



Michigan Department of Health and Human Services

Newborn Screening
Guide for Homebirths
March 2022

333 S. Grand Avenue, PO Box 30195
Lansing, Michigan 48909
Phone 517-335-4181 • Fax 517-335-9419 or 517-335-9739
Toll-free 866-673-9939

Michigan.gov/NewbornScreening

Table of Contents

| | |
|---|----|
| INTRODUCTION..... | 4 |
| OVERVIEW OF MICHIGAN NEWBORN SCREENING | 4 |
| Dried Blood Spot Screening..... | 4 |
| Hearing Screening | 5 |
| Critical Congenital Heart Disease Screening..... | 5 |
| NEWBORN SCREENING PRACTICE AND PROCEDURE..... | 6 |
| Role of the Homebirth Attendant..... | 6 |
| Educating Parents about NBS | 6 |
| Obtaining the NBS Card | 6 |
| Completing the NBS Card..... | 7 |
| EXPIRATION DATE..... | 9 |
| NOTES FIELD | 9 |
| Recording the NBS Card Number | 10 |
| Michigan BioTrust for Health..... | 10 |
| SPECIMEN COLLECTION..... | 12 |
| SHIPPING THE NBS SPECIMEN TO THE STATE NBS LABORATORY | 12 |
| Instructions for using UPS labels | 12 |
| Friday envelopes only | 12 |
| HEALTHCARE PROVIDER INFORMATION | 12 |
| Follow-up of Positive NBS Results..... | 12 |
| NBS Result Request Policy..... | 13 |
| Questions on Positive Reports Received | 14 |
| Documentation of NBS Results..... | 14 |
| BIRTH CERTIFICATES..... | 14 |
| Persons Required to Report a Live Birth..... | 14 |
| FREQUENTLY ASKED QUESTIONS | 15 |
| Resource List | 16 |
| CONTACT INFORMATION | 17 |
| NBS Follow-up Program | 17 |
| Contact Information | 18 |
| NBS Lab | 18 |
| Contact Information | 18 |
| NBS Hepatitis B | 18 |
| Contact Information | 18 |
| MDHHS Vital Records | 18 |
| Contact Information | 19 |

| | |
|--|----|
| Early Hearing Detection and Intervention..... | 19 |
| Contact Information | 20 |
| NBS Follow-up Coordinating Centers..... | 20 |
| Appendix 1 – Legislative Mandates | 21 |
| Appendix 2 – Blood Specimen Collection and Handling Procedure | 22 |
| Appendix 3 – NBS Card Images..... | 23 |
| Appendix 4 – Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule..... | 24 |
| Appendix 5 – Ordering NBS Card for Homebirths..... | 25 |
| Appendix 6 – Notifying NBS Follow-up of Change in Infant Status | 26 |
| Appendix 7 – Disorders List..... | 27 |
| Appendix 8 – Specimen Directives | 28 |
| Appendix 9 – Birth Certificates | 29 |
| Appendix 10 – Fax Reporting | 30 |
| Appendix 11 – Fax Reporting Continued | 31 |
| Appendix 12 – Military Time | 32 |
| Appendix 13 – Weight Conversion Chart..... | 33 |
| Appendix 14 – NBS Report Request Form | 34 |
| Appendix 15 – NBS Disorders Identified..... | 35 |

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 7](#) 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 do not permit NBS to be collected, it is advised that the birth attendant request that the parent sign a waiver stating that they were informed of the risk to their newborn if the screen is not performed. Return the form to the NBS Program. The form can be faxed to 517-335-9419 or mailed to:

Michigan Department of Health and Human Services Attn: Newborn Screening
333 S. Grand Ave., 2nd floor
PO Box 30195
Lansing, Michigan 48909

Blood specimens should be collected at 24-36 hours of life, ideally 24-30 and air dried in a flat position 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 to assure prompt receipt. See [Appendix 10](#) for instructions on how to receive faxed NBS results. 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 the PCP's contact information entered on the NBS card is correct. If a PCP has not been selected yet, include midwife information instead.

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 \(Michigan.gov/ehdi\)](http://Michigan.gov/ehdi).

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 18 for additional [EHDI contact information](#).

