addition, all results are electronically downloaded into the Mississippi State Department of Health's Newborn Screening Program system. Primary care providers can obtain a copy of the newborn screening results from the hospital of birth or by faxing a written request ([Request For Newborn Screening Results Form](#) – see Appendix D) to the Newborn Screening Program (NBS) at 601-576-7498 or call the NBS Program at 601-576-7619 for questions Monday – Friday, 8am – 5 pm.

The following information is needed to provide newborn screen results:

- Name
- Date of birth
- Mother's name
- Hospital of birth

Parents should ask their baby's physician about the Newborn Screening results at the first well baby checkup. For more information on what parents should know about newborn screening and FAQs (See Appendices E and F).

UNACCEPTABLE OR INCONCLUSIVE RESULTS

The NBS Program coordinates repeat specimen collection for unacceptable or inconclusive test results. Repeat specimen collection is addressed by the hospital of birth or the health department in the county of residence.

IMMEDIATE SHORT TERM FOLLOW-UP OF ABNORMAL OR PRESUMPTIVE POSITIVE RESULT

All abnormal or presumptive positive screening results are reported to the NBS Program by the screening laboratory. If the infant is a hospital inpatient, the attending physician is notified of the results. If the infant has been discharged, the primary care physician of record is notified of the screen results. In either instance a disease specific American College of Medical Genetics (ACMG) ACTION sheet is provided to the notified physician. The ACMG ACTION sheet provides a brief overview of the condition description, differential diagnosis, diagnostic evaluation and course of action which can be used in conjunction with consultation with a tertiary care specialist (www.acmg.net).

Once the primary care physician of record is notified of the screen result, the NBS Program may facilitate a referral to the tertiary care specialist as requested by the physician. Diagnosis will require evaluation and confirmatory testing in a tertiary care center. Evaluation and treatment may require ongoing clinic visits with the tertiary care specialist (see Appendix G).

**IMMEDIATE SHORT TERM FOLLOW-UP OF ABNORMAL OR PRESUMPTIVE
POSITIVE RESULT AFTER HOURS/WEEKENDS**

After normal business hours, which includes weekends and holidays, abnormal or presumptive positive screening results are reported to the NBS Program staff. The NBS Program staff who is on call immediately contacts the hospital of birth and the on call physician. The results are given to the physician via telephone with instructions on how to access the ACMG website (www.acmg.net) for a disease specific ACTION sheet, and also how to contact the appropriate on call tertiary care specialist (see Appendix G). The next business day, a copy of the newborn screen result will be faxed to the hospital of birth and the physician.

APPENDICES

- A.** Neonatal Screening: Blood Specimen Collection And Handling Procedure
- B.** Refusal Of Newborn Screening
 - Sample: Refusal Of Newborn Screening Form
- C.** Newborn Screening Supply Form
- D.** Request For Newborn Screening Results
- E.** What Parents Should Know About Newborn Screening
- F.** Newborn Screening In Mississippi: Frequently Asked Questions
- G.** Tertiary Care Center
- H.** Mississippi Newborn Screening Flow Chart

Neonatal Screening

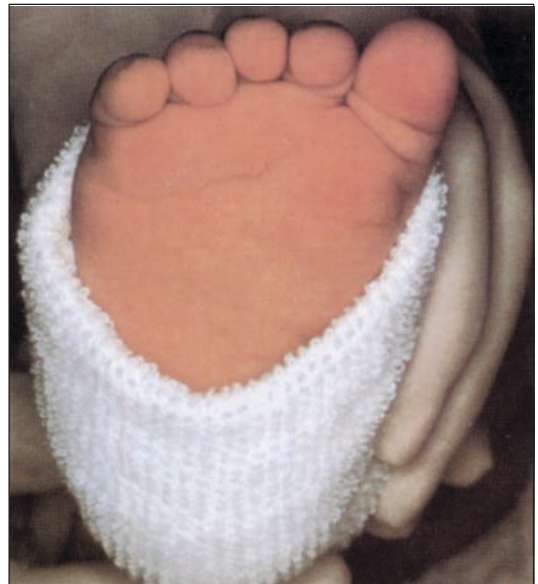
Blood Specimen Collection and Handling Procedure



