



Michigan Department of Health and Human Services

Newborn Screening  
Guide for Homebirths  
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## **INTRODUCTION**

Newborn screening (NBS) saves lives and protects the health of Michigan newborns. Since 1965, all Michigan newborns have been screened shortly after birth to determine if they are at risk for having rare but treatable genetic disorders. If untreated, these disorders can lead to illness, physical disability, intellectual disability, or death. Medication and changes in diet can help prevent many health problems caused by disorders detected by NBS.

Midwives and other homebirth attendants play an important role in guarding the health of newborns whose births they attend. While the disorders included on the NBS panel are rare, approximately 270 Michigan newborns are identified with these disorders each year. The NBS guide is intended to be a reference tool and contains background information, general guidance on common issues related to NBS, specific forms and contact information.

# OVERVIEW OF MICHIGAN NEWBORN SCREENING

## Dried Blood Spot Screening

Michigan now screens for more than 50 disorders plus hearing loss and critical congenital heart disease. [Appendix 10](#) contains a complete list of disorders included in the NBS panel. Michigan law mandates that all birth attendants offer NBS. [Appendix 1](#) summarizes Michigan NBS legislation. If parents object to screening, the homebirth attendant should ask the parents to sign a waiver stating that they were informed of the risk to their newborn if screening is declined and return the form to the NBS Program. See [Appendix 8](#) for a sample waiver form for parents who do not want their newborn to be screened. This form is just a sample. Each homebirth attendant should seek legal guidance to develop his/her own refusal form.

Blood specimens should be collected at 24-36 hours of life, ideally 24-30 and air dried for a minimum of three hours. Specimens should be mailed in the pre-paid envelope provided by the NBS Program. Instructions for sending NBS specimens are provided later in this document. Laboratory testing is typically completed within one or two days of specimen receipt, and all NBS results are mailed/faxed to the person who submitted the specimen. The NBS Laboratory would like all providers, including homebirth attendants, to receive NBS results by fax in order to assure prompt receipt. See [Appendix 13](#). NBS Laboratory operations are Monday through Saturday, excluding most State holidays.

The NBS Program is unable to perform stat laboratory testing. If you are caring for a newborn who appears acutely ill, call 9-1-1 and arrange for the newborn to be transported to the nearest hospital emergency department.

It is very important that parents identify a primary care provider (PCP) for their newborn and that all of the PCP's contact information entered on the NBS card is correct. The NBS Program will notify the PCP immediately if the specimen is:

- Positive for a disorder
- Unsatisfactory for testing
- Early (obtained before 24 hours of life)

## Hearing Screening

Approximately 150 hearing impaired newborns are identified annually by newborn hearing screening in Michigan. Michigan has instituted a mandated screening and reporting system for universal newborn hearing screening, therefore each homebirth attendant should have a procedure in place to assist families to obtain a hearing screen for their newborn. The Michigan Early Hearing Detection and Intervention (EHDI) Program is available to assist you in setting up your procedure. A list of Michigan birthing hospitals and respective hearing rescreen sites is maintained on the [MDHHS EHDI website](#).

Hearing screening should be completed no later than one month of age through either of the following methods: otoacoustic emissions (OAE) or automated auditory brainstem response (AABR). Newborns who exhibit evidence of hearing loss should have a hearing assessment by an audiologist no later than three months of age and receive early intervention services no later than six months of age.

The EHDI Program works with families, birth attendants and primary care providers to assure that every Michigan newborn has access to hearing services. See page 23 for additional [EHDI contact information](#).

## Critical Congenital Heart Disease Screening

Congenital heart defects are the most common group of birth defects, affecting 9 in 1000 newborns. Critical congenital heart diseases (CCHDs) are those requiring surgery or catheter intervention in the first year of life. CCHDs remain one of the most significant causes of infant death in the United States.

Effective April 1, 2014, the Michigan Department of Health and Human Services (MDHHS) implemented statewide screening of all Michigan newborns for critical congenital heart disease using pulse oximetry. The NBS Program and the CCHD Advisory Committee recommend that newborns be screened as close to 24 hours of age as possible, using the approved MDHHS CCHD Screening Algorithm.

More information about CCHD screening, data reporting and educational materials for healthcare providers and parents are available on the [MDHHS CCHD website](#) or by calling the NBS Program at 517-335-4181.

# NEWBORN SCREENING PRACTICE AND PROCEDURE

## Role of the Homebirth Attendant

The homebirth attendant plays a crucial role in assuring that the NBS process is both effective and efficient. The homebirth attendant fulfills this role by educating parents about NBS, assisting parents to obtain the NBS first sample card, collecting a satisfactory NBS specimen, and assuring prompt delivery of the dried specimen to the NBS Laboratory.

## Educating Parents about NBS

The NBS Program provides a variety of educational materials at no cost upon request. This includes *Michigan Newborn Screening Saves Babies* and the *Michigan BioTrust for Health* brochures. Brochures may be ordered by a link available at [www.michigan.gov/nbsorders](http://www.michigan.gov/nbsorders).

Ideally, the homebirth attendant should discuss the purpose and benefits of NBS with parents during prenatal visits. The NBS nurse consultant is available to answer any questions parents might have. See page 21 for [contact information](#). Updated information about NBS is also maintained on the [NBS website](#).

## Obtaining the NBS Card

Parents or homebirth attendants should obtain the NBS first sample card at least one month prior to the client's expected due date. Payment for the card(s) must be included with the order. A postage-paid return envelope is included with the card ordered for a homebirth. Additional envelopes are provided upon request. See [Appendix 5](#) for ordering information. Orders placed online are usually shipped within two days. Fee-waived requests and payments made by check can take up to four weeks to process.

Some families are eligible for a fee-waived card based on WIC income guidelines. See [Appendix 7](#) for ordering information.

Replacement cards are available free of charge for any card purchased that cannot be used. Reasons could include: card pieces are torn or separated, unsatisfactory specimen, wrong demographic information is entered, or parents refuse NBS. See [Appendix 8](#) for the *Newborn Screening Card Replacement* form and mailing instructions. Cards that have been submitted to the NBS Laboratory for testing are not eligible for replacement.

## Completing the NBS Card

It is extremely important to fill out the NBS card completely and accurately. Press firmly using a black or blue pen and **clearly print** the information. The card will be scanned into the NBS database, so legibility is critical. The specimen submitter is legally responsible for the accuracy and completeness of the information on the NBS card. Include the following information in the spaces provided:

### INFANT INFORMATION:

- ✓ **INFANT'S NAME:** Record the expected legal last name followed by the first name. If no first name is available at the time of specimen collection, the last name followed by "boy" or "girl" should be used. For single mothers, use the last name specified by the mother (preferred) or the mother's last name. **DO NOT LEAVE THIS AREA BLANK.**
- ✓ **GENDER:** Completely shade in the appropriate oval to designate newborn's gender as male or female.
- ✓ **BIRTH DATE:** Use a six-digit number (mm/dd/yy) for the date of birth. For example, a birth on January 4, 2019 would be recorded as 010419.
- ✓ **BIRTH TIME:** Record time of birth in military time. For example, a birth at 4:40 p.m. would be recorded as 1640. For help with time conversions see [Appendix 15](#).
- ✓ **BIRTH WEIGHT, GRAMS:** Record the birth weight in grams in the boxes provided on the first sample ("blue") card. Do not use pounds and ounces. For help with weight conversions see [Appendix 16](#).
- ✓ **CURRENT WEIGHT, GRAMS:** Record the current weight in grams in the boxes provided on the repeat sample ("pink") card. Do not use pounds and ounces. For help with weight conversions see [Appendix 16](#).
- ✓ **WEEKS GESTATION:** Record weeks of gestation at time of birth. Note: This information is requested for the first sample ("blue") card *only*. It is not necessary to add this information to the repeat sample ("pink") card.
- ✓ **SINGLE BIRTH:** Completely shade in oval for single birth.
- ✓ **MULTIPLE BIRTH ORDER:** Completely shade in oval to record birth order by "A", "B", "C", for twins, triplets, etc.
- ✓ **ANTIBIOTICS:** Mark 'yes' next to antibiotics if the newborn received postnatal antibiotics prior to the first sample specimen collection or is currently receiving antibiotics at the time of a repeat sample collection. Do not check antibiotics if the newborn received antibiotics in the past but has not received them within 48 hours of collection. It is no longer necessary to include information about the mother's perinatal antibiotic use.
- ✓ **SPECIMEN DATE:** Use a six-digit number (mm/dd/yy) representing the date on which the specimen was obtained.
- ✓ **COLLECTION TIME:** Record time of specimen collection in military time. For help with time conversion see [Appendix 15](#).
- ✓ **COLLECTED BY:** Record initials of person collecting the specimen.
- ✓ **NICU/SPECIAL CARE:** This designation is used by hospitals and does not apply to homebirths.
- ✓ **RBC TRANSFUSION:** This is not likely to apply to homebirths and may be left blank.



