

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

- Ascension Providence Southfield
- Aspirus Ironwood
- Bronson Methodist
- Henry Ford Jackson
- Henry Ford Jackson SCN
- Holland SCN
- Huron Valley – Sinai
- Huron Valley – Sinai SCN
- McLaren Port Huron
- Three Rivers Health
- Trinity Health Ann Arbor
- Trinity Health Livonia
- 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:

- ✓ NBS conference registration.
- ✓ NBS card expiration alert.
- ✓ Common card error: partial date.
- ✓ Ten years of CCHD screening.
- ✓ New staff highlight.
- ✓ BioTrust consent: IRB and equity.
- ✓ MPS II coming soon to NBS panel.
- ✓ Sickle cell disease care and treatment.
- ✓ Summer baby fair.
- ✓ Monthly Minute video.
- ✓ NICU Corner: blood transfusions.

During the fourth quarter of 2023, 14 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. Four hospitals had 100 percent of CCHD screens performed on time.

- Aspirus Keweenaw
- Corewell Ludington
- Corewell Niles
- UP Health System - Portage

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 percent of newborns with a blood spot screen have pulse oximetry screen completed between 20 and 28 hours after birth.

Newborn screening conference

Are you registered for the upcoming NBS 2024 conference? If not, there is still time!

We will be hosting day-long virtual conferences on May 7 and May 22. This year, there will be a highlight of CCHD screening, including an expert sharing information about pulse oximetry screening and a family's story about the impact screening had for their child. In addition, we will present on parent education, blood spot resources, common misconceptions in early hearing screening and more. The conference is offered at no cost to attendees, and nursing contact hours will be provided. [Register today at https://www.surveymonkey.com/r/PSM9SBP](https://www.surveymonkey.com/r/PSM9SBP).



2024 MDHHS Newborn Screening (NBS) Conferences

May 7 and May 22
9:00 a.m. – 2:35 p.m.



Join us to learn more about:

- Critical Congenital Heart Disease highlight: Celebrating ten years of screening.
- Educating parents about NBS: Resources and tips.
- How to navigate Newborn Screening Online (NBSO) to order materials.
- Blood spot screening: Resources and the new hospital metric dashboard.
- Early Hearing Detection and Intervention common misconceptions and family stories.
- Michigan BioTrust for Health.

Registration
QR code

NBS card expiration alert

Please check your inventory for first and repeat sample cards that are due to expire in June and use those cards first. The expiration date is the middle right side of the NBS card (see image below). Cards with a June 2024 expiration date may be used through June 30, 2024. Specimens collected on an expired card will be unsatisfactory and a repeat collection will be required.

Unused expired cards can be returned for replacement by completing the “Newborn Screening Card Replacement 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](#).

The form includes sections for: BABY (Last Name, First Name, Gender, Birth Date, Birth Time, Birth Weight, Wks Gestation, Birth Order, Antibiotics, Specimen Date, Collection Time, Collected By, NICU or Special Care, Any RBC Transfusion, Transfusion Date, Trans. Start Time, Medical Record #, Ethnicity, Race, Type of Collection, TPN/Amino Acids, Other Feeding), MOTHER (Last Name, First Name, Address, Phone, City, State, Zip, Medical Record #, Birth Date, HEPATITIS B SURFACE ANTIGEN (HbsAg) Test Date, Result), PROVIDER (Last Name, First Name, Address, Phone, Fax, City, State, Zip), and SUBMITTER (Submitter Name, Address, Phone, City, State, Zip, Hospital Code, Birth Hospital). A red circle highlights the expiration date 'EXPIRES: 2024-06-30' on the right side of the card, with a red arrow pointing to it.

Check expiration
date here.

Common card error: partial collection date

Accurate completion of the newborn screening card is a critical step in the screening process. 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 occurs when staff entering the demographic information include a partial collection date and/or omit the collection time.



A new box has been added to the NBS card to remind hospital staff to complete the collection information. An important quality control step to implement is to have a team member quickly review each card prior to packaging to ensure all fields are complete.

Points to remember:

1. Make sure all the fields on the card are complete.
2. Make necessary corrections before packaging the card for courier pickup.

Card errors can result in:

1. Infant distress caused by an entry error that led to an unnecessary repeat specimen.
2. Additional work for NBS laboratory and follow-up staff.
3. Inaccurate test interpretation due to age-dependent analyte cutoffs.

10 Years of Screening for
CRITICAL CONGENITAL HEART DISEASE

Michigan's Newborn Screening Program mandated screening infants for CCHD on April 1, 2014

More than 928,000 babies screened

More than 70 babies diagnosed with secondary conditions

More than 30 babies diagnosed with a CCHD

Michigan DHHS | Michigan Newborn Screening
Michigan.gov/NewbornScreening

Celebrating ten years of screening

Michigan's NBS program is celebrating ten years of screening for CCHD using pulse oximetry. Screening began on April 1, 2014, and since that day more than 928,000 babies have been screened. As a result of screening, more than 30 babies have been diagnosed with a CCHD and more than 70 babies have been diagnosed with a secondary condition (including hemoglobinopathy, hypothermia, infection, lung disease, noncritical congenital heart defect, persistent pulmonary hypertension and other hypoxemic conditions not otherwise specified). 96.2% of babies born in well baby nurseries in 2022 had pulse oximetry values reported to the NBS program.



