

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



NBS Quarterly Reports and Stellar Performance



During the third quarter of 2023, 13 hospital units met all six of the NBS blood spot screening performance goals.

- Ascension Providence Rochester
- Corewell Health Beaumont Troy
- Corewell Health Beaumont Troy - NICU
- Corewell Health Gerber
- Corewell Health Niles
- Henry Ford Jackson
- McLaren Greater Lansing
- Sparrow
- Three Rivers Health
- Trinity Health Ann Arbor
- Trinity Health Muskegon
- Trinity Health Oakland
- UP Health System - Portage

Performance Goals for NBS Blood Spot Quarterly Reports

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

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- ✓ NBS dashboard.
- ✓ Card replacement reminder.
- ✓ BioTrust brochure stock.
- ✓ eReport submitter.
- ✓ New staff highlights.
- ✓ Annual report summaries.
- ✓ Sickle cell disease resource.
- ✓ NICU Corner: Early specimens.
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During the third quarter of 2023, 31 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. One hospital had 100 percent of CCHD results reported on time. Congratulations!

- Ascension Genesys

Performance Goals for CCHD Quarterly Reports

1. At least 95 percent of newborns with a blood spot screen have pulse oximetry screen results reported.
2. At least 90 percent 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.



Michigan Newborn
Screening

NBS Follow-up Program Contact Information

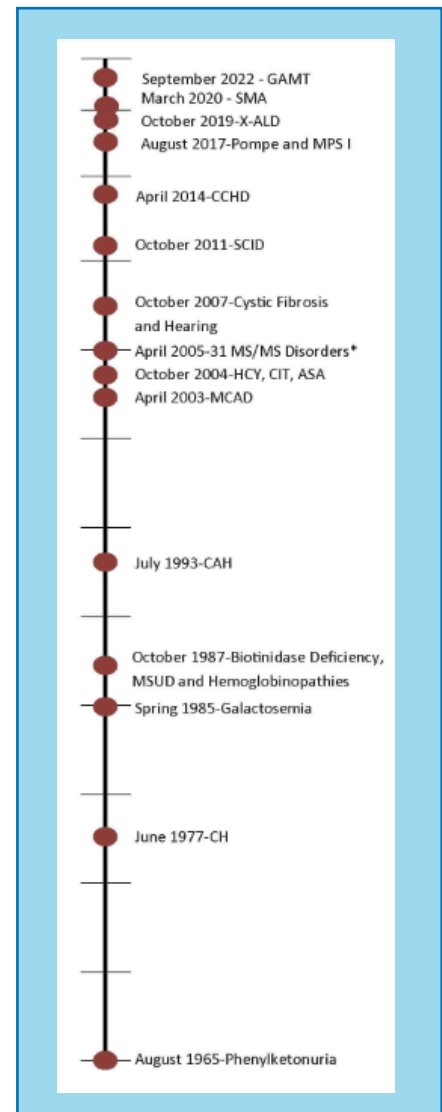
Phone: 517-335-4181

Email: NewbornScreening@Michigan.gov

Newborn screening: More than a PKU test

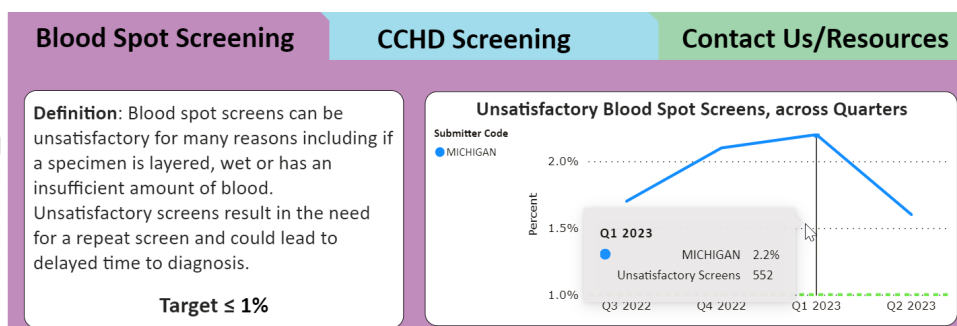
In 1965, newborn screening (NBS) started as a screen for phenylketonuria (PKU). Newborn screening has evolved significantly since its inception and today the Michigan blood spot panel includes 57 disorders. The figure to the right shows a timeline for when disorders were added to the Michigan screening panel. Despite this growth, many healthcare professionals continue to use the term "PKU test". Using outdated or overly specific terms like "PKU test" can lead to confusion and anxiety for parents, especially given the expanded scope of newborn screening today. It is essential for healthcare professionals to use up-to-date terminology and communicate clearly with parents. This will help parents better understand the process and potential outcomes.