Critical Congenital Heart Disease Screening

Congenital heart defects are the most common group of birth defects, affecting 9 in 1,000 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 \(Michigan.gov/cchd\)](http://Michigan.gov/cchd) or by calling the NBS Program Coordinator at (517) 284-4992.

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. These brochures are included in the homebirth kits that are mailed to homebirth attendants. Additional brochures may be ordered at 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 16 for [contact information](#). Updated information about NBS is also maintained on the [NBS website \(Michigan.gov/newbornscreening\)](http://Michigan.gov/newbornscreening).

Obtaining the NBS Card

All NBS homebirth packets are ordered by the midwife. It is no longer necessary to order NBS cards using the NBS Online Ordering System (NBSO). See [Appendix 5](#) for ordering information.

If you have a parent that has changed their mind about the newborn screening blood spot and the card has already been filled out, please return the Midwife Newborn Screening Deferred Invoicing Partnership form with void marked as the reason. Other reasons for voiding a card could include: any card pieces are torn or separated, unsatisfactory specimen before submitting for testing, wrong demographic information is entered, etc. 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. Inaccurate information can lead to critical delays in identifying and reporting of abnormal results. 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. The *Completing the Newborn Screening Card* infographic (homebirth version) is a simple tool to help midwives correctly complete the demographic section of the card. This resource is available at the [newborn screening website](http://newbornscreening.michigan.gov) (Michigan.gov/newbornscreening) in the “Resources for Hospitals and Health Professionals” section. 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.**
- ✓ **SEX:** Completely shade in the appropriate oval to designate newborn’s sex as male, female, or ambiguous.
- ✓ **BIRTH DATE:** Use a six-digit number (mm/dd/yy) for the date of birth. For example, a birth on January 4, 2021 would be recorded as 010421.
- ✓ **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 12](#).
- ✓ **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. Accuracy is critical as lab cutoff levels can be dependent on weight. For help with weight conversions see [Appendix 13](#).
- ✓ **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 13](#).
- ✓ **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.
- ✓ **COLLECTION DATE:** Use a six-digit number (mm/dd/yy) representing the date on which the specimen was obtained. Previously referred to as specimen date.
- ✓ **COLLECTION TIME:** Record time of specimen collection in military time. For help with time conversion see [Appendix 12](#).
- ✓ **COLLECTED BY:** Record initials of person collecting the specimen.

- ✓ **NICU/SPECIAL CARE:** This designation is used by hospitals and does not apply to homebirths, so completely shade the “NO” oval.
- ✓ **RBC TRANSFUSION:** This is not likely to apply to homebirths, so completely shade the “NO” oval.
- ✓ **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, so completely shade the “NO” oval.
- ✓ **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. If the father’s ethnicity is unknown, mark the mother’s ethnicity Note: Ethnicity information is requested for the first sample (“blue”) card *only*.
- ✓ **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. If the father’s race is unknown, mark the mother’s race.

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 *not* going to be released to the care of the mother at birth, next to ‘If Not Birth Parent’ mark adoptive parent, foster parent, or adoption agency. Please provide the contact information for the adoptive parent, foster parent, or adoption agency in place of the mother’s information* (refer to the HBsAg section on how to document the birth mother’s HBsAg test date and result). 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 517-242-8319 or fax to 517-763-0470. 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. Note: HBsAg information is requested for first sample ("blue") cards only. *If "Not Birth Parent", the birth mother's HBsAg results would not be documented under this section. However, if the birth mother's HBsAg result is positive, please contact the PHBPP at 517-242-8319.

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. Only include midwife information here if a PCP has not been selected yet.
- ✓ **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.

EXPIRATION DATE

- ✓ **EXPIRATION DATE:** The expiration date is located on the middle of the right-hand side on the newest cards and in the lower right-hand corner of older cards. Check the expiration date each time you collect a blood spot specimen. Cards used after the expiration date will be marked 'unsatisfactory/expired card' and a repeat specimen will be requested.

NOTES FIELD

- ✓ **NOTES FIELD:** The Notes field added to the lower right-hand corner of newer cards can be used to notify the NBS Program of information such as newborn transfer, family history of a disorder, meconium ileus, the mother's name in the event the baby will not be released to her care, etc.

