

Fall 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 second quarter of 2024, 12 hospital units met all six of the NBS blood spot screening performance goals.

- Ascension Borgess
- Ascension Providence, Southfield
- Corewell Health Beaumont Troy
- Corewell Health Trenton
- Henry Ford Jackson
- Henry Ford Macomb
- Henry Ford West Bloomfield
- McLaren Port Huron
- Trinity Health Ann Arbor
- Trinity Health Livonia
- Trinity Health Muskegon
- Trinity Health Oakland

### Performance Goals for NBS Blood Spot Quarterly Reports

1. Less than 1% of screens are collected more than 36 hours after birth.
2. More than 90% of screens arrive in the state laboratory by the appropriate day.
3. Less than 1% of screens are unsatisfactory.
4. More than 95% of electronic birth certificates have the NBS card number recorded.
5. More 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:

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During the second quarter of 2024, 20 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. Six hospitals had 100% of CCHD screens completed on time.

- Aspirus Ironwood
- Corewell Health Big Rapids
- Corewell Health Greenville
- Corewell Health Niles
- McLaren Lapeer Region
- UP Health System Portage

### 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.

## NBS card fee change

The fee for NBS cards is adjusted annually to reflect changes in the Detroit Consumer Price Index, to cover the cost of adding new disorders to the NBS panel, and to reflect changes in laboratory methodology for active screening assays. The Detroit Consumer Price Index increased 3.4% from June 2023 to June 2024. In addition, the NBS laboratory has updated screening methodologies for Mucopolysaccharidosis Type I (MPS I), Pompe disease and guanidinoacetate methyltransferase (GAMT) deficiency that require additional increases. To reflect these changes, MDHHS will apply a \$8.23 increase to the cost of each initial (blue) newborn screening card and a \$7.70 increase to the cost of each repeat (pink) card purchased.

**On January 1, 2025, the cost for the initial NBS card will increase to \$174.61 (from \$166.38). The cost for the repeat cards will change to \$158.63 (from \$150.93).** The fee supports the NBS Laboratory, Follow-up, and Coordinating Centers.

For questions about the fee change, please email [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov).

## Common card error - Recording the new year

The last performance metric on the quarterly NBS 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 during the first few months of the year is incorrect recording of birth and collection year on the NBS card. Date related errors can result in extra work for hospital and newborn screening staff to verify correct information.

Points to remember:

1. Remind staff to use caution when completing the year fields of the NBS card.
2. Check for incorrectly written dates and make necessary corrections before packaging the card for courier pickup.
3. Rapid response to date inquiries is necessary for timely results.
4. For more information about completing the NBS card, please see NBS Hospital Guide located at [Michigan.gov/NewbornScreening](https://Michigan.gov/NewbornScreening) under the “Resources for Hospitals and Health Professionals” section.



LAST NAME	
BIRTH DATE	
M   M   D   D   Y   Y	BIRTH TIME (Military)
H   H   M   M	
COLLECTION DATE	
M   M   D   D   Y   Y	COLLECTION TIME
H   H   M   M	(Military)

Diagram illustrating the common card error: A calendar icon with a checkmark is shown on the left. Two red arrows point from the calendar to the 'BIRTH DATE' and 'COLLECTION DATE' fields of the NBS card form. The year fields (YY) in both date fields are highlighted with red boxes, indicating the common error of incorrect recording of the year.

## Courier phone calls

Courier staff should NEVER call the hospital to see if there are NBS specimens to be picked up. Both hospital staff and the NBS team work diligently to ensure specimens arrive quickly to the laboratory for testing. The goal is that 90% or more of collected screens meet the receipt by appropriate day metric. This appropriate day of receipt is uniquely calculated for each site based on specimen drying time and courier pick-up time.

Miscommunication can occur when couriers call the hospital to inquire whether the hospital has screens that need to be picked up. Couriers must keep a set routine; stopping at every location on their route. This ensures a consistent schedule and reduces early arrivals and missed stops. For courier related concerns, please email [MDHHS-NBScourier@Michigan.gov](mailto:MDHHS-NBScourier@Michigan.gov).

## Baby Fair live and on demand

The NBS program is excited to share an opportunity at MDHHS for new and expecting parents or professionals that work with this target audience 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 and professionals.

