

Fall 2022



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 Newborn Screening Laboratory and coordinating centers to find and treat infants who need early medical care.



NBS Quarterly Reports and Stellar Performance



During the second quarter of 2022, six hospitals met all six of the NBS blood spot screening performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Beaumont Hospital – Troy
- Henry Ford Jackson
- McLaren Port Huron - SCN
- Bronson Methodist Hospital
- Henry Ford Macomb
- St. Joseph Mercy Ann Arbor

Performance Goals for NBS Blood Spot Quarterly Reports

1. Less than 2% of screens are collected >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. Greater than 90% of newborns with a dried blood spot have pulse oximetry screening results reported.

We hope you will be able to use 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:

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- ✓ Hospital Discharge Sheet
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- ✓ BioTrust FAQs
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- ✓ Common Card Error – New Year

During the second quarter of 2022, 31 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. Three hospitals with the highest percent of CCHD results reported to the Newborn Screening Program within ten days are listed below. Congratulations to the following hospitals on their impressive efforts:

- Munson Healthcare Otsego Memorial
- My Michigan Medical Center – West Branch
- OSF St. Francis

Performance Goals for CCHD Quarterly Reports

1. At least 90% of newborns with a blood spot screen have pulse oximetry screen results reported.
2. **At least 90% 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.



NBS Follow-up Program Contact Information

Phone: 517-335-4181

Email: NewbornScreening@Michigan.gov



Submitter Code Reminder

Each hospital is assigned a three-digit hospital code that must be recorded on the NBS card. The hospital code field on the card has six spaces. Please write the hospital code in the first three boxes. Be sure to add the nursery type final digit following the pre-printed zeros.

The last digit indicates the type of nursery: 0 means regular nursery, 1 means NICU, and 2 means SCN. The submitter code is used to make separate quarterly reports for each unit, so it is important that we can correctly identify which unit submitted each specimen. Please also indicate if the baby is in the NICU or Special Care Nursery in the field at the top of the card.

MDHHS encourages hospitals to use pre-printed labels with the hospital address and submitter code on all NBS specimen cards. Please remember to use the correct last digit code on the labels.

Communication Tool - Hospital Discharge Sheet

Are you looking for an easy way to communicate information about an infant to the NBS Follow-up Program **after** you submitted the card? The Hospital Discharge Sheet is a quick and easy tool available for your team to connect with us! Some common uses for this form include:

- Updated primary care provider for an infant.
- Corrected parent contact information.
- New adoption status and adoptive parent/agency contact information. If applicable, include a statement requesting that birth parent information not be released.
- Hospital/NICU name for infant transfer.
- Notification that parent would not permit collection of newborn screen.
- Family history of disorder related to newborn screening.

The Hospital Discharge Sheet can be found on our website at Michigan.gov/NewbornScreening under the "Resources for Hospitals and Health Professionals section." Click [here](#) for a direct link to the form.

Guanidinoacetate methyltransferase (GAMT) deficiency

- Michigan began screening all newborns for guanidinoacetate methyl transferase (GAMT) deficiency on September 12, 2022.
 - GAMT deficiency is an inborn error of metabolism that affects creatine synthesis.
 - Lack of treatment can lead to lifelong cognitive impairments which may be severe.
 - Treatment is most effective if started early in life before symptoms arise.
- Michigan is the third state in the United States to screen for GAMT deficiency.
 - Utah began screening for GAMT deficiency in 2015 and New York in 2018.



Is your patient ready for their baby's first test?

Talking with your patients about their baby's NBS can make all the difference. Here are a few tips for talking with parents throughout the NBS process.

Prior to Delivery

Encourage parents to pick a primary care provider for their newborn and tell them to be ready to provide the name and phone number of the provider during the hospital stay.

During Hospital Stay

Make sure to talk to parents about each step of the NBS process as you are conducting the blood spot and both point-of-care screens.

Encourage parents to ask questions about their child's NBS. Use NBS staff as a resource as needed.