Notifying NBS Follow-up of Changes to Infant's Health or Guardian Status

It is very important that you notify NBS Follow-up of any changes to the infant's status that occurred after you sent the infant's blood spot specimen to the laboratory. Complete and return the NBS Follow-up

Change in Infant Status form found in [Appendix 6](#) or call the NBS Follow-up section at 517-335-4181 (toll-free 866-673-9939).

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 in a later section.

Missing NBS Bloodspot Specimens

Each week the NBS Program staff link electronic birth certificate (EBC) records to newborn screening specimens received. This process enables quick identification of infants with a Michigan birth certificate, but no record of a blood spot screen. Due to the critical importance of identifying affected infants and initiating treatment as quickly as possible, midwives are alerted of these potentially missed newborn screens.

After the linkage, a manual review occurs for all infants not listed as deceased who show as having no blood spot on file. This includes a search of the NBS database and review of notifications received from midwives documenting why a screen was not collected. If explanatory records are not found, NBS Program staff will send a midwife letter and parent letter to notify them of the missing screen and to request information about why the screen was not collected. If the screen was truly missed, the NBS Program requests that the midwife contacts the family to have a screen collected as soon as possible.

If the parent did not permit collection, please notify the NBS Follow-up Program in one of the following methods:

- ✓ Write "refused" in the field where the NBS Kit number would be placed on the Birth Certificate form.
- ✓ Call the NBS Follow-up Program at 517-335-4181 or 877-673-9939
- ✓ Fax notification to 517-335-9419 or 517-335-9739
- ✓ Mail notification to:

MDHHS Newborn Screening Follow-up
333 S. Grand Ave., 2nd floor
PO Box 30195
Lansing, MI 48909

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. Homebirth 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. MDHHS staff, upon request, will provide onsite training on the BioTrust and the parental consent process. This training is also available on the [newborn screening](#) website (Michigan.gov/newbornscreening). [Appendix 5](#) contains information on how to obtain *After Newborn Screening, Your Baby's Blood Spots* consent brochures. 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 for up to 100 years 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.

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. [Appendix 8](#) contains this 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 \(Michigan.gov/newbornscreening\)](http://NBS.website(Michigan.gov/newbornscreening)). 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.
 - Only the parent or legal guardian can sign the consent form. In cases of adoption, the birth mother could sign the consent form while she remains the legal guardian. However, the future adoptive parent may wish to select a different option. An option is to return the NBS specimen without the BioTrust consent form. Then provide the form and brochure to the adoptive family and/or adoption agency caring for the infant. Once legal guardianship is established, that person can make the BioTrust decision and return the form to MDHHS.
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](http://clsi.org) (clsi.org) for additional information.
- Specimens should be collected between 24-36 hours of age, ideally 24-30 hours.
- Specimens should be air dried in a horizontal position for a minimum of three hours.
- Do not expose the specimen to fans, heat or other fluctuations in temperature and humidity.
- Tips for avoiding unsatisfactory specimens can be found in the “Resource for Hospitals and Health Professionals” section of the [newborn screening website](http://Michigan.gov/newbornscreening) (Michigan.gov/newbornscreening).

SHIPPING THE NBS SPECIMEN TO THE STATE NBS LABORATORY

Two different types of UPS labels, “1” and “1+S”, are included with midwife homebirth packet orders to use for shipping NBS cards. Using a UPS label properly guarantees next day delivery. Prepaid envelopes for mailing are no longer provided except under special circumstances.

Instructions for using UPS labels

1. Use the UPS Medical Envelope provided with the homebirth packet.
2. *If you are not shipping the card on Friday*, apply the preprinted UPS “1” shipping label that was included with your order of homebirth packets.
3. Make sure you know your outlet’s cutoff time, which is usually around 4:00 p.m. The cutoff time for next day delivery can vary depending on the UPS store, drop location, or Staples store you use.
4. **Fluctuations in temperature and humidity can adversely affect specimen quality. UPS drop boxes should not be used unless it is very close to the pickup time.**
5. UPS does not pick up or deliver on the following holidays: New Year’s Day, Memorial Day, July 4th, Labor Day, Thanksgiving Day, and Christmas Day.
6. You may put more than one dried specimen in a UPS envelope as long as it does not result in a shipping delay. Make sure the protective flap covers the filter paper of each card and they are placed in opposite directions.
7. Record the UPS tracking number on the tracking log provided with your homebirth packet order. You may track your shipment by visiting the [UPS website](http://ups.com) (ups.com)