Staff Highlight

The Public Health Genomics Section, in collaboration with the NBS program, welcomed Michele Fritz on January 16 as the new genomics and newborn screening research coordinator. Michele will lead coordination of the [BioTrust for Health Program](#). She is a native Michigander and Michigan State University (MSU) alumni. She earned a master's degree in epidemiology, a bachelor's degree in veterinary technology/nursing and a graduate certificate in community engaged scholarship. Michele has more than 17 years of research experience at MSU spanning human, veterinary and academic settings.

For BioTrust related questions, [please email Biotrust@michigan.gov](mailto:Biotrust@michigan.gov).

Important reminders for the BioTrust consent process: Institutional Review Board (IRB) and equity

The BioTrust consent process is approved and monitored by the MDHHS IRB to ensure all parents have an opportunity to decide if their child's leftover blood spots from newborn screening can be used in health research studies. The MDHHS IRB also reviews each project that requests access to leftover blood spots to ensure there is scientific merit and that adequate protections are in place for confidential and identifying information.

Research findings are used to inform NBS programs, treatment options for babies with rare diseases, and the relationships between exposures detected by NBS and health events later in life. You can help ensure that these findings are generalizable to every person in Michigan by offering every parent an opportunity to participate in the Michigan BioTrust for Health. Supporting equitable research participation means that all people will be represented in research findings, and health care practices will positively impact all people.

The BioTrust brochure, titled *"After Newborn Screening: Your baby's blood spots"*, is a required part of the consent process that each parent must receive around the time of NBS. The BioTrust research coordinator will review your brochure order inventory and send routine reminders to help your hospital stay on track of your inventory.

Below are helpful resources for staff to be familiar with:

- For instructions on how to complete the consent process with families, [click here to view our BioTrust staff instruction sheet](#).
- [Visit Michigan.gov/NBSOrders](https://michigan.gov/NBSOrders) for more information on ordering BioTrust brochures.
- The Newborn Screening online education model includes information on conducting the BioTrust consent process with families and offers nursing contact hours. [To complete the course, visit https://courses.mihealth.org/PUBLIC/](https://courses.mihealth.org/PUBLIC/).

For any questions related to the BioTrust consent process, please contact the new BioTrust Research Coordinator, Michele Fritz, at 517-335-6497 or [via email at Biotrust@michigan.gov](mailto:Biotrust@michigan.gov).

Summer virtual baby fair

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. We are sharing this with you in hopes that you will pass this message and save the date along to your patients or other professionals who may be interested.

[To register for the event, please visit Michigan.gov/VirtualBabyFair.](https://www.michigan.gov/VirtualBabyFair)



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.

Wednesday, July 10, 2024, from 9:00-11:00 a.m.
Tuesday, July 23, 2024, from 6:00-8:00 p.m.

Register at
<https://www.surveymonkey.com/r/6L3976X>

Participating MDHHS Programs:

- Newborn Screening
- BioTrust for Health
- Infant Safe Sleep
- Women, Infants, & Children (WIC)
- Vital Records
- Unintentional Injury Prevention
- Oral Health Program
- Care for MiWell
- Childhood Lead Poisoning 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
- Children's Special Healthcare Services

Scan here to register!

For more information please contact
MDHHS-VirtualBabyFair@Michigan.gov
517-284-4992

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, important health and safety information and can 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 Program, Care for MiWell, PFAS Education, Michigan Maternal Mortality Surveillance Hear Her Michigan Campaign, MDHHS Doula Initiative and Breastfeeding Support.

Monthly Minute video

The Monthly Minute is a series of short videos created by Michigan's Vital Records program to highlight common errors hospital staff should avoid when working in the Vital Events Registration Application (VERA). The NBS Program collaborated with the Vital Records Program to create a monthly minute video highlighting important things to consider when filing a birth certificate to allow for timely newborn screening.



The NBS program uses birth certificate data to identify babies whose screening may have been inadvertently missed. On a weekly basis, birth certificate data is linked to NBS records with the aim of identifying babies who did not receive screening. Accurate demographic information is important in this linking process. Inaccuracies in this data can interfere with record linkage, leading to increased staff time spent rectifying these issues and critical time delays. The NBS program is unable to identify babies potentially missed before the birth certificate is filed. As such, it is important to ensure birth certificates are filed within five days. We encourage you to share this video with anyone from your hospital involved in filing the birth certificate information. [Click here to view the video \(https://youtu.be/LMxE-D4Psk\).](https://youtu.be/LMxE-D4Psk)

Mucopolysaccharidosis Type II to be added to Michigan's NBS panel

On November 8, 2023, the Michigan NBS Quality Assurance Advisory Committee unanimously recommended the addition of mucopolysaccharidosis type II (MPS II) to Michigan's NBS panel. The recommendation has since been approved by the MDHHS director and legislative health policy committees. Nationally, MPS II was added to the Recommended Uniform Screening Panel in 2022 following review by the Advisory Committee on Heritable Disorders in Newborns and Children.