Make parents aware of the options they have with the blood spots after NBS is completed.

Give parents their baby's results for the two point-of-care screens (hearing and pulse oximetry).

After Discharge

Parents can ask their baby's primary care provider for the results of the newborn blood screen. The results should be ready before their baby is one week old.

MDHHS Virtual Baby Fair

The NBS Program is excited to share an opportunity at MDHHS for new and expecting parents across the state of Michigan! We are sharing this with you in hopes that you will pass this message and save the date along to expecting or new parents.

At this free virtual baby fair, parents can learn how to be better prepared for their best adventure yet! They will have an opportunity to learn about available resources and important health and safety information, and will have an opportunity to ask experts questions.

The following MDHHS programs are participating in this event:

NBS, Michigan BioTrust for Health, Infant Safe Sleep, Women, Infants, & Children (WIC), Childhood Lead Poisoning Prevention Program, Vital Records, Unintentional Injury Prevention, Immunizations, Early Hearing Detection & Intervention, Maternal Infant Health Program, Michigan Home Visiting Initiative, Children's Special Health Care Services, Eat Safe Fish, Birth Defects Education and Outreach, Oral Health and State Breastfeeding Promotion.

If you have any questions, or would like a shareable version of the flyer, please [click](#) here or send an email to Kristen Thompson (ThompsonK23@Michigan.gov).

REGISTER NOW!
Michigan Department of Health and Human Services
Virtual Baby Fair

Are you a new or expecting parent? Join us for a virtual baby fair to learn how to be better prepared for your best adventure yet! Learn about resources available to you, important information, and ask questions to experts.

Tuesday, December 6, 2022, from 9:00-11:00 a.m.
Monday, December 12, 2022, from 9:00-11:00 a.m.
Wednesday, December 14, 2022, from 6:30-8:30 p.m.

Register at
<https://www.eventbrite.com/e/virtual-baby-fair-tickets-446197848777>

Participating MDHHS Programs:

- Newborn Screening
- BioTrust for Health
- Infant Safe Sleep
- Childhood Lead Poisoning Prevention Program
- Women, Infants, & Children (WIC)
- Vital Records
- Unintentional Injury Prevention
- Immunizations
- Early Hearing Detection and Intervention
- Maternal Infant Health Program
- Michigan Home Visiting Initiative
- Birth Defects Education and Outreach
- Breastfeeding Support
- Children's Special Healthcare Services
- Eat Safe Fish

Scan here to register!

For more information please contact Kristen Thompson
ThompsonK23@Michigan.gov
517-284-4992

Updates to the Residual Newborn Blood Spot Directives Forms

In Michigan, blood spots may be stored for up to 100 years after testing is completed. Parents can contact MDHHS to file a directive form requesting that residual blood spots be destroyed once the NBS is complete.

The Michigan NBS Program recently updated the Residual Newborn Screening Blood Spot Directive forms. This form is available in English, Spanish and Arabic on the “[Resources for Hospitals and Health Professionals](#)” tab of the newborn screening website (Michigan.gov/NewbornScreening) or at the direct links listed below:

- [Residual Newborn Screening Blood Spot Directive English](#)
- [Residual Newborn Screening Blood Spot Directive Spanish](#)
- [Residual Newborn Screening Blood Spot Arabic](#)