Friday envelopes only

8. Apply the preprinted orange Saturday Delivery (1+S) UPS shipping label that was provided with your order of homebirth packets. This ensures that the specimen arrives early Saturday morning.
9. Please only use this label for envelopes shipped on Fridays, unless you believe that weather may delay delivery of an envelope dropped off on Thursday. In this case, treat it as a Friday envelope. Otherwise, it may not reach the NBS Laboratory until the following Monday.

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](http://www.mcir.org) (www.mcir.org) 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, the [NBS Report Request Form](#) must be completed, signed by the medical provider, and faxed to the number listed above. The form is in [Appendix 14](#).

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 Friday, 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 9](#) 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.*

As of May 2020, licensed midwives can electronically register homebirths for their clients. The Vital Events Registration Application (VERA) is the secure online application used for reporting births. While the State of Michigan Vital Records is not currently requiring its use, local registrar offices are able to set in place their own requirements for reporting. To gain access to VERA, please contact MDHHS-VR-Registration@Michigan.gov to get the user access process started.

Of note:

- Michigan law requires a birth to be reported within 5 days of the date of occurrence.
- If the mother is unmarried and wishes to name the father on the birth record, an *Affidavit of Parentage* is required per MCL 333.2824 (2).

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. Brochures are included with homebirth kits. Additional NBS materials may be ordered on the newborn screening ordering website (Michigan.gov/nbsorders).

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

Of the 106,126 infants screened in 2019, 376 were diagnosed with a disorder. Overall, one infant out of 282 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 can write this information in the Notes section of the NBS Card or call the NBS Program at 517-335-4181.

What is the NBS Program's specimen storage policy?

Residual NBS specimens are stored for up to 100 years 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 is granted for such research. Specimens collected prior to May 1, 2010 are available for research unless parents contact the MDHHS and opt-out using the form in [Appendix 8](#).

Who decides what disorders are included on the NBS panel?

The legislatively mandated Quality Assurance Advisory Committee makes recommendations on disorder inclusion to the MDHHS director, typically following recommendations from the federal Advisory Committee on Heritable Disorders in Newborns and Children. 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, healthcare 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 517-335-4181 to reach someone in the NBS Program who can answer your question or direct you to the appropriate medical sub-specialist.

Resource List

| Newborn Screening Websites | URL |
|--|---|
| <u>Michigan Newborn Screening</u> | Michigan.gov/newbornscreening |
| <u>Michigan Newborn Screening Online</u> (Order placement website) | <u>Michigan.gov/nbsorders</u> |
| <u>Michigan Critical Congenital Heart Disease Newborn Screening Program</u> | Michigan.gov/cchd |
| <u>Michigan BioTrust for Health Parental Consent Process Training</u> | Michigan.gov/biotrust |
| <u>Genetics Home Reference</u> | medlineplus.gov/genetics |
| <u>Centers for Disease Control and Prevention Genomics Resources</u> | cdc.gov/genomics/resources |
| <u>Newborn Screening Course</u> | https://courses.mihealth.org/PUBLIC/home.html |
| <u>American Academy of Pediatrics</u> | aap.org |
| <u>Sickle Cell Disease Association of America – Michigan Chapter, Inc.(scaami.org)</u> | scaami.org |

| National Newborn Hearing Websites | URL |
|---|--|
| <u>Centers for Disease Control Early Hearing Detection and Intervention</u> | cdc.gov/ncbddd/hearingloss/ehdi-data.html |
| <u>Marion Downs Center</u> | mariondowns.org |
| <u>National Institute on Deafness and Other Communication Disorders</u> | nidcd.nih.gov |
| <u>American Speech-Language-Hearing Association</u> | asha.org |
| <u>American Academy of Audiology</u> | audiology.org |
| <u>Hands and Voices</u> | handsandvoices.org |

