Fall 2023

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



- Ascension Providence Southfield
- Corewell Health Beaumont Troy NICU
- Corewell Health Gerber
- Corewell Health Trenton
- Corewell Health Zeeland
- Holland Hospital NICU
- Huron Valley Sinai Hospital NICU
- Munson Healthcare Otsego Memorial
- MyMichigan Medical Center Sault
- MyMichigan Medical Center Alpena
- Promedica Hickman Hospital
- Corewell Health Ludington
- Three Rivers Health
- Trinity Health Ann Arbor
- Trinity Health St Joseph Mercy Oakland

Performance Goals for NBS Blood Spot Quarterly Reports

- 1. Less than one percent of screens are collected more than 36 hours after birth.
- 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.
- 2. Greater than 90 percent of screens arrive in the state 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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- ✓ Metabolic coordinating center update.
- ✓ NBS card fee change.
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- \checkmark Winter virtual baby fair.
- \checkmark CCHD metric change.
- \checkmark Unite learning community grant.
- ✓ NICU Corner: congenital hypothyroidism.
- \checkmark Holiday schedule.

During the second quarter of 2023, 25 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. One hospital had 100 percent of CCHD results completed between 20 and 28 hours of life.

Sinai-Grace Hospital

Performance Goals for CCHD Quarterly Reports

- 1. At least 90 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.





Important reminders for the BioTrust consent process: verbal consent

Recently, MDHHS has identified an increase in the number of BioTrust consent forms that indicate verbal consent has been obtained from parents. Per departmental policy, these forms are not valid or considered complete since the BioTrust requires written consent from families.

Only a parent or legal guardian of the child can sign the BioTrust consent form. There is never a situation where it is appropriate for a staff member to collect a verbal decision or to sign on behalf of the family. When this occurs, the BioTrust for Health is unable to honor a family's decision to allow blood spots to be used for de-identified health research.

Consent forms do not have to be returned at the same time as the blood spots. If a family needs additional time to make their consent decision, **do not delay** sending the blood spots back for newborn screening. The white copy of the consent form can be picked up by the courier on a different day.

Resources are available to help staff members with questions on how to collect the BioTrust consent decision from families:

- <u>Staff instruction sheet</u>
- Online training modules

For any questions related to the BioTrust consent process, please contact Shelby Heppe at 517-335-6497 or at <u>BioTrust@michigan.gov</u>.

NBS blood spots for transferred newborns

Communication is critical between the birth hospital and the receiving facility to ensure all transferred infants receive screening. The birth hospital is responsible for ensuring that NBS specimens are collected on all newborns and sent to the NBS Laboratory regardless of age. If an infant is transferred to another hospital, every attempt should be made by the birth hospital to collect a NBS prior to transfer. This is an appropriate reason to collect an early specimen (prior to 24 hours). However, extenuating circumstances may interfere with collection of the screen.

The responsibilities of each hospital are listed below:

Birth Hospital

- Collect the NBS prior to transfer and submit to NBS Laboratory per the usual process.
- Write 'transfer to' and name of receiving hospital in the note section of the NBS card.
- Notify the receiving facility of NBS status.
- Include verification of the screen in transfer paperwork.
- If transfer occurs after the NBS card is submitted, inform the NBS program by phone (517-335-4181) or by fax (517-335-9419) using the hospital discharge sheet. This form is in the Resources for Hospitals and Health Professionals section of the NBS website at Michigan.gov/Newbornscreening. <u>Click here for a direct link to the form.</u>
- Do not send an incomplete NBS card to the receiving hospital with infant.

Receiving Hospital

- Verify the NBS status of all transferred newborns
 - If verification cannot be obtained, collect the NBS.
- If the NBS collection was collected prior to 24 hours, collect a repeat screen at 24-36 hours and a 30-day or discharge screen (as per the NICU protocol).
- Do not use a NBS card from the birthing hospital. Cards should not be transferred with an infant. Only use NBS cards purchased and assigned to your facility.





How to report transfers for CCHD screening

Have you encountered a situation where an infant was transferred prior to screening for CCHD? To prevent receiving follow-up from the NBS Program regarding a missed screen, it is imperative that an infant who has been transferred not be categorized as having missed the screening for CCHD. Instead, it is recommended to utilize the designated "pulse ox not completed" field to indicate a transfer status. If you are using the eReports system for your reporting, this selection can be located below.