- ✓ **MEDICAL RECORD NUMBER-BABY:** This is not likely to apply to homebirths and may be left blank.
- ✓ **ANY TPN FEEDING:** Completely shade in oval “yes” if the newborn is receiving total parenteral nutrition (TPN) at the time the specimen is obtained -OR- received TPN within 24 hours of specimen collection. This is highly unlikely to apply to homebirths and may be left blank.
- ✓ **ETHNICITY:** Completely shade in oval for Hispanic or non-Hispanic. Ethnicity should be filled in first and, in addition, one of the six boxes for race should be filled in. Mark the mother’s ethnicity if the father’s ethnicity is unknown.
- ✓ **RACE:** Completely shade in the oval for one of the six racial categories after the designation of Hispanic or non-Hispanic has been selected. If the newborn has a parent in one racial category and the other parent in a different racial category, fill in the Multi-Racial oval. It is very important to fill in either the Hispanic or non-Hispanic box and in addition fill in one of the six boxes for race. Mark the mother’s race if the father’s race is unknown.

*Example 1:* One parent identifies as Hispanic and both parents identify as Black. The card should be marked Hispanic and Black.

*Example 2:* One parent identifies as Hispanic and White; the other parent identifies as non-Hispanic and Black. The card should be marked Hispanic and Multi-Racial.

*Example 3:* Neither parent identifies as Hispanic. One parent identifies as White; the other parent identifies as Black. The card should be marked non-Hispanic and Multi-Racial.

- ✓ **TYPE OF COLLECTION:** The preferred collection method is by heel stick with a single drop of blood applied directly to each circle on the filter paper. Check both “heel” *and* “capillary” if the blood was collected from the heel using a capillary tube. Note that the use of capillary tubes can result in layered, serum, clotted and damaged specimens. Specimens collected by methods other than heel stick are not likely in the homebirth setting.
- ✓ **OTHER FEEDING:** Check all that apply. For instance, if a mother is both breast and bottle feeding, mark both and indicate the type of formula.

## MOTHER INFORMATION:

- ✓ **MOTHER’S NAME:** Record last followed by first name **as it will appear on the newborn’s birth certificate**. If the newborn is going to be released at birth to adoptive or foster parents, provide contact information of adoptive or foster mother. Please note in black ink above the mother’s name that contact information is for adoptive or foster mother. Do not place sticky notes on the card or use red ink. Neither will be recorded when the card is scanned into the NBS database. If contact information on new parents, foster parents, or the adoption agency is not on the card, the NBS Program will not be able to contact the family if necessary. The NBS Program would like to avoid calling the birth mother if she is no longer responsible for the care of the newborn.
- ✓ **MOTHER’S ADDRESS:** Record mother’s current street address, apartment/unit/lot number, city, state and zip code. Information about the mother is needed to locate newborns in need of clinical evaluation or retesting.
- ✓ **MOTHER’S PHONE:** Record mother’s area code and primary telephone number. If the family does not have a phone, please enter a contact phone number, such as that of a community phone.
- ✓ **MEDICAL RECORD NUMBER-MOTHER:** This is not likely to apply to homebirths and may be left blank.
- ✓ **BIRTH DATE:** Record the mother’s date of birth (mm/dd/yy).
- ✓ **HEPATITIS B SURFACE ANTIGEN (HBsAg):** Provide date of test (mm/dd/yy) and completely shade in the appropriate oval to indicate a positive or negative result. If there is no HBsAg test result

in the mother's record, the test should be done immediately. Positive HBsAg results should be reported to the MDHHS Hepatitis B program via phone at 517-335-9943 or fax to 517-335-9855. This important information helps assure that infants at risk receive the proper treatment WITHIN 12 HOURS OF BIRTH. It is not necessary to add this information on the repeat sample ("pink") card.

## PROVIDER INFORMATION:

- ✓ **PROVIDER'S NAME:** Record last name, followed by first name, of the primary care provider (PCP) the newborn is expected to see for well-child and sick care. The NBS Program will notify the PCP if a repeat screen is needed or if the infant screens positive for a disorder and confirmatory testing is needed. **In most cases, the PCP is not the midwife or birth center.**
- ✓ **PROVIDER'S PHONE:** Indicate the PCP's area code followed by the telephone number. It is very important to provide a complete and correct number. This information is used to contact the PCP with positive screen results and follow-up information.
- ✓ **PROVIDER'S FAX:** Indicate the PCP's area code followed by fax number. The fax number is needed to forward to the PCP screening results that require further follow-up.

## SUBMITTER INFORMATION:

- ✓ **SUBMITTER NAME:** Record the name of the submitter. This is usually the name of the midwife who attended the birth. It is acceptable to apply a pre-printed label that includes the submitter's name, address and phone number.
- ✓ **HOSPITAL CODE:** This code is not used for homebirths or births that occur in a birthing center.
- ✓ **SUBMITTER ADDRESS:** Record the submitter's street address followed by the city, state and zip code. This is usually the address of the midwife who attended the birth or the address of the birth center.
- ✓ **SUBMITTER PHONE:** Record submitter's area code and phone number.
- ✓ **BIRTH HOSPITAL:** Enter "homebirth" or the name of the birthing center.

### Recording the NBS Card Number

The NBS card ('kit') number is located on the lower right-hand corner of the NBS first and repeat sample cards. See [Appendix 3](#) for an image of the NBS first sample card. Please include this number on form DCH-0486 (Rev 12/2013), *Michigan Live Birth Worksheet*, which is provided by the MDHHS Vital Records & Health Statistics Section. Information on how to file a birth certificate is located in a later section.

### Parental Refusal of Newborn Screening

If parents object to NBS, they should be asked to sign a waiver that indicates that they have been informed of the risk to their newborn if screening is not done. Each homebirth attendant should seek legal guidance to develop his/her own refusal form. The homebirth attendant should fax or mail a copy of the signed refusal form to the NBS Program. See [Appendix 9](#) for a sample refusal letter.

Parents whose only objection is that their child's specimen will be stored indefinitely by the State can choose to have the newborn screen done and then have the blood spots destroyed once testing is completed. See [Appendix 11](#) for the *Directive to Destroy Residual Newborn Screening Blood Specimen* form.

## Michigan BioTrust for Health

The Michigan BioTrust for Health (BioTrust) is a program that oversees the storage of residual dried blood spots (DBS) from NBS for their potential use in medical and public health research. All birth attendants should provide the BioTrust consent brochure entitled, *After Newborn Screening, Your Baby's Blood Spots*, to parents and ask if they are willing to grant permission to make their infant's DBS available for health research once NBS is complete. Permission is granted by marking the "yes" check box and signing the consent form located on the back of the NBS first sample card. If parents decline permission for the BioTrust, please have them mark the "no" checkbox and sign the BioTrust form. NBS program staff, upon request, will provide on-site training on the BioTrust and the parental consent process. This training is also available on the [newborn screening website](#) by clicking on *Information for Hospitals and Health Professionals*. A copy of the consent brochure *After Newborn Screening: Your Baby's Blood Spots* is included in the homebirth kit.

If a parent declines the BioTrust, his/her newborn's DBS will still be stored unless the parent requests that the specimen be destroyed. Parents who would like to have their newborn's DBS destroyed should sign and return the *Residual Newborn Screening Blood Spot Directive* form. If a parent is comfortable with his/her newborn's DBS being stored but not made available for research, no additional steps are necessary other than marking the "no" checkbox and signing the BioTrust consent form located on the back of the NBS first sample card. Only DBS with signed (YES) consent forms will be made available for potential research use.

