

Summer 2024



# Michigan Department of Health and Human Services Newborn Screening News

The Michigan Department of Health and Human Services (MDHHS) Newborn Screening (NBS) Follow-up Program works together with the State NBS Laboratory and coordinating centers to find and treat infants who need early medical care.



## NBS Quarterly Reports and Stellar Performance



During the first quarter of 2024, eight hospital units met all six of the NBS blood spot screening performance goals.

- Ascension Providence Southfield
- Corewell Health Beaumont Troy
- Corewell Health Niles
- Henry Ford Jackson
- Henry Ford Macomb - SCN
- Henry Ford West Bloomfield
- Memorial Healthcare
- Trinity Health Muskegon

### Performance Goals for NBS Blood Spot Quarterly Reports

1. Less than 1% of screens are collected more than 36 hours after birth.
2. Greater than 90% of screens arrive in the state laboratory by the appropriate day.
3. Less than 1% of screens are unsatisfactory.
4. Greater than 95% of electronic birth certificates have the NBS card number recorded.
5. Greater than 90% of specimens have a returned BioTrust for Health consent form that is completed appropriately.
6. Less than 2% of newborn screening specimens have errors in the demographic data.

We hope you can use this information in the quarterly reports to improve your part of the NBS system. If you have any questions, please call the NBS Follow-up Program at 517-335-4181.

### In this newsletter:

- ✓ Common card error: Weight field.
- ✓ Repeat NBS collections.
- ✓ 2024 NBS conference summary.
- ✓ Baby fair: New on-demand format.
- ✓ NBS awareness month.
- ✓ Hospital educational site visits.
- ✓ Krabbe recommendation.
- ✓ CCHD reporting.
- ✓ Pocket scripts.
- ✓ Parent education videos.
- ✓ NICU corner: TPN.

During the first quarter of 2024, 36 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. Four hospitals had 100% of CCHD screens reported on time.

- Aspirus Genesys
- Marshfield Medical Center - Dickinson
- OSF St. Francis
- ProMedica Monroe

### Performance Goals for CCHD Quarterly Reports

1. At least 95% of newborns with a blood spot screen have pulse oximetry screen results reported.
2. At least 90% of newborns with a blood spot screen have pulse oximetry screen results reported to the state less than 10 days after screen date.
3. At least 90% of newborns with a blood spot screen have pulse oximetry screen completed between 20 and 28 hours after birth.

## Common card error – Weight field

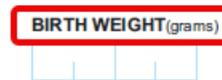
The last performance metric on the quarterly Newborn Screening Quality Assurance Notification is: Less than two percent of specimens have errors in the demographic data (i.e. dates, times, birth weights, etc.).

A common card error is missing or incorrect recording of weight on the NBS card. Weight related errors can result in inaccurate test interpretation as some analyte cutoffs are weight-dependent.

Points to remember:

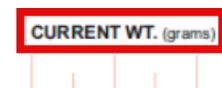
1. Weight must be recorded in grams.
2. Record birth weight on initial (blue) cards.
3. Record current weight on repeat (pink) cards.
4. Rapid response to weight inquiries is necessary for timely results.
5. Check for missing fields and weights not recorded in grams and make necessary corrections before packaging the card for courier pickup.
6. A weight conversion chart can be found in Appendix 14 of the Michigan NBS Hospital Guide located at [Michigan.gov/NewbornScreening](https://Michigan.gov/NewbornScreening) under the “Resources for Hospitals and Health Professionals” section.

Initial (blue) card:



A blue-bordered box with the text "BIRTH WEIGHT(grams)" in red. Below the text are four empty boxes for digits.

Repeat (pink) card:



A pink-bordered box with the text "CURRENT WT. (grams)" in red. Below the text are four empty boxes for digits.

Incorrect weight format	Correct weight format (grams)
 <p>Two examples of incorrect weight formats on "BIRTH WEIGHT(grams)" labels: "3.60" and "0810".</p>	 <p>One example of correct weight format on a "BIRTH WEIGHT(grams)" label: "2705".</p>

## Repeat NBS

Unsatisfactory or borderline NBS results will require a repeat collection. This request often occurs after discharge. The NBS follow-up program staff contact the primary care provider recorded on the NBS card to inform them of the need for a repeat. If a repeat is not received, the follow-up team will send the parent a letter with instructions for obtaining a repeat screen.