CONTACT INFORMATION

NBS Follow-up Program

| NBS Follow-up Program | MDHHS Newborn Screening Follow-up 333. S. Grand Ave., 2 nd floor PO Box 30195 Lansing, MI 48909 | Toll-free: 866-673-9939 Telephone: 517-335-4181 Fax: 517-335-9419 or 517-335-9739 | Email: Newbornscreening@Michigan.gov Website: Michigan Newborn Screening (Michigan.gov/newbornscreening) |
|------------------------------|--|---|---|
| Staff | Title | Phone Number | Contact for questions regarding: |
| Mary Kleyn | NBS Follow-up section manager | 517-335-9296 | Destroying leftover NBS specimens |
| Angela Aldrich | NBS nurse consultant | 517-335-1966 | NBS home birth education NBS collection |
| Becky Shaulis | NBS Quality Assurance specialist | 517-335-8532 | Preliminary results request due to clinical concerns |
| Lacey VanLoenen | NBS operations coordinator | 517-335-1207 | Courier issues NBS card orders |
| Valerie Ewald | NBSO technical administrator | 517-335-1400 | NBS educational brochure orders |
| Kristen Thompson | NBS program coordinator | 517-284-4992 | CCHD NBS parent education |
| Shelby Atkinson | Genomics and NBS Research Coordinator | 517-335-6497 | BioTrust for Health |

Contact Information

NBS Lab

| | | |
|-----------------------|--|--|
| NBS Laboratory | MDHHS Newborn Screening Laboratory 3350 N. Martin Luther King Blvd. PO Box 30689 Lansing, MI 48909 | Telephone: 517-241-6366 Fax: 517-335-9773 |
| Staff | Title | Phone Number |
| Vacant | NBS Laboratory Section Manager | 517-241-6366 |
| Shawn Moloney | NBS Laboratory Metabolic Unit Manager | 517-335-5097 |
| Joseph Hill | NBS Laboratory Endocrine Unit Manager | 517-335-9381 |
| Alayna Bunker | Departmental technician | 517-335-4031 |

Contact Information

NBS Hepatitis B

| | | |
|-----------------------------|--|---|
| Hepatitis B | MDHHS Perinatal Hepatitis B Prevention Program 333 S. Grand Ave., 3 rd floor PO Box 30195 Lansing, MI 48909 | Telephone: 517-242-8319 Fax: 517-763-0470 Website: <u>Perinatal Hepatitis B Prevention Program</u> |
| Staff | Title | Phone Number |
| Pat Fineis | Program coordinator | 517-242-8319 |
| Marcy Smith | Case manager/Out-state | 517-388-4815 |
| Naomi Scherman-Siver | Case manager/SE MI | 517-897-3236 |

Contact Information

MDHHS Vital Records

| | | |
|----------------------|--|--|
| Vital Records | MDHHS Vital Records Office 333 S. Grand Avenue Lansing MI 48913 | Call Center Telephone: 517-335-6506 |
|----------------------|--|--|

Contact Information

Early Hearing Detection and Intervention

| | | |
|----------------------------|---|---|
| Hearing | MDHHS Early Hearing Detection and Intervention 109 W. Michigan Ave., 3 rd floor PO Box 30195 Lansing, MI 48909 | Telephone: 517-335-8955 Fax: 517-763-0183 Website: Michigan Early Hearing Detection and Intervention |
| Staff | Title | Phone Number |
| Nick Drzal | Infant Health Unit manager | 517-241-1914 |
| Erin Estrada | Data analyst | 517-335-8916 |
| Michelle Garcia | Follow-up consultant | 517-335-8878 |
| Krystina Trowbridge | Infant Health Unit secretary | 517-335-8955 |
| Gina Cooper | EHDI coordinator | 517-335-4941 |
| Nan Asher | Program consultant | 517-335-8273 |
| Dona McGovern | EHDI administrative assistant | 517-335-7835 |