Residual DBS of persons born after July 1984 and prior to May 2010 are currently stored and available for research through the BioTrust. Persons over the age of 18 or parents of minor children who would like to have these samples destroyed must sign and return the *Residual Newborn Screening Blood Spot Directive* form. Persons over the age of 18 or parents of minor children who would like these samples to remain in storage but no longer made available for research must sign and return the *Residual Newborn Screening Blood Spot Directive* form. See [Appendix 11](#) for the directive form.

### BIOTRUST CONSENT FORM INSTRUCTIONS:

1. Provide the *Michigan Newborn Screening Saves Babies* brochure and the *After Newborn Screening, Your Baby's Blood Spots* BioTrust consent brochure to parents. Clarify the difference between the mandatory NBS Program and the optional Michigan BioTrust for Health, which allows residual DBS to be used for research.
2. Inform parents about the [Michigan Newborn Screening Saves Babies video](#) and that it can be viewed on the state [NBS website](#). Birth attendants may request a complimentary copy of this video from the NBS Program to view with their families.
3. Complete the demographic information on the front of the NBS first sample card and collect the blood specimen as usual. The BioTrust consent form for residual DBS use is attached to the back of the NBS first sample card. See [Appendix 3](#).  
*Note: Each NBS card has the same unique ID number on all pages, including the BioTrust consent form. This number is used to link a baby's NBS specimen to the parent's BioTrust consent form if received at a later time in the NBS Laboratory.*
4. Prior to obtaining consent, confirm that parents have received the NBS brochure and BioTrust consent brochure.
  - The *Michigan Newborn Screening Saves Babies* brochure explains NBS and introduces the Michigan BioTrust for Health.
  - The *After Newborn Screening, Your Baby's Blood Spots* consent brochure details possible research use of residual DBS and information needed for parents to decide whether to grant permission for use of these DBS for research.
5. If parents wish to allow use of their newborn's residual DBS for research, ask one parent to mark the "yes" checkbox and sign the white copy of the BioTrust consent form located on the back of the blue first sample card.

- If consent is not granted, ask one parent to mark the “no” checkbox and sign the white copy of the BioTrust consent form. Return the white copy to the NBS Laboratory once the parent marks his/her decision and signs the consent form.
  - The pink copy is for the parent to keep.
6. Submit the white copies of the BioTrust consent form in the same envelopes used for DBS specimen cards. *Note: A consent form does not need to be in the same envelope as a particular newborn’s NBS specimen card. **Do NOT delay returning a newborn’s NBS specimen card while waiting for the consent form!***

### Specimen Collection

- Direct specimen collection from a heel puncture is preferred for optimal laboratory results. Blood collection using capillary tubes is discouraged. Please follow the Clinical and Laboratory Standards Institute (CLSI) guidelines for NBS specimen collection. Refer to the [CLSI website](#) for additional information.
- Specimens should be collected between 24-36 hours of age, ideally 24-30 hours.
- Specimens should be air dried for a minimum of three hours.
- Do not expose the specimen to fans, heat or other fluctuations in temperature and humidity.
- [Examples of specimens.](#)

### Sending the NBS Specimen to the State NBS Laboratory

Homebirth packets now include a UPS label in addition to the prepaid mailing envelope. You may use either option for sending NBS specimens to the State NBS Laboratory. Using a UPS label properly guarantees next day delivery. Specimens received by mail can take up to two weeks to arrive, though most arrive within four days.

### Instructions for using UPS labels

1. Enter your name and address in the “Shipment From” box on the shipping label.
2. Enter the date in the “Date of Shipment” box.
3. Use a UPS Express Envelope that you can obtain from a UPS store or Staples. It is not necessary to use the white postage-paid envelope included in the homebirth packet, though using it does provide added protection to the specimen.
4. The cutoff time for next day delivery can vary depending on the UPS store or Staples store you use. Make sure you know your outlet’s cutoff time, which is usually around 4:00 p.m.
5. UPS drop boxes should not be used unless it is very close to the pickup time. Fluctuations in temperature and humidity can adversely affect specimen quality.
6. UPS does not pick up or deliver on the following holidays: New Year’s Day, Memorial Day, July 4<sup>th</sup>, Labor Day, Thanksgiving Day, Christmas Day and New Year’s Eve.
7. You may put more than one specimen in a UPS envelope.
8. Keep the “Shipper’s Copy” for your records. The “tracking number” can be used to track your shipment by visiting the [UPS website](#).

### Friday envelopes only

9. Check “Saturday delivery” if you are sending the envelope on Friday. Failure to check this box means the envelope will not arrive until the following Monday.
10. Apply an orange “Saturday Delivery” label below the shipping label.
11. If you believe that weather may delay delivery of an envelope dropped off on Thursday, treat it as a Friday envelope. Otherwise it may not reach the NBS Laboratory until the following Monday.

### Mailing the NBS specimen

As soon as the specimen is completely dry, place it in the postage-paid envelope provided by the NBS Program. *Do not place the specimen in a plastic bag.* It is recommended that you mail the specimen

inside the post office and that you *not* place it in an outside mailbox. Fluctuations in temperature and humidity can adversely affect specimen quality. Whenever possible, mail the NBS specimen the same day that the specimen has dried or shortly thereafter. Some disorders can be life-threatening within the first week of life. Failure to submit a specimen promptly may result in an unnecessary delay in diagnosis and treatment of an affected infant. Enter your name, address and the date mailed on the NBS envelope. Keep a record of when and where you mailed the specimen. Contact the NBS coordinator at 866-673-9939 if you believe a specimen you mailed was delayed reaching the NBS Laboratory or was lost in transit. The coordinator will work with the post office on these issues.

## HEALTHCARE PROVIDER INFORMATION

### Follow-up of Positive NBS Results

When the NBS Program identifies a strong positive NBS result, the primary care provider is notified immediately by fax. The following items are included in the fax notification:

- NBS results
- Action required
- Sub-specialist contact information

Simultaneously, the appropriate sub-specialist is notified. The health care provider will be contacted by the consulting sub-specialist to develop a plan of action for necessary diagnostic testing and evaluation that is congruent with clinical status.

The NBS Program may ask the health care provider for additional information over time as part of program evaluation and long-term follow-up. The requests for information are required for NBS follow-up and are not subject to limitations of the Health Information Portability and Accountability Act (HIPAA). See [Appendix 4](#) for an explanation of why information pertaining to follow-up of abnormal NBS results is exempt from HIPAA.

### NBS Result Request Policy

The homebirth attendant who submitted the NBS specimen will receive the *Newborn Screening Laboratory Report* and the *Physician Forward Copy* to send to the newborn's primary care provider.

The NBS Program does not give NBS results over the telephone. NBS results are available on the [Michigan Care Improvement Registry \(MCIR\) website](#) after the NBS record is successfully linked to the newborn's birth certificate and immunization records. Results are not posted to MCIR if the infant is released for adoption or placed in foster care.

Alternatively, if the laboratory has completed testing, results can be obtained by faxing a request on primary care provider letterhead to 517-335-9419 or 517-335-9739. The request should include:

- Baby's name and date of birth
- Mother's name at time of delivery
- Primary care provider fax number
- If you are not the provider recorded on the NBS card, a parent/guardian signed release should be included with the request.

If results for a particular test are needed, please specify the disorder on your request.

## Questions on Positive Reports Received

Contact the follow-up coordinating [center](#) identified on the report if you have questions about clinical symptoms and/or questions about a positive report. Call the NBS Program if you are unable to locate this information or have other questions.

The following are common calls received by the NBS Program for information that is available on the NBS website or in this guide:

- [List of disorders included in the Michigan NBS panel](#)
- Written instructions for completing the NBS card
- NBS specimen collection presentation
- [NBS educational online tutorial](#)
- [NBS Annual Reports that give the number of confirmed cases per year](#)

## Documentation of NBS Results

Documentation that a newborn has been screened should be available for every newborn and included in the record kept by the homebirth attendant. Tracking repeat specimens (because the first sample specimen was borderline positive, collected before 24 hours of life, or unsatisfactory for testing) is important. The newborn's primary care provider is responsible for facilitating subsequent testing.