Did you know that NBS are not collected at the primary care provider’s office? Families are instructed to bring the letter to an outpatient lab at a hospital close to them that delivers babies. This may not be the hospital that delivered the infant. We recommend that families call ahead to ensure a written order is not needed by the physician to obtain the repeat.

## 2024 NBS conferences recap

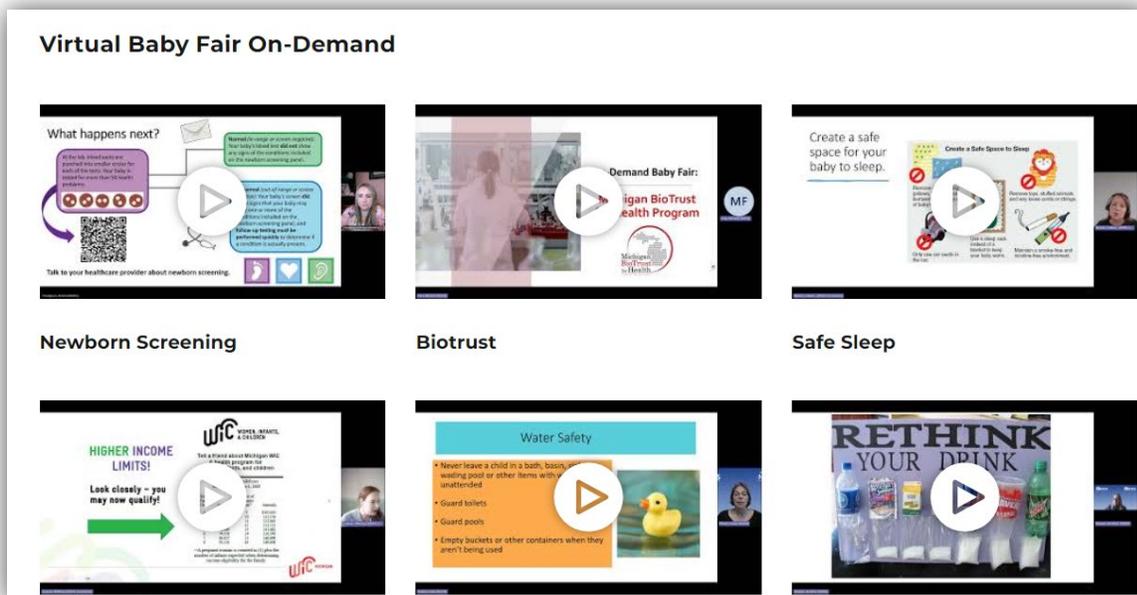
The NBS Program hosted two virtual newborn screening conferences in May for hospital staff and home birth attendants. The conference covered a variety of topics including: a CCHD highlight, parent education, blood spot resources, common misconceptions in early hearing screening and more! A total of 119 attendees, representing 55 birth hospitals across Michigan, participated in these conferences. Please visit the Resources for Hospitals and Health Professionals tab on the MDHHS Newborn Screening website ([Michigan.gov/NewbornScreening](https://Michigan.gov/NewbornScreening)) to view the speaker slides.

## Baby fair: New on demand format

The MDHHS virtual baby fair is a department-wide partnership to share important resources and information that promote health and safety to new and expecting parents. At the MDHHS virtual baby fair, families and professionals that work with families will have an opportunity to learn about available resources, important health and safety information and can ask experts questions.



This year, the department added an on-demand baby fair, which attendees can view at their leisure year-round. This is a great resource we recommend sharing with patients prenatally at birth education classes or hospital tours and during their hospital stay. The on-demand baby fair can be viewed by visiting [Michigan.gov/VirtualBabyFair](https://Michigan.gov/VirtualBabyFair). The department will also continue to host live baby fairs twice a year, in the summer and winter. For questions about the live or on-demand version of the baby fair, please email [MDHHS-VirtualBabyFair@michigan.gov](mailto:MDHHS-VirtualBabyFair@michigan.gov).