The graphic is a promotional flyer for the Michigan Department of Health and Human Services (MDHHS) Virtual Baby Fair. It features a dark blue header with the text 'REGISTER NOW!' and 'Michigan Department of Health and Human Services Virtual Baby Fair'. Below this, it asks if the reader is a new or expecting parent and encourages them to join the fair to learn about resources and ask questions. It lists two live event dates: Monday, December 2, 2024, from 6:00-8:00 p.m. and Thursday, December 5, 2024, from 9:00-11:00 a.m. A green bar contains the registration link: <https://www.surveymonkey.com/r/RZXS9B8>. A list of participating MDHHS programs is provided, including Newborn Screening, BioTrust for Health, Infant Safe Sleep, WIC, Vital Records, Unintentional Injury Prevention, Oral Health Program, Care for MiWell, Childhood Lead Prevention Education, Michigan Maternal Mortality Surveillance, Hear Her Michigan Campaign, PFAS Education, Eat Safe Fish, Immunizations, Early Hearing Detection and Intervention, Maternal Infant Health Program, Michigan Home Visiting Initiative, Birth Defects Education and Outreach, Breastfeeding Support, and Children's Special Healthcare Services. On the right side, there is a photo of a woman holding a baby, a QR code with the text 'Scan here to register!', and contact information for MDHHS: 'For more information please contact MDHHS-VirtualBabyFair@Michigan.gov 517-284-4992'.

The MDHHS virtual baby fair is a department wide partnership to share important resources and information that promote health and safety to new parents and health care professionals. The department will be hosting two live events, on Dec. 2, 2024 from 6:00 to 8:00 p.m. and December 5, 2024 from 9:00 to 11:00 a.m. Participants can also view the baby fair on-demand, which is available year-round. The on-demand baby fair can be viewed by visiting [Michigan.gov/VirtualBabyFair](https://Michigan.gov/VirtualBabyFair). The live events allow participants the unique opportunity to ask questions directly to program experts, while the on-demand event allows participants to view the information being presented at their own pace.

At these free virtual baby fairs, 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.

The following MDHHS programs are participating in these events:

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 Program, Care for MiWell, PFAS Education and Breastfeeding Support.

## 2023 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 on the NBS program website ([www.michigan.gov/newbornscreening](http://www.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 2023, a total of 96,914 infants were screened in Michigan and 316 (0.3%) were diagnosed with a disease on the blood spot panel. Overall, one infant out of 307 screened was diagnosed with one of the disorders. Since the NBS Program began in 1965, more than 8,300 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 128 and 60 infants born in 2023, respectively.

## 2023 CCHD NBS annual report summary

The Michigan NBS program is continually working with hospitals to ensure that all babies are receiving the required pulse oximetry screen to ensure that CCHD cases are identified and that interventions are started as quickly as possible for affected infants.

The CCHD Annual Report gives a general overview of the 2023 year in review, 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](http://Michigan.gov/CCHD).

Some key points from the 2023 report include:

- 97.8% of infants in well-baby nurseries had pulse oximetry screen results reported to the NBS program.
- A total of 55 infants failed the screen and one CCHD case was identified through a pulse oximetry screening.
- An additional 13 secondary conditions were detected after the infants received a pulse oximetry screen.
- 70.0% of screens taken in well-baby nurseries were reported on-time, defined as within 10 days of screening.
- 96.1% of infants received timely screens in well-baby nurseries, defined as taking place between 20 and 28 hours after birth.



## Pulse oximetry screening and skin pigmentation

MDHHS was informed by clinical partners about potential concerns of the accuracy of pulse oximetry measures in persons with darker skin pigmentations. These concerns were brought to light in adult populations throughout the COVID-19 pandemic and several studies have since shown inaccuracies in pulse oximetry measurements in adults with darker skin with lower recognition of hypoxia. Research focused on newborns and children remains limited at this time, but studies conducted thus far confirm that racial disparities in measurements by pulse oximetry may exist<sup>1,2,3</sup>.

At this time, given the limited data currently available, the MDHHS CCHD Advisory Committee is not making formal changes to the current CCHD screening algorithm. However, the committee strongly recommends hospitals advise staff conducting the CCHD screens of the potential inaccuracies of pulse oximeter measures based on skin pigmentation. The committee continues to stress the importance of using clinical judgement when assessing a symptomatic patient or when interpreting CCHD screening results. As always, CCHD screening is just a screen, and clinical assessment is a very important tool when detecting infants with a CCHD.