Do not assume that no news is always good news. If you have not received results of the newborn screen within two weeks of when you sent the specimen, contact the NBS Follow-up Program Monday through Saturday, 866-673-9939 or 517-335-4181, to obtain a copy of the results.



# BIRTH CERTIFICATES

## Persons Required to Report a Live Birth

Homebirth attendants are required to report live births in the state of Michigan. The issuance of birth certificates is governed by Section 333.2822, Act 368 of the 1978 Public Health Code. See [Appendix 12](#) for a link to the entire section. The following is an excerpt:

- (b) If a live birth occurs outside an institution, the record shall be prepared, certified, and filed with the local registrar by 1 of the following individuals in the following order of priority:*
- (i) The physician in attendance at or immediately after the live birth.*
  - (ii) Any other individual in attendance at or immediately after the live birth.*
  - (iii) The father, the mother, or, in the absence of the father and the inability of the mother, the individual in charge of the premises where the live birth occurs.*

Local registrars are instructed by the state of Michigan to register out-of-hospital births.

- Blank birth records are not to be provided
- The registrar may provide a worksheet to the mother, attendant or informant to complete.
- Parents who use the services of a midwife might also be expected to have in their possession the following:
  - A driver's license or State Police I.D.
  - A marriage license (if married)
  - A properly filled out affidavit of parentage or probate court paternity documents (if unmarried)
  - A completed birth certificate worksheet with the midwife's signature at the bottom under the signature of the mother or informant

The local registrar may also request the following:

- A baptismal certificate
- A statement from a social services worker that the client was pregnant
- A similar verification from a physician or public health nurse
- A signed statement from a midwife documenting the name of the mother who delivered, the date of the event and place, etc.
- The infant be presented in person in order to register his/her birth

The local registrar or his/her authorized representative should type the birth certificate.

The completed birth certificate should be signed by the attendant and informant at the registrar's office. It is not given to the mother, informant, or attendant to take out of the registrar's office.

Each individual local registrar is responsible for ascertaining whether or not a woman has actually given birth when a request is made in the local clerk's office for a birth certificate to be created because of a homebirth. The staff may employ any reasonable means to confirm the birth.

Parents should be informed that the reporting of live births should be completed as soon as possible with the local registrar.

## FREQUENTLY ASKED QUESTIONS

### **Who informs parents about NBS?**

The homebirth attendant is ultimately responsible for informing parents about the NBS process. Education is ideally done during the prenatal period. To facilitate talking with parents, the NBS Program recommends using the *Michigan Newborn Screening Saves Babies* educational brochure as a tool.

### **What is the chance that a newborn will have a disorder detected by NBS?**

Of the 109,740 infants screened in 2017, 304 were diagnosed with a disorder. Overall, one infant out of 361 screened was diagnosed with one of the disorders included in the Michigan NBS panel.

### **What if a newborn has a family history of a disorder detected by NBS?**

Please inform the NBS Program if a family has a history of a disorder on the Michigan NBS panel. You may also write this information on the top of the NBS card.

### **What is the NBS Program's specimen storage policy?**

Residual NBS specimens are stored indefinitely once NBS is completed. Stored specimens may be used for quality control purposes or for new test development. Medical or public health researchers may use coded specimens through the Michigan BioTrust for Health once their proposal has been reviewed and approved by the BioTrust Scientific Advisory Board and the MDHHS Institutional Review Board. NBS specimens collected after May 1, 2010 can only be used if parental consent was granted for such research. Specimens collected prior to May 1, 2010 are available for research unless parents contact the MDHHS and opt-out.

### **Who decides what disorders are included on the NBS panel?**

Based on nationally accepted criteria, the NBS Quality Assurance Advisory Committee makes recommendations on disorder inclusion to the MDHHS director. The NBS Quality Assurance Advisory Committee meets once each year. Members include parents of affected children, health care providers, hospital representatives, and other medical experts.

### **What if I need to talk to someone at the NBS Program or a medical sub-specialist?**

Call 866-673-9939 to reach someone in the NBS Program who can answer your question or direct you to the appropriate medical sub-specialist.



## RESOURCE LIST

[Michigan Newborn Screening website](#)

[Genetics Home Reference website](#)

[NBS educational online tutorial](#)

[National Newborn Screening and Genetics Resource Center](#)

[The American Academy of Pediatrics](#)

### **National Newborn Hearing Websites**

[Centers for Disease Control Early Hearing Detection and Intervention](#)

[Marion Downs National Center for Infant Hearing](#)

[National Center for Hearing Assessment and Management](#)

[National Institute on Deafness and Other Communication Disorders](#)

[American Speech Language Association](#)

[American Academy of Audiology](#)

[Hands and Voices](#)

## CONTACT INFORMATION

### NBS Follow-up Program

[Michigan Department of Health and Human Services](#)  
[Newborn Screening Follow-up](#)

333 S. Grand Ave.  
PO Box 30195  
Lansing, Michigan 48909

**Toll-free:** 866-673-9939

**Phone:** 517-335-4181

**Fax:** 517-335-9739 or 517-335-9419

**E-mail:** [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov)

### STAFF

**Mary Kleyn**

NBS Section Manager  
517-335-9296

**Lois Turbett**

NBS Nurse Consultant  
517-335-1966

**Karen Andruszewski**

Quality Assurance Coordinator  
517-335-8532

**Valerie Ewald**

NBSO Administrator  
517-335-1400

**Kristen Thompson**

NBS Program Coordinator and CCHD contact  
517-373-0937

**Shawn Moloney**

NBS Operations Coordinator  
517-335-1207

## **CONTACT INFORMATION**

### **NBS Laboratory**

**Michigan Department of Health and Human Services**

**Newborn Screening Laboratory**

3350 N. Martin Luther King Jr. Blvd.

P.O. Box 30689

Lansing, Michigan 48909-8189

### **STAFF**

**Mary Seeterlin, manager**

NBS Laboratory Section

517-335-9779

**Alayna Bunker**

Departmental technician

517-335-4031

## CONTACT INFORMATION

### Early Hearing Detection and Intervention

#### [Michigan Department of Health and Human Services](#)

#### [Early Hearing Detection and Intervention](#)

Division of Family and Community Health

109 W. Michigan Avenue, 3<sup>rd</sup> floor

P.O. Box 30195

Lansing, MI 48909

**Phone:** 517-335-8955

**Fax:** 517-335-8036

### STAFF

#### **Nick Drzal**

Infant Health Unit manager

#### **Michelle Garcia**

Follow-up consultant

517-335-8878

#### **Debra Behringer**

EHDI coordinator

517-373-8601

#### **Nan Asher**

Program consultant

517-335-8273

#### **Erin Estrada**

Data analyst

517-335-8916

#### **Patricia Taylor**

Infant Health Unit secretary

517-335-8955

#### **Karen Wisinski**

Parent consultant

517-241-7066

#### **Dona McGovern**

EHDI administrative assistant

517-335-7835

## CONTACT INFORMATION

### Hepatitis B

[Michigan Department of Health and Human Services](#)  
[Perinatal Hepatitis B Prevention Program](#)

333 S. Grand Avenue  
P.O. Box 30195  
Lansing, MI 48909

**Toll-Free:** 800-964-4487  
**Phone:** 517-335-9443

### STAFF

**Patrick Fineis**  
Program coordinator  
517-335-9443

**Detroit Regional Office**  
**Michigan Department of Health and Human Services**  
3056 W. Grand Blvd., Ste. 3-220  
Detroit, MI 48202

**Phone:** 313-456-4431  
**Fax:** 517-335-9855

**Kari Tapley**  
Surveillance specialist  
313-456-4431

### Vital Records

**Michigan Department of Health and Human Services**  
**Vital Records Office**  
333 S. Grand Avenue  
Lansing MI 48913

**Vital Records Call Center**  
517-335-6506

## CONTACT INFORMATION

### Follow-up Coordinating Centers

**Hemoglobinopathies – Sickle cell anemia (Hb SS), hemoglobin SC disease, sickle beta thalassemia zero (S $\beta$ <sup>0</sup>), sickle beta thalassemia plus (S $\beta$ <sup>+</sup>), and hemoglobin H disease.**

**Sickle Cell Disease Association of America, Michigan Chapter**

18516 James Couzens  
Detroit, MI 48235  
Telephone: 313-864-4406  
Toll-free: 800-842-0973  
Fax: 313-864-9980  
[info@scdaami.org](mailto:info@scdaami.org)

**Children's Hospital of Michigan**

3901 Beaubien Blvd.  
Detroit, MI 48201-2192  
Telephone: 313-745-5613  
Fax: 313-745-5237  
Call for a referral to social work and counseling sites in Benton Harbor, Kalamazoo, Grand Rapids, Muskegon, Lansing, Flint, Saginaw and Pontiac.