Baby's First Name	Mother's First Name	
Baby's Last Name	Mother's Last Name	
Medical Record Number	Newborn Screening Kit Number	
Date of Birth (mm/dd/yyyy)	Birth Hospital Name	~
Pulse Ox 1	Multiple Birth Order	~
Date (mm/dd/yyyy)		
Time (HH:MM)	Perfusion Index Foot	
Foot Sat%	Perfusion Index Right Hand	
Right Hand Sat %		
Difference	Pulse Ox Not Completed	Transfer 🗸
Outcome	✓ Other	
Pulse Ox 2		
Date (mm/dd/yyyy)	Perfusion Index Foot	
Time (HH:MM)	Perfusion Index Right Hand	
Foot Sat%		
Right Hand Sat %		
Difference	Pulse Ox Not Completed	~
Outcome	✓ Other	
Pulse Ox 3	Internal Use	Only
Date (mm/dd/yyyy)	Perfusion Index Foot	
Time (HH:MM)	Perfusion Index Right Hand	
Foot Sat%		
Right Hand Sat %	Internal Use	Only
Difference	Pulse Ox Not Completed	×
Outcome	✓ Other	
Submitter:		~
Submit	tar	

Alternatively, if your hospital uses file transfer protocol (FTP), you will find this option denoted in the "R" column of the reporting template, pulse ox not completed.

А	В	С	D	E Demographics	F	G	н	I.	J	к	L	М	N Pulse (O Divimetry re	Pading	Q	R	s
Newborn_ Screening_ Kit_Numbe r	Hospital _ Name	Baby_First_ Name	Babys_Last _ Name	Multiple_Birth_	Baby_DOB	Baby_Medical_ Record_Number		Mother_Last_ Name	PO1_Date		PO1_ Foot_	PO1_Fo ot_Perf	PO1_ Right_	PO1_Righ t_Hand_ Perfusion	PO1_ Differ		PO1_Not_ Complete d_ Reason	PO1_Othe r

The classification of "missed" for a CCHD screen should exclusively be used when the screen was not collected at all while the baby was within your care, with no valid reason why it was not completed. If the screen was truly missed, this means the infant was discharged home without undergoing the required screening.

Newborn screening card fee change

The Detroit Consumer Price Index increased 4.7% from June 2022 to June 2023. To reflect this change, MDHHS will apply a \$7.47 increase to the cost of each initial (blue) newborn screening card and a \$6.78 increase to the cost of each repeat (pink) card purchased. No additional disorders have been added, so the fee increase only included changes due to the Detroit Consumer Price Index.

On January 1, 2024, the cost for the initial newborn screening (NBS) card will increase to \$166.38 (from \$158.91). The cost for the repeat (pink) cards will change to \$150.93 (from \$144.15). The fee supports the Newborn Screening Laboratory, Follow-up, and Coordinating Centers. The fee is adjusted annually to reflect changes in the Detroit Consumer Price Index and to cover the cost of adding new disorders to the newborn screening panel.

If you have questions regarding the fee, please contact the Newborn Screening Follow-up Program at <u>newbornscreening@michigan.gov</u>.

NBS emergency weather plan and courier issue reminder

Earlier this year, the Michigan NBS Program created a new email address that will be used to communicate courier updates. These updates will include the announcement of upcoming holidays or emergency weather plans that could affect your courier picking up NBS specimens. The email address is <u>MDHHS-NBScourier@Michigan.gov</u>. We will only email hospitals that are affected by the weather emergency plans. Please ensure that we have the appropriate courier contacts if they have recently changed for your hospital. Please reach out to this email address if you have any questions, concerns or feedback for your courier.



Metabolic highlight – 2nd coordinating center

The NBS Program is excited to share the new referral model for babies who screen positive for inborn errors of metabolism (IEM). Since 2004, the Children's Hospital of Michigan has partnered with MDHHS as the single coordinating center that performs confirmatory testing and care coordination for infants who screen positive for IEM. We are excited to expand this collaboration to include Michigan Medicine as a second site to receive referrals beginning October 1, 2023. Newborns with positive screens for IEM will be referred to either Children's Hospital of Michigan or Michigan Medicine for coordination of confirmatory testing based on their geographic location. Both institutions have been vital to ensuring timely coordination and care for many other NBS disorders over the years.

Winter 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 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.



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

CCHD metric changes

There have recently been some updates to the CCHD metrics on the quarterly reports.