Contact Information

NBS Follow-up Coordinating Centers

| | | |
|---|--|--|
| Hemoglobinopathies | Sickle cell anemia (Hb SS), hemoglobin SC disease, sickle beta thalassemia zero (Sβ ⁰), sickle beta thalassemia plus (Sβ ⁺), 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 |
| Metabolic Disorders | Amino acid disorders, fatty acid oxidation disorders, organic acid disorders, galactosemia, biotinidase deficiency | Children's Hospital of Michigan Metabolic Clinic 3950 Beaubien Blvd. Detroit, MI 48201-2192 Telephone: 313-832-9330 Fax: 313-745-8030 |
| Lysosomal Storage Disorders (LSD) | Pompe Disease & Mucopolysaccharidosis Type (MPSI) | Children's Hospital of Michigan Genetics Clinic 3950 Beaubien Blvd. Detroit, MI 48201-2192 Telephone: 313-832-9330 Fax: 313-745-8030 Michigan Medicine at the University of Michigan Division of Pediatric Genetics, Metabolism, and Genomic Medicine D5240 Medical Professional Bldg. 1500 E. Medical Center Drive Ann Arbor, MI 48109-5718 Telephone: 734-764-0579 Fax: 734-763-6561 |
| Endocrine Disorders Cystic Fibrosis (CF) Spinal Muscular Atrophy (SMA) X-linked Adrenoleukodystrophy (X-ALD) | Congenital adrenal hyperplasia (CAH) Congenital hypothyroidism (CH), CF X-ALD SMA | Michigan Medicine at the University of Michigan Department of Pediatrics 1500 E. Medical Center Dr. D1225 MPB, Box 5718 Ann Arbor, MI 48109-0718 Telephone: 734-647-8938 Fax: 734-936-7918 |
| Primary Immunodeficiency Disorders | Severe combined immunodeficiency disorder (SCID) and other primary immunodeficiency disorders with T-cell lymphopenia | 3950 Beaubien St. Detroit, MI 48201 Telephone: 313-806-6571 Pager: 313-745-0203; 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 (NBS) applies to all newborns who are born in the State of Michigan. A health professional in charge of the care of a newborn infant or, if none, the health professional in charge at the birth of an infant, is mandated to provide NBS. 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 health professional compliance with the statute.

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

Appendix 2 – Blood Specimen Collection and Handling Procedure

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


CHECKLIST:

- Newborn Screen
- Hearing Screen
- Pulse Oximetry Screen
- BioTrust Consent Form


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 specimens at next courier pick-up.



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% isopropyl 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

RIGHT ACCEPTABLE
Circle filled and evenly saturated

WRONG UNACCEPTABLE

Layering

Insufficient, multiple applications

Serum rings present

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 or call (517) 335-1400

SEND SPECIMENS AT NEXT COURIER PICK-UP

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

Appendix 3 – NBS Card Images

NBS First Sample (“blue”) Card

DCHE-1153 Printed: 05/19

Newborn Screening - Michigan Department of Health and Human Services
Bureau of Laboratories P.O. Box 30689 3350 N. MLK Jr. Blvd. Lansing MI 48909
Print Firmly with Black Pen