**Metabolic – Amino acid disorders, fatty acid oxidation disorders, organic acid disorders, galactosemia, biotinidase deficiency, lysosomal storage disorders.**

**Children's Hospital of Michigan Metabolic Clinic**

3950 Beaubien Blvd.  
Detroit, MI 48201-2192  
Telephone (endocrine and cystic fibrosis): 313-832-9330  
Fax (endocrine and cystic fibrosis): 313-745-8030  
Telephone (metabolic): 734-764-0579

**Endocrine – congenital adrenal hyperplasia and hypothyroidism**

**Cystic fibrosis**

**Metabolic - lysosomal storage disorders**

**Michigan Medicine at the University of Michigan**

Department of Pediatrics  
1500 E. Medical Center Dr.  
D1225 MPB, Box 0718  
Ann Arbor, MI 48109-0718  
Telephone: 734-647-8938  
Fax: 734-936-7918

**Severe Combined Immunodeficiency**

**Children's Hospital of Michigan Coordinating Center for Primary Immunodeficiencies**

3901 Beaubien St., 5th floor Carls Building  
Detroit, MI 48201  
Telephone: 313-806-6571  
Pager: 313-745-0203; enter pager number 5706  
Fax: 313-966-9701

## **Appendix 1 – Legislative Mandates**

### [Highlights of the Michigan Newborn Screening Law, MCL 333.5431](#)

The Michigan Public Health Code regarding newborn screening applies to all newborns who are born in the State of Michigan. All birthing attendants, such as midwives who attend homebirths, are mandated to obtain a newborn screen. Violation of this section of the public health code is a misdemeanor.

The Michigan Newborn Screening Laboratory tests all NBS dried blood spots. There is no parental opt-out statute in Michigan because the public health code directs birthing hospital and birth attendant compliance with the statute. Parents may refuse testing, though this rarely happens.

The fee for the NBS card is set each year. Eligibility for a fee-waived card is based on WIC income guidelines.


# Appendix 2 – Blood Specimen Collection and Handling Procedure

These instructions are found on the back of each NBS card (“kit”):


**DO NOT REMOVE OVERLAY**

See attached instructions for specimen collection and sending.

Allow blood to dry for a minimum of 3 hours using the overlay for support. Close the overlay when dry. Send within 24 hours of collection.



Do not send specimens in plastic bags.



**INSTRUCTIONS FOR SPECIMEN COLLECTION AND SENDING**

**SUBMITTER RESPONSIBILITY**

1. Complete the form.
2. Collect an adequate quality specimen.
3. Send specimens promptly i.e., within 24 hours.
4. List the health care provider who will care for the infant after discharge.

**SCREENING REQUIREMENTS FOR ALL NEWBORNS**


1. Initial screen should be collected prior to blood transfusion, regardless of age.
2. Collect sample at 24 - 30 hours of age, or before discharge or transfer.
3. Infants screened before 24 hours require a repeat screen within 7 days.
4. All premature and sick infants should be screened according to DHHS NICU guidelines.

**COMPLETION OF FORM**

1. Legibly print and complete all information required. Do not use red ink.
2. List submitter's return address.
3. List the provider or physician who will be following the infant for well care.
4. List the mother's correct address and phone number.

**COLLECTION OF THE BLOOD SPECIMEN**

1. Do not touch the filter paper circles before or after collection.
2. Select puncture site and cleanse with 70% isopropanol and allow heel to air dry.
3. Use a sterile, disposable incision device (2.5mm wide or less and 1.0mm deep or less) to perform a swift clean incision.
4. Wipe away the first drop of blood with sterile gauze.
5. Gently touch the filter paper against a large drop of blood and allow a sufficient quantity of blood to soak through to completely fill the preprinted circle. Blood must be applied to only one side of the filter paper and the circle should be fully saturated.
6. Do not use capillary tubes or other devices that contain EDTA or Heparin.
7. Apply one large drop of blood to each circle. Fill a minimum of 5 circles.
8. Protect specimens from accidental contact with liquids.
9. Allow blood specimen to air dry horizontal at room temperature for a minimum of 3 hours. Do not stack wet specimens. Do not expose specimens to heat, direct sunlight, or high humidity.



Collect Sample from shaded area





**SEND SPECIMENS TO:**  
 Newborn Screening Laboratory  
 Michigan Department of Health & Human Services  
 3350 N. Martin Luther King Jr. Blvd.  
 PO Box 30689  
 Lansing, MI 48909-8189

**Program Phone Numbers**  
 Newborn Screening: 1-866-673-9939  
 Newborn Hearing: (517) 335-8955  
 Hepatitis Program: (517) 335-8122

**For information on Newborn Screening card, envelope and brochure ordering visit:**  
[www.michigan.gov/NBSorders](http://www.michigan.gov/NBSorders)  
 or call (517) 335-8887

**SEND SPECIMENS BY COURIER WITHIN 24 HOURS OF COLLECTION**

Perkin-Elmer Health Sciences, Inc.  
 177 Mt. Pleasant, Greenville, SC 29615 USA

Please follow the Clinical and Laboratory Standards Institute (CLSI) guidelines for NBS specimen collection. Refer to the [CLSI website](http://www.clsi.org) for additional information.



# Appendix 3 – NBS Card Images

## NBS First Sample (“blue”) Card

Newborn Screening - Michigan Department of Health and Human Services  
Bureau of Laboratories P.O. Box 36659 3359 N. MLK Jr. Blvd., Lansing MI 48909  
Print Firmly with Black Pen

DON'T USE RED INK

BABY

LAST NAME \_\_\_\_\_ FIRST NAME \_\_\_\_\_ GENDER  MALE  FEMALE

BIRTH DATE \_\_\_\_\_ BIRTH TIME (Military) \_\_\_\_\_ BIRTH WT. (grams) \_\_\_\_\_ WKS GESTATION \_\_\_\_\_ BIRTH ORDER  A  B  C  D ANTIBIOTICS?  NO  YES

SINGLE BIRTH  MULTIPLE BIRTH →

SPECIMEN DATE \_\_\_\_\_ COLLECTION TIME (Military) \_\_\_\_\_ Collected By: \_\_\_\_\_ NCU or SPECIAL CARE?  NO  YES → ANY SSC TRANSFUSION?  NO  YES → TRANSFUSION DATE \_\_\_\_\_ TRANS. START TIME (Military) \_\_\_\_\_

MEDICAL RECORD # \_\_\_\_\_ TPN (AMINO ACIDS)  NO  YES  HISPANIC  AMERICAN INDIAN  ARAB DESCENT  NON-HISPANIC  BLACK  ASIAN/PACIFIC ISLAND.  MULTI-RACIAL

TYPE OF COLLECTION:  Heel Stick  Capillary Tube  Line Draw (central, other) \_\_\_\_\_ Type of Flush (heparin, saline, other) \_\_\_\_\_ OTHER FEEDING:  BREAST  MILK-BASE  SOY  NONE

MOTHER

LAST NAME \_\_\_\_\_ FIRST NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_ PHONE \_\_\_\_\_

CITY \_\_\_\_\_ STATE \_\_\_\_\_ ZIP \_\_\_\_\_

MEDICAL RECORD # \_\_\_\_\_ BIRTH DATE \_\_\_\_\_ HEPATITIS B SURFACE ANTIGEN (HBsAg) TEST DATE \_\_\_\_\_ RESULT  POSITIVE  NEGATIVE

PROVIDER

LAST NAME \_\_\_\_\_ FIRST NAME \_\_\_\_\_

PHONE \_\_\_\_\_ FAX \_\_\_\_\_

SUBMITTER

SUBMITTER NAME \_\_\_\_\_ HOSPITAL CODE (if applicable) \_\_\_\_\_

ADDRESS \_\_\_\_\_ PHONE \_\_\_\_\_

CITY \_\_\_\_\_ STATE \_\_\_\_\_ ZIP \_\_\_\_\_

BIRTH HOSPITAL (if different from submitter) \_\_\_\_\_

**FIRST SAMPLE**


HOSPITAL CODE (if applicable) **00**

MDHHS USE ONLY

2611601

MDHHS By Authority of Act 508  
P.A. MCLA 333.5431  
PerinatalMer 220

111064 / 30510001 EXPIRES: 2020-11-30

 Before signing this form please read, Your Baby's Blood Spots. It gives details on how small drops of blood (blood spots) collected for newborn screening may be used in research through the Michigan BioTrust for Health. If you have questions, please call the Michigan Department of Health and Human Services (MDHHS) toll free at 1-866-673-9939.