Metric 1: Reported Screens

Defined as all newborns with a right hand and foot pulse oximetry screen reported to the state divided by the total number of newborns with a bloodspot screen. Starting with the Quarter 3 report and moving forward, the goal for this metric is to achieve a minimum of 95% of screens reported to the NBS Program. Previously, the goal was to achieve a minimum of 90% of screens reported to the NBS Program.

Metric 2: Reported on Time

Defined as all newborns with a right hand and foot pulse oximetry screen reported to the state fewer than 10 days after the screen date divided by total number of newborns with a bloodspot screen. The goal for this metric is to attain a minimum of 90% of screens reported on time. **No changes to this metric have been made.**

Metric 3: Timely Screens After Birth

A new definition for this was implemented Quarter 2. The change was detailed in the last newsletter. As a reminder, **the metric is now defined as all newborns with a right hand and food pulse oximetry screen completed between 20 and 28 hours after birth divided by the total number of newborns with pulse oximetry screens reported**. It was previously divided by the total number of newborns with a bloodspot screen. The goal for this metric is to achieve a minimum of 90% of screens performed on time.

If you have any questions or concerns about these metrics, please reach out to Kristen Thompson at <u>ThompsonK23@michigan.gov</u>.

Unite learning community grant

The Newborn Screening Follow-up Program and the Early Hearing Detection and Intervention (EHDI) Programs have partnered on a new grant opportunity. The programs were recently awarded a \$30,000 stipend to participate in the "Unite Newborn Screening Learning Community." This grant is funded by the National Center for Hearing Assessment and Management (NCHAM) at Utah State University.

In most states, newborn screening is managed through the state department of health. Since blood spot and EHDI programs are frequently led by different areas within the health department, there are opportunities to develop a more cohesive approach to these services. The purpose of this learning community is to bring together up to five state blood spot programs, EHDI programs and parent representatives to develop best practices for collaboration within the newborn screening system. Over the course of the 9-month project period, the programs will collaborate to produce and test a best practice guide that will serve a resource to other states/territories who would like to improve their blood spot and EHDI collaboration.

Our Michigan team is excited to have the opportunity to participate in this national effort to improve collaborations within state newborn screening systems.

NBS program office holiday schedule

Thursday, November 23 - Closed Friday, December 22 - Open Saturday, December 23 - Closed Friday, December 29 - Closed Saturday, December 30 - Closed Monday, January 1 - Closed

NICU corner: Congenital Hypothyroidism and preterm infants

In January 2023, the American Academy of Pediatrics published a clinical report in *Pediatrics* (Volume 151) titled *Congenital Hypothyroidism (CH): Screening and Management* (DOI: https://doi.org/10.1542/peds.2022-06041). This report includes recommendations specific screening to preterm infants (<32 weeks gestation) for CH. The Pediatric Endocrine Advisory Council (PEAC) of the state of Michigan recently reviewed the report and are making the following recommendations:

- 1. Follow the NICU protocol which recommends a second NBS for all infants remaining inpatient for eight days or longer at 30 days of life or discharge, whichever is earlier.
- If the second NBS performed before 36 weeks corrected gestational age is normal, a serum TSH should be collected four weeks after the second newborn screen (6–8 weeks of life) or at 36 weeks corrected gestational age, whichever is earlier.

Upcoming holiday courier schedule

Lower Peninsula hospitals:

Friday, November 10 – Holiday/Sunday schedule Thursday, November 23 – Holiday/Sunday schedule Friday, November 24 – Holiday/Sunday schedule Friday, December 22 – Regular schedule Monday, December 25 – Holiday/Sunday schedule Friday, December 29 – Regular schedule Monday, January 01– Holiday/Sunday schedule Monday, January 15– Holiday/Sunday schedule

Upper Peninsula hospitals:



Saturday, November 11 – Normal operations Thursday, November 23 – UPS will be closed Friday, November 24 – Normal operations Monday, December 25– UPS will be closed Monday, January 01– UPS will be closed Monday, January 15– Normal operations

Technical assistance

- □ Angela Aldrich, NBS nurse consultant, is available to work with staff in any hospital that requests help with specimen collection. <u>Click here to reach her by email</u> (AldrichA1@Michigan.gov).
- □ Kristen Thompson, NBS coordinator, is available to work with hospitals on CCHD pulse oximetry screening and reporting. <u>Click here to reach Kristen by email</u> (ThompsonK23@Michigan.gov).
- □ Shelby Heppe, NBS section manager, is available to assist with questions related to BioTrust for Health. <u>Click here</u> <u>to reach Shelby by email (Heppes@michigan.gov)</u>.

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.