## September is NBS Awareness Month

Thank you for your hard work to ensure that all babies in Michigan get their newborn screen.

Because of you, more than 100,000 babies received a newborn screen in 2023.

Each year, approximately 310 Michigan babies are identified with a disorder on the NBS panel and given the opportunity for better health outcomes.

To hear firsthand the difference newborn screening can make, read family experiences on the Baby's First Test site. ([babysfirsttest.org](https://babysfirsttest.org))



## Hospital educational site visits

Every three years the NBS program meets virtually with individual hospitals to discuss their newborn screening process. This two-hour meeting provides an excellent opportunity to learn more about blood spot collection and NBS card completion, pulse oximetry screening for CCHD, parent education, transport of specimens to the state lab and the BioTrust for Health.

The visit includes NBS updates and resources, review of the hospital's metrics from the previous year and technical assistance for any areas of concern. This meeting is most successful if there is key representation from the hospital, including the NBS coordinator, backup coordinator, CCHD contact and lab, if applicable.

Please watch for an email from Angie Aldrich, NBS nurse consultant, regarding scheduling your visit. If you would like to proactively schedule a visit, send a request to [NewbornScreening@michigan.gov](mailto:NewbornScreening@michigan.gov).

## Krabbe disease recommended for the RUSP

On January 30 the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) voted to recommend the addition of Krabbe disease to the Recommended Uniform Screening Panel (RUSP). The recommendation will now be forwarded to the U.S. Department of Health and Human Services Secretary for final approval.

Krabbe disease is both a lysosomal storage disorder and leukodystrophy. It is inherited in an autosomal recessive pattern, occurring in approximately 1/100,000 – 1/250,000 live births. Krabbe disease is caused by a deficiency of the lysosomal enzyme galactocerebrosidase (GALC), responsible for the breakdown of galactolipids in the nervous system. The accumulation of galactolipids leads to demyelination and progressive neurodegenerative disease. Although onset of symptoms and rate of progression are variable, the majority of affected individuals become symptomatic in infancy or early childhood and have significantly reduced life expectancy. There is currently no cure for Krabbe disease. Hematopoietic stem cell transplants, however, have been shown to improve neurologic function and survival if performed prior to symptom onset. Early identification through newborn screening can help provide the best opportunity for early treatment.

Newborn screening for Krabbe disease is performed by measuring GALC in dried blood spots. For babies with decreased GALC, a second-tier test is typically used to look for elevations in the glycolipid psychosine. Psychosine levels are useful in predicting disease onset and guiding clinical management, particularly for infantile Krabbe disease for which treatment in the first month of life is recommended. Screening for Krabbe disease has already been implemented in eleven states. With the recent RUSP recommendation, the Michigan NBS program will be taking next steps with its advisory committees to consider adding Krabbe disease to Michigan's NBS panel.



## Reporting pulse oximetry results to the NBS program

Michigan has three options for hospitals to utilize to securely report CCHD data electronically to the state:

- eReports.
- File Transfer Protocol (FTP).
- Health Level 7 (HL7) messaging.

HL7 is an option for hospitals to report pulse oximetry results for CCHD screening to the NBS program more efficiently and accurately. A HL7 national standard has been developed for NBS blood spot orders, receiving NBS results and CCHD pulse oximetry results. This technology allows for electronic submission of NBS demographic data and blood spot test orders that are currently handwritten on the card, as well as returning NBS results to your hospital electronically.

HL7 messages are a nearly instantaneous transmission of individual level patient data upon entry into the electronic medical record. Submitting CCHD screening results using HL7 improves timeliness, reduces staff time involved in reporting CCHD screening results to the NBS program and decreases reporting errors.