**Yes, my baby's leftover newborn screening blood spots may be used for health research.**  
By checking this box you understand:

- After newborn screening, blood spots are coded only with a number and stored up to 100 years at a secure site (Biobank). MDHHS can link the coded blood spots to your baby. This allows use of specific spots for research. It also allows MDHHS to find the right spots if you, or your grown child, change your mind.
- Researchers only receive coded blood spots. Details that could identify you, or your baby, are not provided.
- The risk of using blood spots in research is that your baby could still be identified. This risk is very low because many steps are taken to protect privacy.
- Research using blood spots must be approved by MDHHS. Blood spots can only be used for studies to better understand disease or improve the public's health such as research on cancer, birth defects and diabetes.
- Many laboratory methods are used to study biological or environmental factors such as genes, infectious agents, toxins and metals.
- Blood spot research may not directly help you, your child or your family. This type of research aims to improve the health of communities.
- Participation is voluntary. You can call MDHHS at any time if you change your mind. There is no penalty or loss of benefits for saying no or changing your mind.

**No, my baby's leftover newborn screening blood spots may not be used for health research.**  
By checking this box you understand:

- Blood spots will be stored for up to 100 years but not used for research. The blood spots are stored so that the state lab can perform quality control tests and improve newborn screening.
- You must contact MDHHS if you do not want blood spots stored for any reason after newborn screening.

Parent Signature \_\_\_\_\_ Date \_\_\_\_\_

Your choice applies to all blood spots collected for newborn screening. Please visit [www.michigan.gov/biotrust](http://www.michigan.gov/biotrust) for further information. For questions about your research rights or whom to contact in case of a research-related injury, please call the MDHHS IRB at 517-241-1928.

MDHHS Copy

2611601

DO NOT REMOVE OVERLAY

See attached instructions for specimen collection and sending.

Allow blood to dry for a minimum of 3 hours using the overlay for support. Close the overlay when dry. Send within 24 hours of collection.

Do not send specimens in plastic bags.

BIOHAZARD

If deleted, affix patient label on this bag, if the white consent form, inspect and sign by aged BioTrust biobank. Do not punch, mutilate and signatura. Return completed white consent form to MDHHS. One parent only copy.

Michigan BioTrust for Health Consent Form  
(Attached to the back of the NBS First Sample card)

## **Appendix 4 – Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule**

The HIPAA Privacy Rule recognizes the legitimate need for public health authorities and others responsible for ensuring public health and safety to have access to protected health information to carry out their public health mission. The Rule also recognizes that public health reports made by covered entities are an important means of identifying threats to the health and safety of the public at large, as well as individuals. Accordingly, the Rule permits covered entities to disclose protected health information without authorization for specified public health purposes.

The Privacy Rule can be found in its entirety on the [HIPAA Privacy Rule and Public Health](#) website.

## Appendix 5 – NBS Online Ordering System (NBSO)

NBS brochures and mailing envelopes are available at no charge. Orders for NBS cards require payment when the order is placed.

**NBSO Payment Options:** The NBSO system allows you to enter your practice's purchase order number and assign it to your order. Payment options include eCheck or credit card. These payments will be processed through the PayPlace, a secure site used by the State of Michigan for financial transactions. Learn more about PayPlace privacy on the [PayPlace privacy](#) website.

eChecks are an efficient and secure form of payment. They are used just like a check, but the bank routing number and account number will be entered electronically on the web-based order form instead of on a paper check. eCheck is NOT the same as an electronic fund transfer (EFT). An eCheck is processed like a check and the account is not debited until the check clears. If you are using eCheck to make your purchase, please call 517-335-1400 to get your permanent eCheck verification code, which you will need to use for all future orders. Learn more on the [eCheck](#) website.

If you are using a credit card, make sure the approved credit limit on the card is sufficient to cover the full cost of cards being purchased, and that the name, billing address, and zip code associated with the credit card account match the information you enter in PayPlace. **There is an annually adjusted processing fee of approximately 2.8% added to each credit card purchase.**

### Follow these steps to get started:

1. Visit [www.michigan.gov/nbsorders](http://www.michigan.gov/nbsorders)
2. Click NBSOnline Web Store – Order NOW!
3. Click *Register* if you don't have an account.
4. Upon completion of the registration process, a link will be sent to the email address used to register.

**Still have questions?** Please contact the NBSO Administrator, Valerie Ewald, at [nbsorders@michigan.gov](mailto:nbsorders@michigan.gov) or 517-335-1400.

## Appendix 6 – Ordering the NBS Card for Homebirths

### Michigan Department of Health and Human Services Newborn Screening Card Order for Homebirths

<p><b>Online:</b> visit <a href="http://www.michigan.gov/nbsorders">www.michigan.gov/nbsorders</a> click on link "Order Now"</p> <p><b>Make check payable to:</b> Michigan Department of Health and Human Services</p> <p><b>Mail order to:</b> MDHHS - Newborn Screening 333 S. Grand Ave., 2<sup>nd</sup> fl. P.O. Box 30195 Lansing, MI 48909 (allow three to four weeks for processing)</p>	<p><b>NBS Cards Contact Information:</b></p> <p><b>Valerie Ewald</b>  <b>Phone:</b> 517-335-1400  <b>Fax:</b> 517-335-9419  <b>E-mail:</b> <a href="mailto:nbsorders@michigan.gov">nbsorders@michigan.gov</a></p>
---	---

**Mail card to:**  **Mother**     **Midwife**

<p><b>Mother</b> Name: Address:  Email: Phone: Mother's due date: Mother's date of birth:</p>	<p><b>Midwife</b> Name: Address:  Phone:</p>
---	--

**First Sample (blue) cards**

Individual cards – indicate # of cards

**\$130.36 per card** (Effective October 1, 2018)

	Total price
--	-------------

**Repeat Sample (pink) cards**

Individual cards – indicate # of cards

**\$117.69 per card** (Effective October 1, 2018)

	Total price
--	-------------

To place your order online using credit card, please visit [www.michigan.gov/nbsorders](http://www.michigan.gov/nbsorders). There you will find a link to the NBSO ordering system. Once registered, select Midwife/Homebirth Kit.

Obsolete for orders placed after  
September 30, 2019

## Appendix 7 – Ordering a Newborn Screening Fee-Waived Card

Effective **October 1, 2018 to September 30, 2019**, the fee for a newborn screening card is \$130.36. The fee is waived if income matches or is less than the income guidelines listed below. Use this signed form when ordering a fee-waived NBS card for a homebirth.

Income Eligibility Guidelines (Effective from July 1, 2018 to June 30, 2019)					
Michigan gross income at or below					
Household Size	Annually	Monthly	Twice Monthly	Bi-Weekly	Weekly
1	\$22,459	\$1,872	\$936	\$864	\$432
2	30,451	2,538	1,269	1,172	586
3	38,443	3,204	1,602	1,479	740
4	46,435	3,870	1,935	1,786	893
5	54,427	4,536	2,268	2,094	1,047
6	62,419	5,202	2,601	2,401	1,201
7	70,411	5,868	2,934	2,709	1,355
8	78,403	6,534	3,267	3,016	1,508
Each add'l family member add	+ \$7,992	+ \$666	+ \$333	+ \$308	+ \$154

My family is eligible for a waiver of the newborn screening fee for **ONE of the following reasons**:

initial

I am the expectant mother and receive full Medicaid, # \_\_\_\_\_

Enter 8 or 10-digit State I.D. number, not 9-digit Medicaid health plan number

initial

My household size of \_\_\_\_\_ (include pregnancy) and annual income of \$ \_\_\_\_\_ qualify my family to receive a fee-waived card.