Many parents turn to the internet to search for information before they have an opportunity to meet with the pediatrician or specialist. If told that their newborn had an abnormal PKU test, they may spend hours researching and worrying about a potential PKU diagnosis, when their baby is at risk for an entirely different disorder. Referring to the procedure as "newborn screening" rather than the "PKU test" is more accurate and better reflects the comprehensive nature of the screening process. [To review the full list of disorders included on the Michigan newborn screening panel, please click here \(Michigan.gov/NewbornScreening\).](#)



Introducing the newborn screening dashboard

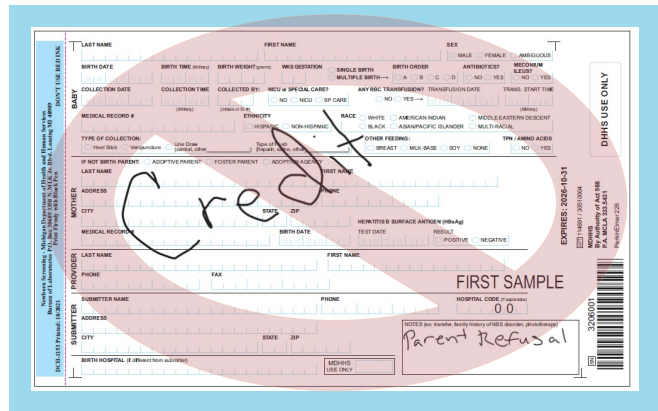
An exciting new feature has been added to the NBS website. The NBS Dashboard is a convenient way to review hospital blood spot and critical congenital heart disease (CCHD) screening metrics. Search options include viewing specific hospital quarterly metrics and trends, as well as comparison between all Michigan reporting hospitals and the overall Michigan average. The dashboard will provide an opportunity for facilities to view their performance over time. To protect privacy, the submitter code assigned to each hospital will be used in place of the hospital name. [Please visit the Resources for Hospitals and Health Professionals page at Michigan.gov/NewbornScreening to view the dashboard.](#) A link is available on the website to access a tip sheet to help navigate the dashboard.



Newborn screening card replacement reminder

Are you throwing money away? Replacement cards can be requested for card errors and poor-quality blood spot specimens that are recognized prior to submission to the NBS Lab. The NBS Program has noted an increase in hospital staff submitting newborn screening cards marked 'void', 'credit', and 'parent refused' to the NBS Laboratory. To ensure card replacement, cards must be submitted correctly.

Please complete the NBS Card Replacement Form and submit to the address specified on the form. The NBS Card Replacement Form is located at Michigan.gov/NewbornScreening under the "Resources for Hospitals and Health Professionals" section in the "Forms" section. [Click here for a direct link.](#)



Points to remember:

- DO** mail just the white face sheet, not the remaining portions of the kit such as the filter paper.
- DO** send the face sheets with the NBS Replacement Form to the address on the form.
- DO** place the face sheet in a biohazard bag if there is blood on it.
- DO** remove the portion of the filter paper with blood before submitting it.
- DO NOT** send your replacement request to the NBS Laboratory or in courier envelopes, as this will delay replacement.
- DO NOT** write parental refusal on the NBS card only.*

*On the rare occasion a parent will not permit the collection of blood spots, the hospital should have the parents sign a document acknowledging the risks associated with not completing the screening. This document should be faxed to the NBS Follow-up Program at 517-335-9419 or 517-335-9739.

The importance of maintaining a stock of BioTrust brochures

Hospital staff play a critical role ensuring that the BioTrust consent process is administered appropriately to all Michigan families shortly after delivery. Because of this important partnership, MDHHS can offer families the opportunity to decide if their child's left over blood spots from newborn screening can be used for de-identified medical and public health research studies.

The BioTrust brochure, titled "After Newborn Screening: Your baby's blood spots", is a required part of the consent process. When providing the BioTrust consent form to families around the time of newborn screening, **all families should receive a copy of this brochure.** It provides important information that families should know before making their decision about the research use of blood spots.

It is imperative that all hospitals maintain a stock of the BioTrust brochure that can accommodate all births expected at the facility. These brochures can be ordered online, free of charge, and are available in English, Spanish, and Arabic. [The instructions for ordering them online are located on the Michigan Newborn Screening website NBSO ordering instructions.](#)

[For technical assistance or training related to the BioTrust consent process, please contact MDHHS staff at \[BioTrust@michigan.gov\]\(mailto:BioTrust@michigan.gov\).](#)



Importance of identified eReports submitter

Every month, the Newborn Screening Program sends birthing hospitals a list of babies from their facility who had a blood spot screen submitted, but no critical congenital heart disease (CCHD) screening results were received. CCHD screening results can be submitted after this notification is received. The easiest way to report these results to the Newborn Screening Program is through eReports, the online reporting module for CCHD screening results. For this reason, every hospital should have at least one staff person registered to use eReports, even if the main reporting method for CCHD screening results is file transfer protocol or health level 7.