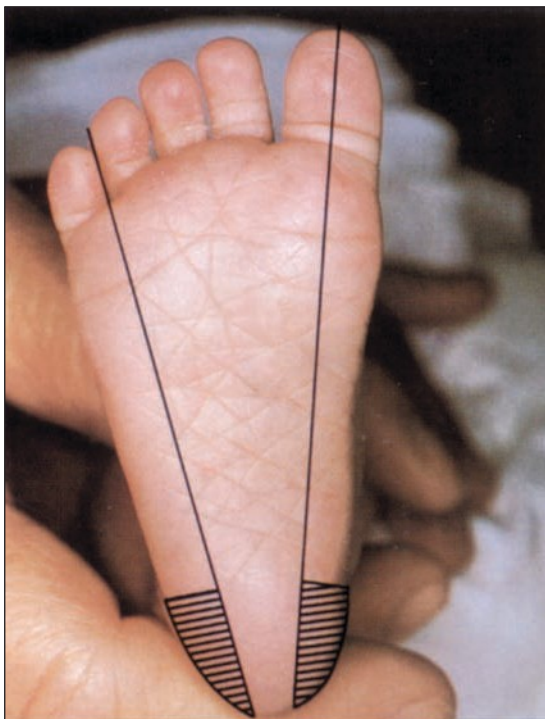
1 Equipment: sterile lancet with tip approximately 2.0 mm – sterile alcohol prep, sterile gauze pads, soft cloth, blood collection form, gloves.



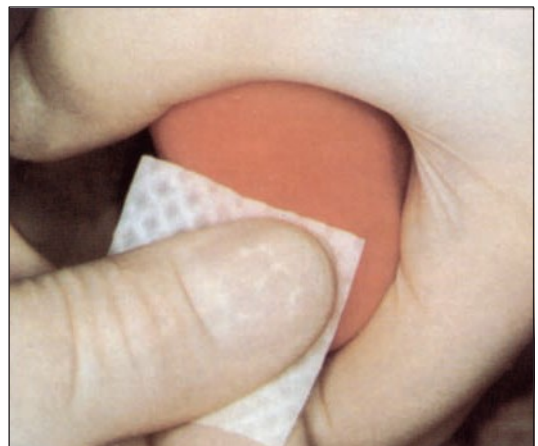
2 Complete ALL information. Do not contaminate filter paper circles by allowing the circles to come into contact with spillage or by touching before or after blood collection. Keep "SUBMITTER COPY" if applicable.