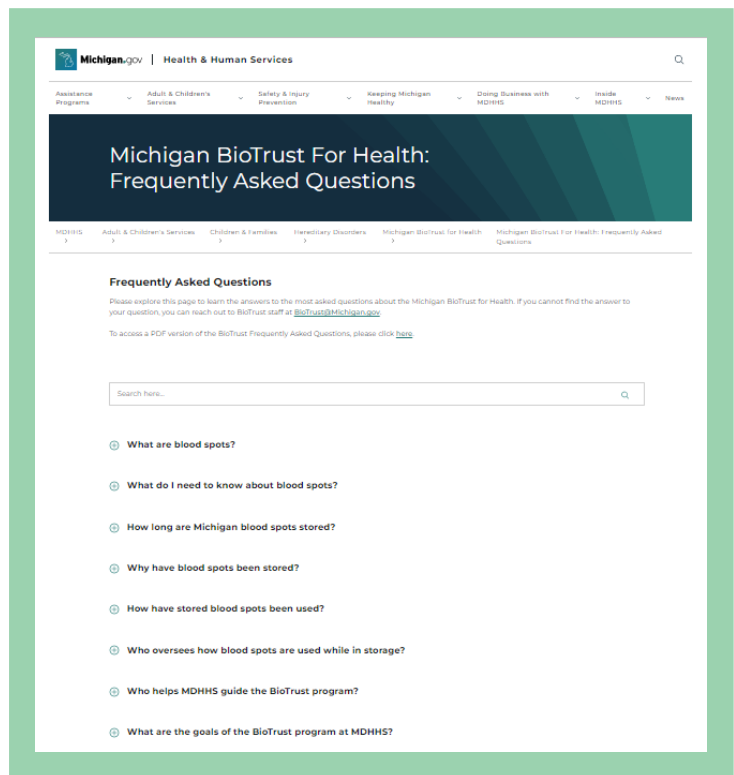
Families wishing to request that residual blood spots be destroyed must complete the Directive form and return it to MDHHS with a copy of their child’s birth certificate and a copy of their government-issued identification. For questions about the blood spot destruction process, please click [here](#) to email the NBS Program (newbornscreening@michigan.gov).

New Frequently Asked Questions (FAQ) Launched for the BioTrust for Health Program

The Michigan BioTrust for Health recently launched a new FAQ webpage. The page can be found by choosing the “Frequently Asked Questions” icon on the BioTrust website at Michigan.gov/BioTrust.

This is an excellent resource for parents who have questions during the BioTrust consent process. Families can navigate to the page using a tablet, phone or other smart device and can use the search function to locate answers to commonly asked questions. Topics covered include why blood spots are stored, how they can be used while in storage, where they are kept, and what parents’ options are for leftover specimens.

If families have questions beyond those listed on the website, they are welcome to contact BioTrust staff directly. Click [here](#) to reach them by email (biotrust@michigan.gov) or by phone at 1-866-673-9939.



Parent Education – Quality Improvement Grant Summary

The Michigan NBS Program was awarded a quality improvement grant funded by the Association of Public Health Laboratories (APHL), aimed at improving parent education regarding NBS and the BioTrust for Health programs during the prenatal period. Many studies have found that parents generally have limited awareness of NBS and that providing information to expectant parents may increase satisfaction with the process or lead to increased support for screening. To address this gap, NBS Program staff created a new educational document, referred to as the NBS and BioTrust checklist, that is designed to equip parents with the information they need to know prior to giving birth, so they can more actively participate in the newborn screening and BioTrust processes.

We partnered with three Michigan birth hospitals to distribute this new educational checklist to expecting parents during hospital tours or through educational packets provided at prenatal care provider offices. To evaluate the effectiveness of the checklist, a survey was sent to parents at participating hospitals shortly after they gave birth. NBS Program staff sent 1,000 surveys to parents who did not receive the checklist and 1,000 surveys to parents who had the opportunity to receive the checklist.

Overall, 23% of surveys were completed and returned. No statistically significant difference in NBS or BioTrust knowledge was found between parents who had the opportunity to receive the checklist and those who did not receive the checklist. However, some information was learned about parental knowledge of NBS which will help with future educational outreach efforts.

- Just over 95% of survey respondents were aware that NBS was completed at the hospital.
- While awareness of blood spot and hearing screening were high (90.5% and 98%, respectively), parents were less likely to be aware of pulse oximetry screening (64.5%).
- The most common sources of NBS information for parents were nursing/medical staff at the hospital (74%), a previous birth (53%), brochures at the hospital (44%), and prenatal medical staff (28%).