Follow these easy steps to register for eReports:

1. [Click here to obtain a MILogin account \(http://www.michigan.gov/mdhhs-milogin-info\)](http://www.michigan.gov/mdhhs-milogin-info).
2. Subscribe to the DCH Newborn Screening eReports application.
3. Complete an eReports User Agreement. [To obtain this user agreement, or for questions related to CCHD reporting, email Kristen Thompson at ThompsonK23@Michigan.gov.](mailto:ThompsonK23@Michigan.gov)

Staff Highlights

We are excited to announce our newest NBS team members:

Alayna Bunker is our newest Newborn Screening follow-up technician. She received a bachelor's degree from Michigan State University in kinesiology. While she is new to the follow-up area, Alayna previously worked in the newborn screening laboratory, where she gained 7 years of experience. As a follow-up technician, Alayna will work on a small team that is responsible for answering the main NBS phone line. Other roles include notifying physicians and parents when a repeat screen is necessary or when a newborn needs to be referred to a clinical coordinating center for confirmatory testing after an abnormal newborn screen.

Eleanor Surtman recently joined our team as a program assistant. She received a bachelor's degree from Michigan State University in professional writing. Prior to joining our team, she served as the Government Affairs Coordinator for the Michigan Manufacturers Association. Eleanor provides programmatic and administrative support to both the Newborn Screening Follow-up section and the Public Health Genomics section. In this role, she assists the newborn screening area with data entry, scheduling, in-office activities such as mail processing, and other project management activities.

2022 Newborn Screening (NBS) annual report summary

Every year, the NBS Program releases an annual report that provides detailed information about the previous birth year. [These reports are available at Michigan.gov/NewbornScreening](https://Michigan.gov/NewbornScreening) and contain information on updates that occurred during that birth year, the number of babies screened overall and the number identified with disorders on the NBS panel, performance metrics for each disorder including detection rate, false positive rate, and positive predictive value, and quality assurance information including the performance measures on the quarterly reports and time to treatment by disorder.

In 2022, a total of 100,176 infants were screened in Michigan and 322 (0.3%) were diagnosed with a disease on the blood spot panel. Overall, one infant out of 311 screened was diagnosed with one of the disorders. Since the NBS Program began in 1965, more than 8,000 Michigan newborns have been identified with disorders on the NBS blood spot panel. Congenital hypothyroidism and sickle cell disease are the most commonly identified disorders, affecting 144 and 43 infants born in 2022, respectively.

2022 Critical Congenital Heart Disease (CCHD) annual report summary

The Michigan Newborn Screening Program is continually working with hospitals to ensure that all babies are receiving the required pulse oximetry screen to enable early identification and intervention for children affected with a CCHD.

The CCHD Annual Report gives a general overview of CCHD screening indicators during 2022, including NBS Program presentations and involvement in external groups, CCHD screening practices and methods, screening results, and quality assurance information. [CCHD Annual Reports can be viewed at Michigan.gov/CCHD](https://Michigan.gov/CCHD).

Some key points from the 2022 report include:

- 96.2% of infants in well-baby nurseries had pulse oximetry screen results reported to the NBS program.
- A total of 66 infants failed the screen and two CCHD cases were identified through a pulse oximetry screening.
- An additional nine secondary conditions were detected after the infants received a pulse oximetry screen.
- 69.4% of screens were reported on-time, defined as within 10 days of screening.
- 95.0% of infants received timely screens, defined as taking place between 20 and 28 hours after birth.

Sickle Cell Disease resource

A new resource is available on “Women with Sickle Cell Disease and Postpartum Care: What to Know After Delivering Your Baby.” This fact sheet was developed by the CDC in partnership with the Foundation for Women & Girls with Blood Disorders, Sickle Cell Reproductive Education Directive, and the American Society of Hematology. With specialized care, women with sickle cell disease can have a healthy pregnancy. Without appropriate care, expectant/post-partum mothers are at increased risks for maternal and fetal complications, acute pain, acute chest syndrome, infections, and hemorrhage. [Click here to review and share the handout.](https://www.cdc.gov/ncbddd/sicklecell/documents/Postpartum_SickleCell-2023-508.pdf)

(https://www.cdc.gov/ncbddd/sicklecell/documents/Postpartum_SickleCell-2023-508.pdf)



NICU corner: Early specimens

Clinical circumstances in the NICU often require collection of blood spots prior to 24 hours of life. These specimens are considered early and will require a repeat collection as soon as possible. It is important to write the reason for the early collection in the notes field on the NBS card. This notation reduces the number of calls your unit will receive from the NBS Lab to verify collection date and time.

Collect an early specimen using an initial (blue) NBS card prior to:

- Red blood cell transfusion
- Surgery
- Initiating extracorporeal membrane oxygenation (ECMO)
- Transfer to another hospital

A repeat specimen is required as soon as possible, but no later than two weeks of life. The repeat specimen should be collected as soon as possible once the infant is at least 24 hours old using a repeat (pink) NBS card. If a newborn is unlikely to survive the first 24 hours of life, a NBS specimen should be collected at the parent's discretion.

Upcoming holiday courier schedule

Lower Peninsula hospitals:

Monday, February 19 – Holiday/Sunday schedule

Upper Peninsula hospitals:

Monday, February 19 – 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 Heppe, NBS section manager, is available to assist with questions related to BioTrust for Health. [Click here to reach Shelby by email](#) (Heppes@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](https://www.michigan.gov/NewbornScreening).