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

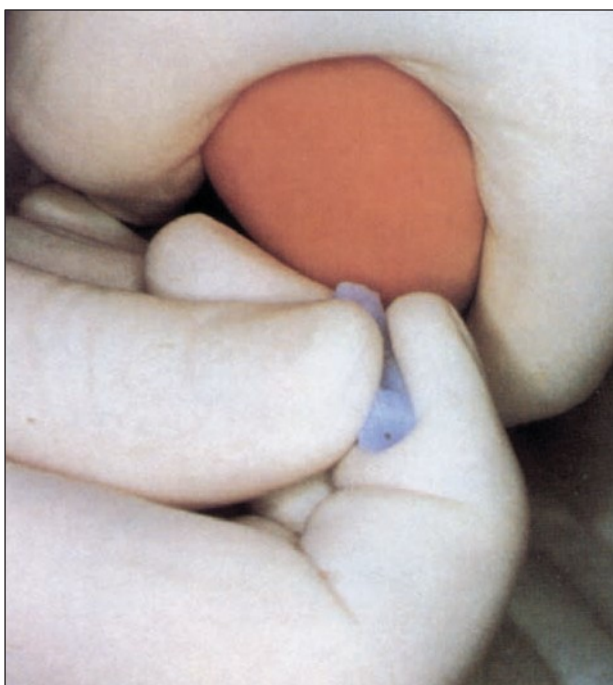


3 Hatched area (//) indicates safe areas for puncture site.

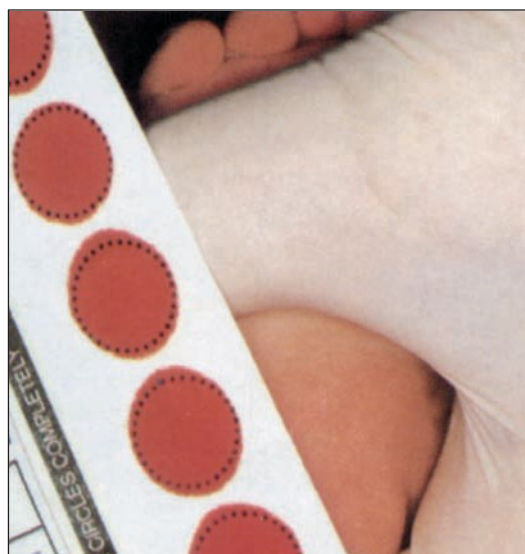


5 Cleanse site with alcohol prep. Wipe DRY with sterile gauze pad.

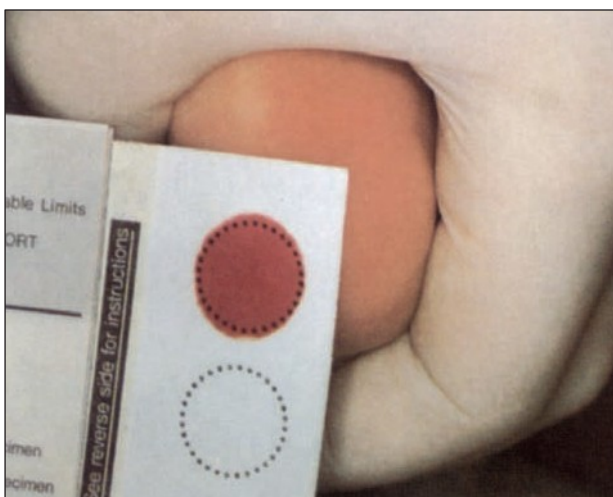
APPENDIX A



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



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.



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.

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.

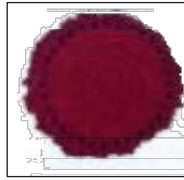
Information provided by The New York State Department of Health.

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 677011 • E-mail: information@whatman.com
 Whatman GmbH • Tel: +49 (0) 5561 791 0 • Fax: +49 (0) 5561 791 536 • E-mail: information@whatman.com
 Japan – Whatman Japan KK • Tel: +81 (0) 3 5215 1242 • Fax: +81 (0) 3 5215 1246 • 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(US) S9036-812(EU) 09/05

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.

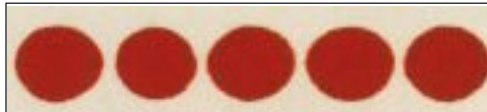
Invalid specimen:



1. Specimen quantity insufficient for testing.



2. Specimen appears scratched or abraded.



3. Specimen not dry before mailing.



4. Specimen appears supersaturated.



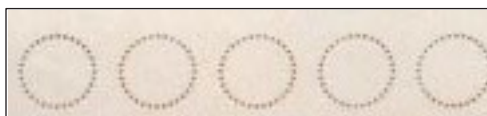
5. Specimen appears diluted, discolored or contaminated.