By signing this form, I am certifying that the information is accurate and complete to the best of my ability. I understand that I may need to show proof of this information.

\_\_\_\_\_  
Print mother's name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Mail card to:  **Mother**     **Midwife**

<p><b>Mother</b> Name: Address:  Email: Phone: Mother's due date: Mother's date of birth:</p>	<p><b>Midwife</b> Name: Address:  Phone:</p>
<p><b>Questions?</b> Call Valerie Ewald MDHHS, 517-335-1400 Toll-free 866-673-9939</p>	<p>Complete online with link available at: <a href="http://www.michigan.gov/nbsorders">www.michigan.gov/nbsorders</a> Fax completed waiver to: 517-335-9419 Mail completed waiver to: MDHHS - Newborn Screening 333 S. Grand Ave., 2<sup>nd</sup> fl. P.O. Box 30195 Lansing, MI 48909</p>

# Appendix 8 – NBS card replacement form



Date: \_\_\_\_\_

FACILITY NAME: \_\_\_\_\_

ATTN: (DEPT) \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY, STATE, ZIP: \_\_\_\_\_

CONTACT NAME: \_\_\_\_\_ TELEPHONE # \_\_\_\_\_

NUMBER OF CARDS RETURNED FOR REPLACEMENT: \_\_\_\_\_

I.D. NUMBERS ON THE CARDS RETURNED:


- This form should be filled out completely and mailed with the **white face sheet(s) only** of the card(s) intended for replacement to the address below. **It is not necessary to include the remaining portions of the kit.**
- To ensure a quicker turnaround time, send 10 face sheets or less.
- If there is blood on the white face sheet, place it in a biohazard bag.
- **DO NOT send card replacement requests to the NBS Laboratory.** Failure to send your request to the address below may result in no replacement card being issued.  
Please note: Courier envelopes are for blood spot specimens. **DO NOT** use courier envelopes for card replacement requests.

SEND FACE SHEET(S) OF CARD(S) TO BE REPLACED AND THIS FORM TO:

**Michigan Department of Health and Human Services**  
**Attn: Newborn Screening**  
333 S. Grand Avenue, 2<sup>nd</sup> floor  
PO Box 30195  
Lansing, Michigan 48909

# Appendix 9 – Parental Refusal for Newborn Screening Sample Form

(Page 1 of 2)

I (We) \_\_\_\_\_, the parent(s) or guardian(s) of \_\_\_\_\_, birth date \_\_\_\_\_, object to and refuse the requirement that my (our) child be screened for the presence of the disorders listed on the enclosed Michigan Department of Health & Human Services (MDHHS) newborn screening panel and posted on the [MDHHS Newborn Screening website](#).

I (We) have been fully informed of and fully understand the possible devastating consequences to my (our) child's health, including severe mental and/or physical impairment or death resulting from the disorders screened for by the MDHHS Newborn Screening (NBS) Program.

Therefore, I (we) release the Michigan Department of Health & Human Services, the hospital of birth and the person responsible for collection of the specimen from responsibility for screening my (our) child for the disorders listed on the MDHHS newborn screening panel. Furthermore, I (we) release and hold the Michigan Department of Health & Human Services, the hospital of birth and the person responsible for collection of the specimen harmless for any injury, illness, and/or sequelae that may result to my (our) child as a consequence of my (our) refusal to consent to the screening for the disorders listed on the MDHHS newborn screening panel.

\_\_\_\_\_  
Signature of parent or guardian

\_\_\_\_\_  
date

\_\_\_\_\_  
Signature of parent or guardian

\_\_\_\_\_  
date

\_\_\_\_\_  
Signature of witness

\_\_\_\_\_  
date

\_\_\_\_\_  
Signature of witness

\_\_\_\_\_  
date

Return signed copy by mail:

MDHHS  
NBS Follow-up SG2  
P. O. Box 30195  
Lansing, MI 48909

Or fax to:

Fax: 517-335-9419 or 517-335-9739

To assist in improving the newborn screening program we ask that you please indicate why you are refusing the blood spot test for your baby:

Cannot afford to pay for the card       Religious reasons       Privacy concerns

Other: \_\_\_\_\_

**Amino Acid Disorders**

1. Argininemia (ARG)
2. Argininosuccinic acidemia (ASA)
3. Citrullinemia Type I (CIT-I)
4. Citrullinemia Type II (CIT-II)
5. Homocystinuria (HCY)
6. Hypermethioninemia (MET)
7. Maple syrup urine disease (MSUD)
8. Phenylketonuria (PKU)
  9. Benign hyperphenylalaninemia defect (H-PHE)
  10. Biopterin cofactor biosynthesis defect (BIOPT-BS)
  11. Biopterin cofactor regeneration defect (BIOPT-REG)
12. Tyrosinemia Type I (TYR-I)
  13. Tyrosinemia Type II (TYR-II)
  14. Tyrosinemia Type III (TYR-III)

**Fatty Acid Oxidation Disorders**

15. Carnitine acylcarnitine translocase deficiency (CACT)
16. Carnitine palmitoyltransferase I deficiency (CPT-1A)
17. Carnitine palmitoyltransferase II deficiency (CPT-II)
18. Carnitine uptake defect (CUD)
19. Dienoyl-CoA reductase deficiency (DERED)
20. Glutaric acidemia type II (GA-2)
21. Long-chain L-3-hydroxy acyl-CoA dehydrogenase deficiency (LCHAD)
22. Medium/short-chain L-3-hydroxy acyl-CoA dehydrogenase deficiency (M/SCHAD)
23. Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)
24. Medium-chain ketoacyl-CoA thiolase deficiency (MCKAT)
25. Trifunctional protein deficiency (TFP)
26. Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)

**Organic Acid Disorders**

27. 2-Methyl-3-hydroxy butyric aciduria (2M3HBA)
28. 2-Methylbutyryl-CoA dehydrogenase deficiency (2MBG)
29. 3-hydroxy 3-methylglutaric glutaric aciduria (HMG)
30. 3-Methylcrotonyl-CoA carboxylase deficiency (3-MCC)
31. 3-Methylglutaconic aciduria (3MGA)

32. Beta-ketothiolase deficiency (BKT)
33. Glutaric acidemia type I (GA1)
34. Isovaleric acidemia (IVA)
35. Malonic Acidemia (MAL)
36. Methylmalonic acidemia cobalamin disorders (Cbl A,B)
37. Methylmalonic aciduria with homocystinuria (Cbl C,D)
38. Methylmalonic acidemia methylmalonyl-CoA mutase (MUT)
39. Multiple carboxylase deficiency (MCD)
40. Propionic acidemia (PROP)

**Hemoglobinopathies**

41. S/Beta thalassemia
42. S/C disease
43. Sickle cell anemia
44. Variant hemoglobinopathies
45. Hemoglobin H disease

**Endocrine Disorders**

46. Congenital adrenal hyperplasia (CAH)
47. Congenital hypothyroidism (CH)

**Lysosomal Storage Disorders**

48. Glycogen storage disease type II (Pompe)
49. Mucopolysaccharidosis type I (MPS I)

**Other Disorders**

50. Biotinidase deficiency (BIOT)
51. Galactosemia (GALT)
52. Cystic fibrosis (CF)
53. Severe combined immunodeficiency (SCID)
  54. T-cell related lymphocyte deficiencies
55. Hearing
56. Critical congenital heart disease (CCHD)

**Disorders Coming Soon**

These conditions have been approved for addition to Michigan’s panel but implementation is in progress and screening has not yet begun.

- X-linked adrenoleukodystrophy (X-ALD)
- Guanidinoacetate methyltransferase (GAMT) deficiency



## Appendix 11 – Specimen Directives

The [Residual Newborn Screening Blood Spot Directive](#) form is located on the [newborn screening](#) website.