| | | | | | |
|---|--|----------------------------------|---|--|--|
| LAST NAME | | FIRST NAME | | SEX <input type="radio"/> MALE <input type="radio"/> FEMALE <input type="radio"/> AMBIGUOUS | |
| BIRTH DATE | BIRTH TIME (Military) | BIRTH WEIGHT (grams) | WKS GESTATION | SINGLE BIRTH <input type="radio"/> MULTIPLE BIRTH <input type="radio"/> | BIRTH ORDER A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D |
| COLLECTION DATE | COLLECTION TIME | COLLECTED BY: (Initials or ID #) | NICU or SPECIAL CARE? <input type="radio"/> NO <input type="radio"/> NICU <input type="radio"/> SP CARE | ANY RBC TRANSFUSION? <input type="radio"/> NO <input type="radio"/> YES | TRANSFUSION DATE |
| MEDICAL RECORD # | ETHNICITY <input type="radio"/> HISPANIC <input type="radio"/> NON-HISPANIC | | RACE <input type="radio"/> WHITE <input type="radio"/> AMERICAN INDIAN <input type="radio"/> MIDDLE EASTERN DESCENT <input type="radio"/> BLACK <input type="radio"/> ASIAN/PACIFIC ISLANDER <input type="radio"/> MULTI-RACIAL | | |
| TYPE OF COLLECTION: <input type="radio"/> Heel Stick <input type="radio"/> Venipuncture <input type="radio"/> Line Draw (central, other) | | | OTHER FEEDING: <input type="radio"/> BREAST <input type="radio"/> MILK-BASE <input type="radio"/> SOY <input type="radio"/> NONE | | TPN / AMINO ACIDS <input type="radio"/> NO <input type="radio"/> YES |
| IF NOT BIRTH PARENT: <input type="radio"/> ADOPTIVE PARENT <input type="radio"/> FOSTER PARENT <input type="radio"/> ADOPTION AGENCY | | | | | |
| MOTHER | | MOTHER | | | |
| LAST NAME | | FIRST NAME | | PHONE | |
| ADDRESS | | CITY | | | |
| CITY | | STATE | ZIP | HEPATITIS B SURFACE ANTIGEN (HBsAg) | |
| MEDICAL RECORD # | BIRTH DATE | TEST DATE | RESULT | <input type="radio"/> POSITIVE <input type="radio"/> NEGATIVE | |
| PROVIDER | | PROVIDER | | | |
| LAST NAME | | FIRST NAME | | PHONE | |
| PHONE | | FAX | | HOSPITAL CODE (if applicable) | |
| SUBMITTER | | SUBMITTER | | SUBMITTER | |
| SUBMITTER NAME | | PHONE | | HOSPITAL CODE (if applicable) | |
| ADDRESS | | CITY | | | |
| CITY | | STATE | ZIP | NOTES (ex: Meconium ileus, transfer, family history of NBS disorder, phototherapy) | |
| BIRTH HOSPITAL (if different from submitter) | | MDHHS USE ONLY | | | |

EXPIRES: 2025-07-31

11 3604 / 30510003

MDHHS
By Authority of Act 568
P.A. MCLA 333.5481
PerkinElmer 226

DHHS USE ONLY

3007901

SN

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.

MDHHS Copy

Parent Signature _____ Date _____

Your choice applies to all blood spots collected for newborn screening. Please visit 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.

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

23

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 \(cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.html\)](https://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.html) website.

Appendix 5 – Ordering NBS Card for Homebirths

All NBS homebirth packets are ordered by the midwife/homebirth attendant. It is no longer necessary to order NBS cards using the NBS Online Ordering System (NBSO). Midwives/homebirth attendant may continue to use NBSO to place orders for NBS educational material at no charge.

- **Phone:** Orders may be placed by calling 517-335-1400 during business hours Monday-Friday.
 - Voicemail messages left on this line will be answered by the next business day.
- **Email:** You may email your order to NBSOrders@Michigan.gov. Please provide:
 - Midwife/homebirth attendant name
 - Number of first sample homebirth packets needed for a three-month supply
 - Number of repeat sample homebirth packets needed to keep on hand
 - Number of extra lancets, if needed
 - Your method of providing pulse oximetry screening results: eReports or mailed.

Complete instructions will be included with each order. Call Lacey VanLoenen, 517-335-1207, or email VanloenenL1@Michigan.gov if you have questions.

Appendix 6 – Notifying NBS Follow-up of Change in Infant Status

NBS Follow-up phone: 517-335-4181 or 877-673-9939

NBS Follow-up fax: 517-335-9419 or 517-335-9739

Infant's name: _____

Infant's date of birth: _____

Mother's name: _____

Status change

Transferred to hospital: _____ on _____

Primary care provider (PCP): _____

PCP phone: _____ PCP fax: _____

Guardian name: _____

Guardian phone: _____

Guardian address: _____

Additional information: _____

Appendix 7 – Disorders List

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. X-linked adrenoleukodystrophy (X-ALD)
56. Hearing
57. Critical congenital heart disease (CCHD)

58. Spinal muscular atrophy (SMA)

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.

- Guanidinoacetate methyltransferase (GAMT) deficiency

Updated April 2020

Appendix 8 – 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 <input type="checkbox"/> 1 st <input type="checkbox"/> 2nd <input type="checkbox"/> 3rd <input type="checkbox"/> 4th <input type="checkbox"/> 5th |
| 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 Representatives _____ | Relationship to Child _____ |
| Print 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: biotrust@michigan.gov Fax: 517-335-9419 or Post Mail: BioTrust Coordinator, NBS Follow-up Program, PO Box 30195, Lansing, MI 48909</p> <p><i>Please note that MDHHS cannot guarantee email security if you choose to submit this form and accompanying documents to the department via email.</i></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.