MPS II, or Hunter syndrome, is an X-linked lysosomal storage disorder (LSD) associated with progressive organ dysfunction, skeletal deformities, neurodegenerative disease in some patients gives shortened life expectancy. Although there is no cure for MPS II, enzyme replacement therapy is effective in improving somatic symptoms and prolonging survival. Early diagnosis and treatment give boys with MPS II a greater chance for better outcomes and quality of life.

MPS II will be the third LSD on Michigan's NBS panel following the addition of MPS I and Pompe disease in 2017. Statewide screening is anticipated to begin next year after laboratory preparations are completed and follow-up processes are in place. Collaborative efforts to ensure successful implementation are currently underway between the NBS Program, LSD Coordinating Centers and LSD Advisory Committee.

Public Health Genomics focus - sickle cell disease care and treatment

As an extension of NBS efforts, the Public Health Genomics Section (PHG) within MDHHS continues to focus on strategies that expand and enhance access to care, medical adherence and quality improvement for sickle cell disease (SCD) services across the lifespan.

In fiscal year (FY) 2022, PHG established the Sickle Cell Clinic Expansion and Enhancement program, with funding obtained from the Michigan legislature. This funding was part of the Children's Special Health Care Services (CSHCS) age expansion efforts to provide CSHCS coverage to all individuals diagnosed with SCD, regardless of age. The program originally sought to establish and/or improve SCD treatment services provided through Henry Ford Health, Michigan State University and the University of Michigan. Beginning in FY2024, two more sickle cell clinics have been added to the original awardees, including a clinic at Children's Hospital of Michigan in Detroit and one at Bronson Health Foundation in Kalamazoo.

In FY2023, MDHHS received additional funding from the Michigan legislature to work with the Sickle Cell Disease Association of America – Michigan Chapter (SCDAA-MI) to establish a Sickle Cell Center of Excellence (CoE) in the greater Detroit area. This center represents a \$5 million investment over multiple years. The SCDAA-MI has recently entered into an agreement with Henry Ford Health to house the CoE, which will work to improve both clinical outcomes and quality of life for individuals living with SCD by offering culturally responsive, comprehensive, multi-disciplinary medical services that are informed by state-of-the-art innovation, best practices and research.

Through all these efforts, the PHG Section strives to make positive changes to the system of care through service integration. According to Dr. Wanda Whitten-Shurney, CEO and Medical Director, SCDAA-MI, "The CoE will provide a desperately needed, true medical home for adults living with sickle cell disease - similar to the pediatric program established over 40 years ago by my father Dr. Charles F. Whitten at Children's Hospital of Michigan."

To learn more about Michigan's sickle cell clinics, the CoE and/or other sickle cell projects currently underway, [email Mary Robinson, Hemoglobinopathy Coordinator, at RobinsonM31@michigan.gov.](mailto:RobinsonM31@michigan.gov)

NICU corner: Transfusions

Red blood cell (RBC) transfusions can lead to confusion in the timing of newborn screening collection. Under ideal circumstances, the first sample specimen should be collected between 24-30 hours of life and prior to RBC transfusion. If baby remains in the NICU for at least eight days, a repeat sample specimen should be collected at discharge or 30 days of life, whichever comes first.

For the rare circumstances where the ideal collection cannot take place, please follow these steps:

- **If the first sample specimen cannot be collected prior to RBC transfusion:**
 - A first sample specimen should be collected 28 hours post RBC transfusion start time.
 - A repeat sample specimen should be collected at discharge or 30 days of life, whichever comes first.
 - Another repeat sample specimen should be collected 90 days following the last RBC transfusion.
- **If the first sample specimen is collected prior to RBC transfusion but less than 24 hours of life (early screen):**
 - A repeat sample specimen should be collected at 28 hours post transfusion start time.
 - If another transfusion begins prior to the 28-hour period, wait to collect the repeat sample until a full 28 hours after the next transfusion.
 - Another repeat sample should be collected at discharge or 30 days of life, whichever comes first.

Upcoming holiday courier schedule



Lower Peninsula hospitals:

- Monday, May 27 - Holiday/Sunday schedule
- Wednesday, June 19 - Holiday/Sunday schedule
- Thursday, July 04 - Holiday/Sunday schedule

Upper Peninsula hospitals:

- Monday, May 27 - UPS will be closed
- Wednesday, June 19 - Normal operations
- Thursday, July 04, 2024 - UPS will be 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](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 Michelle 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 or [visit our website at Michigan.gov/NewbornScreening](https://www.michigan.gov/NewbornScreening).