6. Specimen exhibits serum rings.



7. Specimen appears clotted or layered.



8. No blood.

Possible causes:

- Removing filter paper before blood has completely filled circle or before blood has soaked through to second side.
- Applying blood to filter paper with a capillary tube.
- Touching filter paper before or after blood specimen collection with gloved or ungloved hands, hand lotion, etc.
- Allowing filter paper to come in contact with gloved or ungloved hands or substances such as hand lotion or powder, either before or after blood specimen collection.
- Applying blood with a capillary tube or other device.
- Mailing specimen before drying for a minimum of four hours.
- Applying excess blood to filter paper, usually with a device.
- Applying blood to both sides of filter paper.
- Squeezing or "milking" of area surrounding the puncture site.
- Allowing filter paper to come in 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.
- Not wiping alcohol from puncture site before making skin puncture.
- Allowing filter paper to come in contact with alcohol, hand lotion, etc.
- Squeezing area surrounding puncture site excessively.
- Drying specimen improperly.
- Applying blood to filter paper with a capillary tube.
- Touching the same circle on filter paper to blood drop several times.
- Filling circle on both sides of filter paper.
- Failure to obtain blood specimen.

Information provided by The New York State Department of Health.

APPENDIX B

Refusal of Newborn Screening

Parent(s) are allowed to refuse the newborn screening test for their infant only if their religious beliefs and practices do not allow this testing. When a parent refuses to have the newborn screening test for their infant, staff *should*:

- Give parent a copy of the Newborn Screening pamphlet and discuss the significance of the NBS test
- Asked for a signed statement from parent stating refusal to have baby screened for the very serious conditions (See example: [Genetic Services – Newborn Screening Refusal](#))
- Place signed form or statement in the baby's hospital medical record

APPENDIX B
Newborn Screening Refusal Form

Patient's Name _____

Date of Birth _____

Hospital _____

Person(s) Counseled _____

Date _____

I, _____, have been counseled on the importance of Newborn
(Parent's Name)
Screening tests and have received literature on Newborn Screening. I do understand that the Mississippi state law requires every baby to be screened between 24 – 48 hours of birth. I understand that many of these disorders may cause life threatening conditions, serious medical conditions, mental retardation or even death. As a result of early detection, treatment and follow-up, the serious effects of many disorders may be lessened. However, due to my religious beliefs, I decline to have these tests performed on my child, and accept full responsibility for my actions.

Signed _____

Witnessed _____

APPENDIX C

NEWBORN SCREENING SUPPLY FORM

Fax completed request to the Newborn Screening Program 601-576-7498

Mississippi State Department of Health Bureau of Genetic Services PO Box 1700 Jackson, MS 39215-1700 (601) 576-7619		Date:	
Requested by:		ATTN: Ship to:	
Telephone Number:			
Description	Quantity Requested	Quantity Shipped	
Newborn Hearing Screening "What to Expect" (#5272 English)			
Newborn Hearing Screening "What to Expect" (#5272S Spanish)			
Newborn Screening Lab Slips (Filter Paper)			
Newborn Screening Pamphlet (#5198 English)			
Newborn Screening Pamphlet (#5198 Spanish)			
What Does A Safe Sleep Environment Look Like (#5404 English)			
What Does A Safe Sleep Environment Look Like (#5404S Spanish)			
Mail request to the above address, Attn: Genetic Services, fax to 601-576-7498 or call 601-576-7619.			
<i>Supplier Use Only</i>			
Filled by:		Date:	

APPENDIX D

REQUEST FOR NEWBORN SCREENING RESULTS

Please print legibly

Fax completed request to the Newborn Screening Program 601-576-7498.

Name of Facility: _____ Date: _____

Contact Person: _____

Facility Address: _____

Facility Telephone: (____) _____

Facility Fax Number : (____) _____

Child's Name (at birth): _____
Last First

Date of Birth: _____ Gender: M / F (Circle One)

If child has a different last name please list below:

Place patient label here (if available)

Mother's Name: _____
First Maiden Last

Mother's Address: _____

Mother's DOB: _____

County of residence at birth: _____

CONFIDENTIALITY NOTE: This information has been disclosed to you from records whose confidentiality is protected. Statutes/Regulations prohibit you from making further disclosures other than treatment, payment or health care operation, without the specific written authorization of the person to whom it pertains, or as otherwise permitted by such regulations.