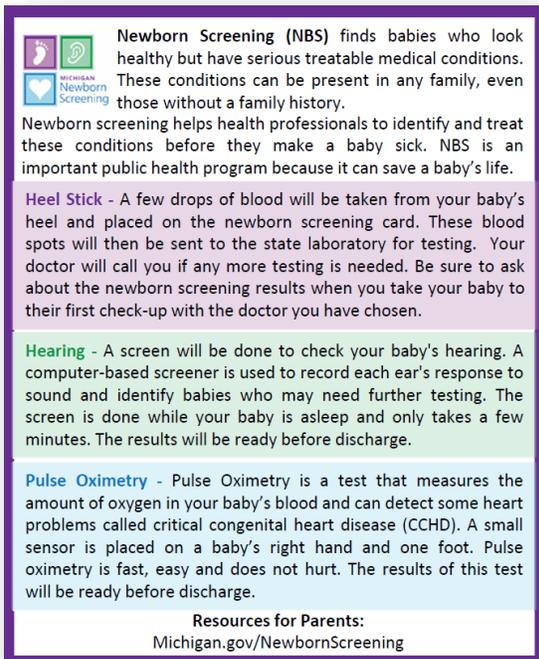


If you are interested in more information about HL7 reporting of NBS blood spot orders, receiving NBS results or submitting CCHD pulse oximetry results, please email Kristen Thompson at [ThompsonK23@Michigan.gov](mailto:ThompsonK23@Michigan.gov) or visit [Michiganhealthit.org/public-health/newborn-screening](http://Michiganhealthit.org/public-health/newborn-screening) for detailed information on how to implement HL7 messaging at your hospital.

## Pocket script resource for BioTrust consent

Hospital staff and birthing attendants are important partners in the BioTrust consent process. The MDHHS BioTrust for Health program relies on you to educate families about the BioTrust so they can make an informed decision about allowing their child's residual dried blood spots to be used in research after newborn screening (NBS) is completed.

**We have a resource available to help you talk about the BioTrust!** Our pocket script is a laminated card designed to fit into your scrub pocket. One side contains a script for introducing the NBS program to parents while the other side has a script for introducing the BioTrust, along with two QR codes that link you to our FAQ webpage and a BioTrust informational video. The pocket script is great for staff who are new, are occasionally involved in obtaining BioTrust consent, or who are unsure about what to say to families. To order, please contact [BioTrust@michigan.gov](mailto:BioTrust@michigan.gov) or call 866-673-9939.



**Newborn Screening (NBS)** finds babies who look healthy but have serious treatable medical conditions. These conditions can be present in any family, even those without a family history.

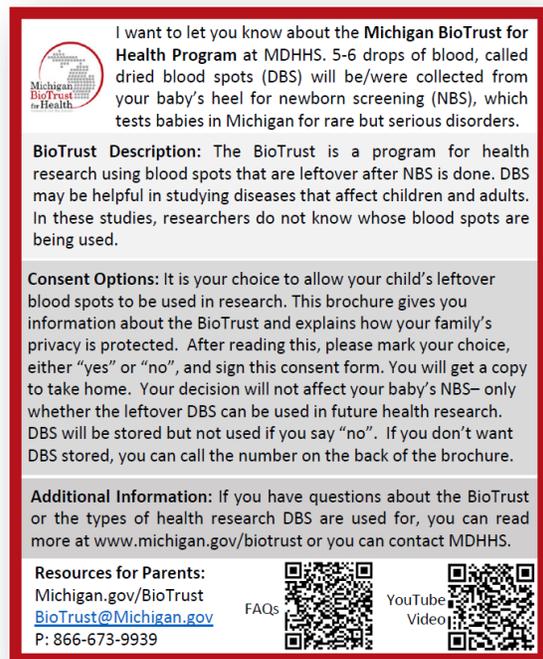
Newborn screening helps health professionals to identify and treat these conditions before they make a baby sick. NBS is an important public health program because it can save a baby's life.

**Heel Stick** - A few drops of blood will be taken from your baby's heel and placed on the newborn screening card. These blood spots will then be sent to the state laboratory for testing. Your doctor will call you if any more testing is needed. Be sure to ask about the newborn screening results when you take your baby to their first check-up with the doctor you have chosen.

**Hearing** - A screen will be done to check your baby's hearing. A computer-based screener is used to record each ear's response to sound and identify babies who may need further testing. The screen is done while your baby is asleep and only takes a few minutes. The results will be ready before discharge.