Authority: Michigan Public Health Code, Act 368 of 1978

Appendix 9 – Birth Certificates

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

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

Appendix 10 – 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.

Direct any questions to Alayna Bunker, 517-335-4031, email BunkerA@Michigan.gov; or Jenny Kramer, 517-335-8095, email KramerJ8@Michigan.gov.

Please keep this letter for your records.

Appendix 11 – 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 12 – 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.

| Regular Time | Military Time | Regular Time | Military Time |
|---------------------|----------------------|---------------------|----------------------|
| 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 13 – 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 |

Appendix 14 – NBS Report Request Form



Phone: 517-335-4181
 Fax: 517-335-9419 or
 517-335-9739

NBS Report Request Form

Please be sure ALL FIELDS are filled in before faxing your request.

Fax this form, along with your cover page, to 517-335-9419 or 517-335-9739.

CHILD/PATIENT INFORMATION

| | | |
|--|--------------------------------|---|
| Child/patient name | First Name: | Last Name: |
| Child/patient date of birth | Sex (circle one) F M | |
| Birth facility/city | | |
| Baby from multiple birth delivery | Circle One Yes No | Specify birth order (e.g., Twin 1, Twin B, Triplet C) |
| Mother's name at time of patient's birth | First Name: | Last Name: |
| Mother's alternate last name(s) | | |

PROVIDER INFORMATION

| | | |
|---|-----------------------------------|------------|
| Requestor's name | First Name: | Last Name: |
| Facility name/city | | |
| Health care provider's name | First Name: | Last Name: |
| Health care provider's NPI#: | Credential: (MD, DO, NP, etc.) | |
| Direct phone number (+ extension) of requestor/provider | | |
| Fax number where report is to be sent | | |

The requested document(s) contains confidential patient health information that is legally privileged. This information is intended only for the use of the individual or entity named above. Any unauthorized review, use, disclosure, or distribution of this communication(s) is expressly prohibited.

I certify the child listed above is my patient and hereby grant permission to the Michigan Department of Health and Human Services Newborn Screening Program to release the newborn screening record, including laboratory test reports of the child state d above, for diagnosis and treatment purposes only.

 Signature of Health Care Provider

 Date

Please return this completed document with your office fax cover page to the MDHHS Newborn Screening Program at 517-335-9419 or 517-335-9739.

To access this form visit Michigan.gov/newbornscreening and select "Resources for Hospitals and Health Professionals"



The [NBS Report Request](#) form is located on the [newborn screening](#) (Michigan.gov/newbornscreening) website in the "Resources for Hospitals and Health Professionals" section.

Appendix 15 – NBS Disorders Identified

Disorders Identified in Michigan Newborn Residents via Newborn Screening, 1965-2019

| Type of Disorder Classification (Year Screening Began) | Cases in 2019 (N) | Cases Through 2019 (N) | Cumulative Detection Rate |
|---|-------------------------|------------------------------|---------------------------------|
| Galactosemia (1985) | 9 | 219 | 1:20,436 |
| Biotinidase deficiencies (1987) | 8 | 360 | 1:11,667 |
| Amino acid disorders (1965) | 13 | 793 | 1:9,375 |
| Organic acid disorders (2005) | 9 | 100 | 1:17,205 |
| Fatty acid oxidation disorders (2003) | 12 | 287 | 1:6,903 |
| Congenital hypothyroidism (1977) | 126 | 2585 | 1:1,625 |
| Congenital adrenal hyperplasia (1993) | 5 | 175 | 1:19,002 |
| Sickle cell disease (1987) | 64 | 2092 | 1:2,004 |
| Hemoglobin H disease (2012) | 4 | 16 | 1:55,110 |
| Cystic fibrosis (October 2007) | 16 | 322 | 1:4,165 |
| Primary immunodeficiencies (October 2011) | 12 | 120 | 1:8,214 |
| Lysosomal storage disorders (August 2017) | 5 | 17 | 1:15,297 |
| X-linked adrenoleukodystrophy (October 2019) | 1 | 1 | 1:25,710 |
| Total | 284 | 7,092 | - |