RESIDUAL NEWBORN SCREENING BLOOD SPOT DIRECTIVE			
Michigan Department of Health and Human Services			
Child's Name at Birth		Date of Birth	
Child's Current Name		Check Birth Order if Multiple Birth	
Mother's Name at Time of Child's Birth		Hospital of Birth	
<p>I am a legal representative* of the child named above. I am asking the Michigan Department of Health and Human Services (MDHHS) to (check one):</p> <p><input type="checkbox"/> Destroy all remaining blood spots. I understand that by checking this box, NO blood spots will be available for any future use including medical, identification, or research purposes.</p> <p><input type="checkbox"/> Destroy only the portion of blood spots stored for research use. I understand by checking this box, one blood spot will be held by MDHHS. I must direct any potential future use including medical, identification or research purposes.</p> <p><input type="checkbox"/> Store but not use blood spots for research after newborn screening is complete. I understand that the blood spots will be kept by the laboratory but not used for research of any kind unless directed in writing by me.</p>			
<p>* Legal representative means a parent or guardian of a minor who has authority to act on behalf of the minor or the individual from whom the specimen was collected if 18 years or older or legally emancipated.</p>			
Signature of parent, guardian or other legal representative		Relationship to Child	
Printed Name		Date	
Street Address	City	Zip Code	Phone Number
<p>If you are asking MDHHS to destroy any blood spots, you must also attach a copy of the birth certificate belonging to the person whose blood spots are being destroyed AND the driver's license, state issued identification card or passport of the person who signed above.</p> <p>Return document(s) via:            Email: <a href="mailto:biotrust@michigan.gov">biotrust@michigan.gov</a> Fax: 517-335-9419 or            Post Mail: BioTrust Coordinator, NBS Follow-up Program, PO Box 30195, Lansing, MI 48909</p>			
<p>The Michigan Department of Health and Human Services (MDHHS) does not discriminate against any individual or group because of race, religion, age, national origin, color, height, weight, marital status, genetic information, sex, sexual orientation, gender identity or expression, political beliefs or disability.</p>		<p>Authority: Michigan Public Health Code, Act 368 of 1978</p>	

## **Appendix 12 – Birth Certificates**

**Persons required to report live birth occurring in state, MCL 333.2822**

[Public Health Code \(Excerpt\) Act 368 of 1978](#) website

## Appendix 13 – Fax Reporting

### Automatic Fax Reporting of Newborn Screening Results

The Michigan Department of Health and Human Services encourages the receipt of Newborn Screening laboratory reports via an AUTOMATIC FAX TRANSMISSION. Fax reporting provides significant improvement in screening result turnaround time to your facility.

There are two requirements to convert your facility to an AUTOMATIC FAX TRANSMISSION AGENCY:

- 1) A letter on your agency letterhead must be sent to the MDHHS Bureau of Laboratories, Newborn Screening consenting to becoming an automatic fax agency, and be signed by a person who is authorized to make this request.
- 2) The following statement of understanding (on next page) must be completed, signed and returned along with the consenting letter.

The letter and agreement may be faxed to 517-335-8550 or mailed to MDHHS at the following address:

Michigan Department of Health and Human Services  
Bureau of Laboratories, Newborn Screening Section  
3350 Martin Luther King, Jr. Boulevard  
Lansing, MI 48909

AUTO FAX reporting can occur anytime during the day or night, including weekends. Expect the same number of pages per patient as are currently mailed. Faxes that fail to get through after several automatic redial attempts will be resent promptly.

If your agency chooses this fax reporting option, the delivery of Newborn Screening laboratory reports through the United States Postal System will be eliminated.

**A secure FAX must be available 24 hours per day, 7 days per week (24/7) to receive reports.**

**Please notify MDHHS Newborn Screening Laboratory if your FAX machine is down for repairs.** If an alternate, secure FAX number is available; reporting can be promptly changed to the alternate FAX.

**Please notify MDHHS when your secure FAX number is again operational.** If your FAX machine is down, and you do not have an alternate secure FAX, reports will be mailed until your machine is operational, without any unnecessary delays.

**It is the responsibility of your agency to maintain a secure FAX line.**

If you have any further questions, please contact Paul Kramer by telephone at 517-335-9103 or e-mail [KramerP@michigan.gov](mailto:KramerP@michigan.gov).

Please keep this letter for your records.

## Appendix 14 – Fax Reporting Continued

### STATEMENT OF UNDERSTANDING AGENCIES SELECTING AUTOMATIC FAX TRANSMISSION OPTION

1. I understand that all newborn screening reports of patient testing by the MDHHS Bureau of Laboratories will be sent to this agency by FAX transmission.
2. I understand that upon conversion to a fax transmission agency, no hard copy reports will be sent using the United States Postal Service.
3. The FAX number provided to MDHHS is a **secure facsimile machine**. To be a secure facsimile machine, the following criteria must be met:
  - ✓ Only persons authorized to review confidential clinical laboratory test results use or otherwise have access to incoming FAX transmissions.
  - ✓ The facsimile machine is in a secure location during non-business hours in the event that FAX transmittal occurs after normal business hours.

Date: \_\_\_\_\_

Midwife or Birth Center Name: \_\_\_\_\_

Address: \_\_\_\_\_

Authorized Signature: \_\_\_\_\_

Secure FAX Number: \_\_\_\_\_

Contact Person for FAX Problems (*please print*) \_\_\_\_\_

Contact Person's Phone Number for Problems \_\_\_\_\_

**Please keep a copy for your records**

## Appendix 15 – Military Time

Military time is a concise method of expressing time used by the military, law enforcement, hospitals, and other entities. Military time uses a 24-hour time scale that makes the use of a.m. or p.m. unnecessary. Midnight corresponds to 0000, 1 p.m. corresponds to 1300, and so on.

The following table provides a convenient way to convert between military time and regular time.

<b>Regular Time</b>	<b>Military Time</b>	<b>Regular Time</b>	<b>Military Time</b>
Midnight	0000	Noon	1200
1:00 a.m.	0100	1:00 p.m.	1300
2:00 a.m.	0200	2:00 p.m.	1400
3:00 a.m.	0300	3:00 p.m.	1500
4:00 a.m.	0400	4:00 p.m.	1600
5:00 a.m.	0500	5:00 p.m.	1700
6:00 a.m.	0600	6:00 p.m.	1800
7:00 a.m.	0700	7:00 p.m.	1900
8:00 a.m.	0800	8:00 p.m.	2000
9:00 a.m.	0900	9:00 p.m.	2100
10:00 a.m.	1000	10:00 p.m.	2200
11:00 a.m.	1100	11:00 p.m.	2300

## Appendix 16 – Weight Conversion Chart

Ounces	Pounds												
	0	1	2	3	4	5	6	7	8	9	10	11	12
0		454	907	1361	1814	2268	2722	3175	3629	4082	4536	4990	5443
1	28	482	936	1389	1843	2296	2750	3203	3657	4111	4564	5019	5471
2	57	510	964	1417	1871	2325	2778	3232	3685	4139	4593	5046	5500
3	85	539	992	1446	1899	2353	2807	3260	3714	4167	4621	5075	5528
4	113	567	1021	1474	1928	2381	2835	3289	3742	4196	4649	5103	5557
5	142	595	1049	1503	1956	2410	2863	3317	3770	4224	4678	5131	5585
6	170	624	1077	1531	1984	2438	2892	3345	3799	4252	4706	5160	5613
7	198	652	1106	1559	2013	2466	2920	3374	3827	4281	4734	5188	5642
8	227	680	1134	1588	2041	2495	2949	3402	3856	4309	4763	5216	5670
9	255	709	1162	1616	2070	2523	2977	3430	3884	4337	4791	5245	5698
10	284	737	1191	1644	2098	2551	3005	3459	3912	4366	4819	5273	5727
11	312	765	1219	1673	2126	2580	3034	3487	3941	4394	4848	5301	5755
12	340	794	1247	1701	2155	2608	3062	3515	3969	4423	4876	5330	5783
13	369	822	1276	1729	2183	2637	3091	3544	3997	4451	4904	5358	5812
14	397	850	1304	1758	2211	2665	3119	3572	4026	4479	4933	5386	5840
15	425	879	1332	1786	2240	2693	3147	3600	4054	4508	4961	5415	5868