**Pulse Oximetry** - Pulse Oximetry is a test that measures the amount of oxygen in your baby's blood and can detect some heart problems called critical congenital heart disease (CCHD). A small sensor is placed on a baby's right hand and one foot. Pulse oximetry is fast, easy and does not hurt. The results of this test will be ready before discharge.

**Resources for Parents:**  
[Michigan.gov/NewbornScreening](http://Michigan.gov/NewbornScreening)



I want to let you know about the **Michigan BioTrust for Health Program** at MDHHS. 5-6 drops of blood, called dried blood spots (DBS) will be/were collected from your baby's heel for newborn screening (NBS), which tests babies in Michigan for rare but serious disorders.

**BioTrust Description:** The BioTrust is a program for health research using blood spots that are leftover after NBS is done. DBS may be helpful in studying diseases that affect children and adults. In these studies, researchers do not know whose blood spots are being used.

**Consent Options:** It is your choice to allow your child's leftover blood spots to be used in research. This brochure gives you information about the BioTrust and explains how your family's privacy is protected. After reading this, please mark your choice, either "yes" or "no", and sign this consent form. You will get a copy to take home. Your decision will not affect your baby's NBS—only whether the leftover DBS can be used in future health research. DBS will be stored but not used if you say "no". If you don't want DBS stored, you can call the number on the back of the brochure.

**Additional Information:** If you have questions about the BioTrust or the types of health research DBS are used for, you can read more at [www.michigan.gov/biotrust](http://www.michigan.gov/biotrust) or you can contact MDHHS.

**Resources for Parents:**  
[Michigan.gov/BioTrust](http://Michigan.gov/BioTrust)  
[BioTrust@michigan.gov](mailto:BioTrust@michigan.gov)  
P: 866-673-9939

FAQs 

YouTube Video 

## Parent education videos

The NBS program has two YouTube videos for parent education. These are great for new and expecting parents and can be easily accessed by any smart device in the patient room by scanning the QR codes to the right.

The newborn screening video gives an overview of newborn screening. The BioTrust video gives an overview of the BioTrust and parent options for dried blood spots after screening. Both videos can be viewed in closed captioning in many different languages.

### Newborn Screening Video:



### BioTrust Video:



### NICU corner: Total parenteral nutrition (TPN)

TPN affects the acylcarnitine and amino acid profiles for the amino acid, fatty acid oxidation and organic acid disorders. However, after several years of tandem mass spectrometry experience, the Michigan NBS Laboratory has detected several cases of each of these disorders in newborns on TPN feeding. There have been no known false negatives.

For NICU newborns on TPN who test positive, repeat specimens are requested using the *General Elevation of Acylcarnitines or Amino Acids* letter. Please follow the NICU protocol for obtaining the repeat specimen at 30 days of age or at discharge, whichever is sooner. It is becoming increasingly difficult to obtain repeat collections after an infant is discharged. We appreciate your continued diligence in obtaining the repeat prior to release.

### Upcoming holiday courier schedule

#### Upper and Lower Peninsula hospitals:

- Monday, September 2 - Holiday/Sunday schedule.



### Technical assistance

- Angela Aldrich, NBS nurse consultant, is available to work with staff in any hospital that requests help with specimen collection. [Click here to reach her by email](mailto:AldrichA1@Michigan.gov) (AldrichA1@Michigan.gov).
- Kristen Thompson, NBS coordinator, is available to work with hospitals on CCHD pulse oximetry screening and reporting. [Click here to reach Kristen by email](mailto:ThompsonK23@Michigan.gov) (ThompsonK23@Michigan.gov).
- Michele Fritz, Genomics and NBS Coordinator, is available to assist with questions related to BioTrust for Health. [Click here to reach Michele by email](mailto:Biotrust@michigan.gov) (Biotrust@michigan.gov).

**Together we can achieve our goal that all children diagnosed through newborn screening receive prompt and careful treatment in order to live the healthiest lives possible.**

**Please remember to share the quarterly newsletter with staff!**

If you have questions, please contact the NBS Follow-up Program at 517-335-4181 or [NewbornScreening@Michigan.gov](mailto:NewbornScreening@Michigan.gov) or [visit our website at Michigan.gov/NewbornScreening](https://www.michigan.gov/NewbornScreening).