The NBS Program will continue efforts to provide education to parents in the prenatal setting. If you have ideas on ways to distribute information prenatally, please click [here](#) to email the Newborn Screening Program (newbornscreening@michigan.gov).

Michigan Birth Defects Registry Is Getting An Update

The Michigan Birth Defects Registry (MBDR) was established as a statewide reporting system in 1992 to develop statistical data on birth defects; to conduct birth defect surveillance; to conduct studies of birth defect causes and prevention; and to ensure the families of children with birth defects receive appropriate support services.

The State of Michigan (SOM) is redeveloping the MBDR and how birth defect data is collected. The new registry will be in production December 2022. Currently, MBDR staff are contacting reporting facilities to update reporting measures and data variables. As part of a five-year grant awarded by the Centers for Disease Control and Prevention to MBDR, specific birth defect cases reported to the state will need to be verified via remote records access. Be on the lookout for email correspondence from the MBDR team as we attempt to contact the correct staff member at your facility.

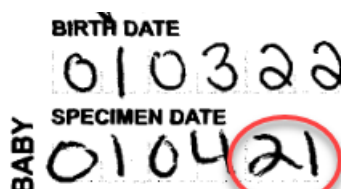
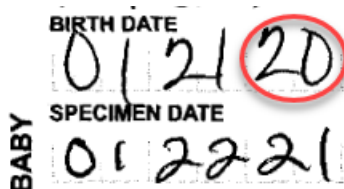


Click [here](#) (Michigan.gov/MBDR) for updated information about the Birth Defects Registry, Reportable Birth Defects, Newsblasts, and contact details. If you have questions about the new MBDR or how your facility reports birth defects to the SOM, please click [here](#) to contact Liz MacIntyre (macintyrel1@michigan.gov) or click [here](#) to contact Erin Cooper (cooperE5@michigan.gov).

Common Card Error – New Year Discrepancy

The last performance metric on the quarterly NBS Quality Assurance Notification is: *Less than 1 percent of specimens have errors in the demographic data (i.e. dates, times, birth weights, etc.).*

The following common card error occurs in the first few months of the year. As we head into 2023, please remind your team to double-check to ensure they are writing the correct birth and collection year on the newborn screen card.



Best Practice Tip:

Encourage team members packaging specimens for shipment to double-check that collection and birth year are correct!

Upcoming Holiday Courier Schedule

Lower Peninsula Hospitals:

Friday, November 11, 2022 – Holiday/Sunday schedule
 Thursday, November 24, 2022 – Holiday/Sunday schedule
 Friday, November 25, 2022 – Holiday/Sunday schedule
 Friday, December 23, 2022 – Holiday/Sunday schedule
 Sunday, December 25, 2022 – Holiday/Sunday schedule
 Monday, December 26, 2022 – Holiday/Sunday schedule
 Friday, December 30, 2022 – Holiday/Sunday schedule
 Sunday, January 1, 2023 – Holiday/Sunday schedule
 Monday, January 2, 2023 – Holiday/Sunday schedule
 Monday, January 16, 2023 – Holiday/Sunday schedule

Upper Peninsula Hospitals:

Friday, November 11, 2022 – Normal Operations
 Thursday, November 24, 2022 – No UPS pickup
 Friday, November 25, 2022 – Normal Operations
 Saturday, December 24, 2022 – Normal Operations
 Sunday, December 25, 2022 – No UPS pickup
 Monday, December 26, 2022 – No UPS pickup
 Friday, December 30, 2022 – Normal Operations
 Saturday, December 31, 2022 – Normal Operations
 Sunday, January 1, 2023 – No UPS pickup
 Monday, January 2, 2023 – No UPS pickup
 Monday, January 16, 2023 – Normal Operations



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 (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 (ThompsonK23@Michigan.gov). Shelby Atkinson, Genomics and NBS Research Coordinator, is available to assist with questions related to BioTrust for Health. Click [here](#) to reach Shelby by email (atkinsons2@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 or visit our website at Michigan.gov/NewbornScreening.