For more information on this topic, please review the following articles:

1. Andrist, Erica et al. "[Association of Race With Pulse Oximetry Accuracy in Hospitalized Children.](#)" *JAMA network open* vol. 5,3 e224584. 1 Mar. 2022, doi:10.1001/jamanetworkopen.2022.4584
2. Foglia, Elizabeth E et al. "[The Effect of Skin Pigmentation on the Accuracy of Pulse Oximetry in Infants with Hypoxemia.](#)" *The Journal of pediatrics* vol. 182 (2017): 375-377.e2. doi:10.1016/j.jpeds.2016.11.043
3. Vesoulis, Z., Tims, A., Lodhi, H. et al. "[Racial discrepancy in pulse oximeter accuracy in preterm infants.](#)" *J Perinatol* **42**, 79–85 (2022). <https://doi.org/10.1038/s41372-021-01230-3>

## NICU corner: CCHD algorithm

NICU infants should be screened for CCHD when medically appropriate following the MDHHS NICU algorithm. The NICU algorithm for CCHD screening can be found at [Michigan.gov/CCHD](https://www.michigan.gov/CCHD) under the Provider Resources section. Assess the infant's oxygen requirement during NICU stay:

- Infants not requiring supplemental oxygen and that are asymptomatic should be screened at or after 24 hours of life.
- Infants requiring oxygen during NICU stay should be screened 24 hours after weaning to room air (requiring no supplemental O<sub>2</sub> or respiratory support).
- Infants going home on oxygen – consider echocardiogram if not already done during hospitalization.

All NICU infants should be screened using these guidelines; if not previously screened, screen prior to discharge from the unit.

Things to keep in mind:



- Infants with a previous echocardiogram or known CCHD diagnosis do not require screening.
- If an infant is less than 35 weeks of age and has been off room air for 24 hours, you can collect the CCHD screen. It is less about gestational age than it is about circulation/oxygenation.

## Update to BioTrust consent brochure

The [BioTrust consent brochure](#) has been updated to reflect MDHHS' current archive of stored blood spots, which now includes individuals born 1989 and later. It is required that every birthing family or legal guardian receive the BioTrust consent brochure to help them make an informed decision about participating in the BioTrust. Annual destruction of stored blood spots occurs after 35 years of storage, unless otherwise requested.



Individuals wanting to change their BioTrust decision or wanting left-over blood spots destroyed during the storage period may complete a [MDHHS-5683 Residual Newborn Screening Blood Spot Directive form](#) and submit it to MDHHS with their required identification. Individuals wanting to change a previous BioTrust decision to now allow blood spot use in research may complete a [MDHHS Directive to Use Bloods Spots in Research form](#). Please contact Michele Fritz at [fritzm3@michigan.gov](mailto:fritzm3@michigan.gov) with any questions.

## Upcoming holiday courier schedule

### Lower Peninsula hospitals:

Thursday, Nov. 5 – Holiday/Sunday schedule.  
Monday, Nov. 11 – Holiday/Sunday schedule.  
Wednesday, Nov. 27 – Holiday/Sunday schedule.  
Thursday, Nov. 28 – Holiday/Sunday schedule.  
Friday, Nov. 29 – Holiday/Sunday schedule.  
Tuesday, Dec. 24 – Holiday/Sunday schedule.  
Wednesday, Dec. 25 – Holiday/Sunday schedule.  
Tuesday, Dec. 31 – Holiday/Sunday schedule.  
Wednesday, Jan. 1– Holiday/Sunday schedule.  
Monday, Jan. 20– Holiday/Sunday schedule.

### Upper Peninsula hospitals:

Thursday, Nov. 5 – Normal operations.  
Monday, Nov. 11 – Normal operations.  
Wednesday, Nov. 27 – Normal operations.  
Thursday, Nov. 28 – UPS closed.  
Friday, Nov. 29 – Normal operations.  
Tuesday, Dec. 24 – Normal operations.  
Wednesday, Dec. 25 – UPS closed.  
Tuesday, Dec. 31 – Normal operations.  
Wednesday, Jan. 1– UPS closed.  
Monday, Jan. 20– UPS closed.

## 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).
- Michele Fritz, Genomics and NBS Coordinator, is available to assist with questions related to BioTrust for Health. [Click here to reach Michele by email](#) (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](http://www.Michigan.gov/NewbornScreening).