MISSISSIPPI STATE DEPARTMENT OF HEALTH

570 East Woodrow Wilson • Post Office Box 1700 • Jackson, MS 39215-1700
601-576-8090 • 1-866-HLTHY4U • www.HealthyMS.com

Equal Opportunity in Employment/Services

What Parents Should Know About Newborn Screening



All babies born in Mississippi are required by law to have a blood sample collected after birth to screen for a number of genetic disorders. Babies with genetic disorders may look healthy at birth, yet be at risk for serious health problems. Serious health problems may be prevented if these disorders are identified as soon as possible after birth. You will receive a pamphlet about newborn screening before you and your baby are discharged from the hospital.

Twenty-four to forty-eight hours after your baby's birth, a nurse or laboratory technician will draw a few drops of blood from your baby's heel. He or she will then send it to a laboratory for testing. Both you and your baby's physician will be notified if the screening indicates that further follow-up is needed, and a copy of the screening results will be sent to the hospital where your baby was born. These results will be included in your baby's medical record. Ask your baby's physician about the newborn screening results at your first "well baby" checkup.

Occasionally a second screening is required to confirm test results. If your baby requires a second screening, it should be done as soon as possible. Your local county health department will contact you if rescreening is necessary. To help in prompt notification, be sure to provide the name of your baby's doctor, your physical address and a telephone number before hospital discharge.

If you have any further questions about newborn screening, talk with your obstetrician and your baby's physician. You may also contact the Mississippi State Department of Health Newborn Screening Program at 601-576-7619 or 1-866-HLTHY4U (1-866-458-4948). You may also visit the Mississippi State Department of Health's website at www.HealthyMS.com.



APPENDIX F

NEWBORN SCREENING IN MISSISSIPPI FREQUENTLY ASKED QUESTIONS

What is Newborn Screening?

Newborn screening refers to a dried blood-spot screening test that is performed on newborns before they are discharged from the hospital. The screen is done before discharge to identify babies who may be at risk for a condition with serious effects who may otherwise not be detected for several days, months, or even years. Only additional testing (diagnostic or confirmatory testing) can tell if the baby has a disorder.

Why should my baby have the screening?

The conditions for which babies will be screened for are individually rare. However, some are also very serious and can result in mental retardation and/or death if not treated. Babies with these conditions appear normal at birth. It is only with time that the condition affects the baby's mental or physical development causing other medical problems, which could result in permanent damage. The newborn screen helps to identify those babies who need treatment, such as medications or special diets.

Newborn screening may not always detect a disorder. If your baby does not seem well, talk to your baby's physician as soon as possible.

My baby looks healthy. Is this screen still necessary?

Yes! Most infants with a condition found by newborn screening show no signs of the condition right after birth and can usually be identified before the baby becomes sick. Infants with a condition will need special medical care.

Do I have to give permission for my baby to be screened for these conditions?

No. The law (MS Statute 41-21-201) states that all babies born in Mississippi must be screened prior to discharge from the hospital regardless of the age of the baby or the feeding status. The only legal reason for not collecting a screening specimen is if the parents object to such testing for religious reasons.

May I refuse the screening test?

As a parent, you may refuse newborn screening only if your religious beliefs and practices do not allow this testing. If you refuse to have the screen performed on your baby, you may be asked to sign a form by the hospital ([Newborn Screening Refusal](#)) stating you refused to have your baby screened for these very serious conditions. This form will go in your baby's hospital medical record.

Is there a fee for the screening test?

A fee is billed to the hospital where your baby was born for the screen.

What conditions are currently screened for in Mississippi?

[Mississippi Genetic Newborn Screening Panel](#)

APPENDIX F

When and how is the screening test done?

The screening specimen is usually collected between 24 – 48 hours of age. A few drops of blood are taken by pricking the baby's heel and dropping blood onto a special screening card and shipped to the screening laboratory.

Will I be told the newborn screen test results?

Results are mailed to the hospital of birth. The physician of record is notified of any abnormal screen results by the Mississippi State Department of Health. It is very important that the hospital have the parent's correct last name, physical address, and a working telephone number. Your baby's physician can request the screen result from the hospital or call the Mississippi State Department of Health's Genetic Services Program for the screen results. Ask your baby's physician about the screen results at the first well baby check up.

If a repeat screen is requested, does it mean my baby may have a condition?

No. There are reasons why a repeat screen may be needed. If the screen is done incorrectly and is not okay for testing, a second test (repeat) is needed. If a screen is collected too early, a repeat screen is needed. A retest for these reasons does not mean that something is wrong with your baby; it means another sample is needed so that the screen can be done.

If the first screen was abnormal for one of the conditions, a second test or a confirmatory test may be required. An abnormal screening result does not mean that your baby has a problem. The screening test does not say "yes" or "no" to whether your baby has a condition. It identifies those few babies out of all of those tested who may need more specific testing. A confirmatory test may say "yes" or "no" to whether or not your child has a condition; it confirms the abnormal screening result.

Can these conditions be cured?

There is no known cure for these conditions. The serious effects of these conditions can be lessened if a special diet, medical treatment, or other intervention is started early.

If my baby has one of these conditions, does it mean my future children will also be affected?

Your doctor can discuss this with you or refer you to a specialist. These specialists have information about the specific conditions and how it is inherited. They can help you understand any risk for your future children.

APPENDIX G

**University of Mississippi Medical Center
Jackson, Mississippi**

TERTIARY CARE CENTER

Amino Acid Disorders, Organic Acid and Fatty Acid Disorders

Clinic	Staff
University Medical Center University of Mississippi Health Care Pediatric Medical Genetics 2500 North State Street Jackson, MS 39216 Emergency after hours: 601-984-1000 (Page metabolic/newborn screening physician)	Georg Hans Bock, MD Omar Ali Abdul-Rahman, MD Chris Friedrich, MD Suzanne Boyer, R.D. Phone No. 601-984-1900 FAX No. 601-984-1916

Endocrine Disorders

Clinic	Staff
University Medical Center University of Mississippi Health Care Pediatric Endocrine Clinic 2500 North State Street Jackson, MS 39216 Emergency after hours: 601-984-1000 (Page pediatric endocrine/newborn screening physician)	George Moll, MD Michael Torchinsky, MD Naznin Dixit, MD Phone No. 601-984-5216 FAX No. 601-815-3672

Cystic Fibrosis

Clinic	Staff
University Medical Center University of Mississippi Health Care Pediatric Pulmonary Clinic 2500 North State Street Jackson, MS 39216 Emergency after hours: 601-984-1000 (Page pediatric pulmonary /newborn screening physician)	Suzanne Miller, M.D. Phone No. 601-984-5205 FAX No. 601-815-1050

APPENDIX G

**University of Mississippi Medical Center
Jackson, Mississippi**

TERTIARY CARE CENTER (continued)

Pediatric Allergy/Immunology

Clinic	Staff
University Medical Center University of Mississippi Health Center Pediatric Allergy/Immunology 2500 North State Street Jackson, MS 39216-4505 Emergency after hours: 601-984-1000 (Page pediatric allergy/immunology)	Anne Yates, MD Phone No 601-984-5247 FAX # 601-984-2608

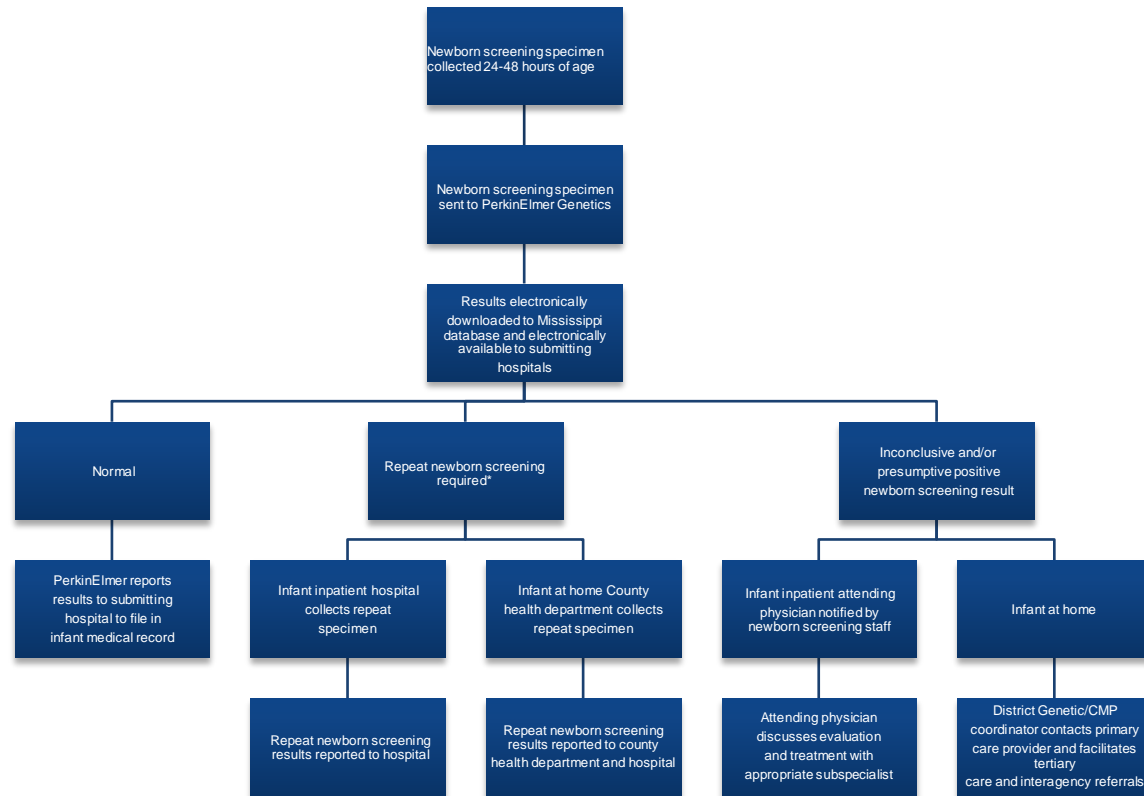
Pediatric Hematology/Sickle Cell Disease

Clinic	Staff
University Medical Center University of Mississippi Health Care Pediatric Hematology 2500 North State Street Jackson, MS 39216 Emergency after hours: 601-984-1000 (Page pediatric hematology/sickle cell/ newborn screening physician)	Gail Megason, MD Rathi Iyer, MD Mary Gail Smith, MD Betsy Herrington, MD Cathy Gordon, MD Suvankar Majumdar, MD Amy Forsythe, CFNP Tobi Breland, CFNP Phone No. 601- 984-5220 FAX No. 601- 984-5279

* Other out of state tertiary centers will be identified upon request of providers/family.

APPENDIX H

MISSISSIPPI NEWBORN SCREENING FLOW CHART



The flow chart above explains the path of a screening specimen from collection to results. This process includes birthing hospitals, the newborn screening laboratory, newborn screening staff, primary care providers, and tertiary care centers.

* Reasons for a repeat newborn screening include, but are not limited to, specimen quantity insufficient for testing, specimen appears diluted or contaminated, and specimen exhibits serum rings.