





Michigan Department of Health and Human Services

Newborn Screening News

The Michigan Department of Health and Human Services (MDHHS) Newborn Screening 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 first quarter of 2022, two 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 NICU
- Munson Healthcare Charlevoix

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:

- **NBS Card Update**
- **NBS Card Fee Increase**
- LSD Screening Change
- **Hospital Educational Site** Visits
- **NBS Conference**
- **CCHD Email Notifications**
- Common NBS Card Errors
- BioTrust Course Link Update
- Sickle Cell Grant Awardees
- **Upcoming Holiday Schedule**

During the first quarter of 2022, 27 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. Ten hospitals with the highest percent of CCHD results reported to the Newborn Screening Program between 20 and 28 hours of life are listed below. Congratulations to the following hospitals on their impressive efforts:

- ➤ UP Health System Portage
- ➤ Beaumont Hospital Troy
- My Michigan Medical Center Gratiot McLaren Port Huron
- ➤ Hillsdale Hospital
- My Michigan Medical Center Alpena
- Munson Healthcare Otsego Memorial
- ➤ Hurley Medical Center
- My Michigan Medical Center Midland
- ➤ Henry Ford Jackson Hospital

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.



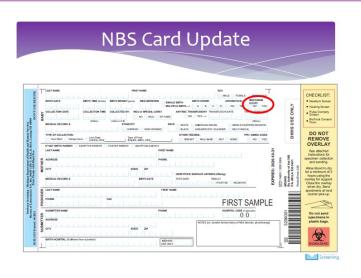
NBS Follow-up Program Contact Information

Phone: 517-335-4181 Email: NewbornScreening@Michigan.gov



Newborn Screening Card Update - Coming Soon!

Updated versions of the newborn screening card will be sent to hospitals in late summer or early fall 2022. A new field has been added to the "Baby" section of the card to report meconium ileus status. Currently, meconium ileus is reported to the Newborn Screening Program either in the notes section of the card or by phone or fax. Meconium ileus depresses the levels of the analyte used for the first-tier screen for cystic fibrosis. Blood spots for infants with meconium ileus should automatically go to second tier variant analysis. This newly added Yes/No field is intended to make reporting easier and more efficient.



Newborn Screening Card Fee Change

The price of the NBS cards will be changing, effective October 1, 2022. The adjustment is based on changes to the Detroit Consumer Price Index and fees associated with screening for new disorders. The NBS Program anticipates including a \$0.39 increase due to the addition of guanidinoacetate methyltransferase (GAMT) deficiency. The Detroit Consumer Price Index information is not known at this time. Notification regarding the new prices will be mailed to all hospital administrators and emailed to all coordinators by early September.

Lysosomal Storage Disorders (LSD) Screening Change

The Newborn Screening Lab staff implemented a new screening method for lysosomal storage disorders in April 2022. The method change improved the screening performance metrics, so fewer specimens are sent on for 2nd tier testing, resulting in fewer "2nd Tier Pending" results being reported out. Since waiting for the 2nd tier results can be stressful, this new method improves the screening process for our Michigan families!



Hospital Educational Site Visits

Every three years the Newborn Screening (NBS) Program nurse consultant meets with individual hospitals to discuss their newborn screening process. The NBS Program has switched from in-person hospital visits to virtual visits via Microsoft Teams. This format has allowed additional NBS staff members to attend and share information about other aspects of NBS, such as pulse oximetry screening for critical congenital heart diseases (CCHD) and the courier process. Information about the BioTrust for Health is also provided.

The visit includes NBS updates and resources, review of the hospital's metrics from the previous year, and technical assistance for any areas of concern. This two-hour meeting is most successful if there is key representation from the hospital, including the NBS Coordinator, backup coordinator, CCHD contact, and lab (if applicable). Please watch for an email from Angie Aldrich, NBS Nurse Consultant, regarding scheduling your visit. If you would like to proactively schedule a visit, please click here to email a request (NewbornScreening@Michigan.gov).

Newborn Screening Conference 2022

The Newborn Screening Program hosted two virtual newborn screening conferences in May for hospital staff and homebirth attendants. The conference covered a variety of topics including: a highlight of endocrine disorders, tips to avoid unsatisfactory specimen collection, accuracy in newborn screening card completion, a parent's experience with having two children diagnosed with congenital adrenal hyperplasia, and more!

A total of 136 attendees, representing 53 birth hospitals across Michigan, participated in these conferences. Please visit the Resources for Hospitals and Health Professionals tab on the MDHHS Newborn Screening website (Michigan.gov/NewbornScreening) to view the speaker slides. Click <a href="https://example.com/health-professionals-newborn-screening-n

CCHD Follow-up Notifications

All notifications for critical congenital heart disease, including failed and missing screens, are being sent via encrypted email using MIEncrypt. These emails are sent to the nurse coordinator and other key staff identified by the hospital to receive these notifications. If you do not receive these and would like to, or you would like to add someone to the list for your hospital, please contact Kristen Thompson at ThompsonK23@Michigan.gov. You may also contact Kristen if you are having trouble opening the MIEncrypt email.

Please note, newborns without pulse oximetry screen results impact your hospital's performance on the CCHD quarterly quality assurance report, so please report results promptly after notification.

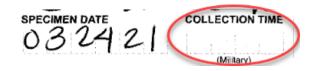


Common Card Errors - Missing collection date and/or time

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

Forty percent of the card errors in the first quarter of 2022 were due to hospital staff not entering the collection date and/or time on the newborn screening card.





Points to remember:

- 1. Make sure all the fields on the card are complete.
- 2. Check for errors and make necessary corrections before packaging the card for courier pickup.

Card errors can result in:

- 1. Infant distress due to an unnecessary repeat specimen.
- 2. Additional work for hospital, NBS laboratory, and follow-up staff.
- Inaccurate test interpretation due to age-dependent analyte cutoffs.

Updated Link for BioTrust Consent Training Module

The online *BioTrust Consent Process Training For Birthing Attendants* has moved to a new location. This is a ~30-minute training module designed for any staff member involved in the BioTrust consent process. It contains historical and background information on the BioTrust Program and provides details about administering the consent process with families. It also highlights important resources available for staff and families to make the consent process easier for all parties. This training is an excellent resource for new staff who will be involved in the consent process.

This training is housed on the newborn screening and BioTrust websites under the "Resources for Hospitals and Health Professionals" page. The new direct link to access the training module is: https://www.youtube.com/watch?v=gFpE5KAhskA. Click here or scan the QR code below for easy access to the module!





Sickle Cell Clinic Expansion and Enhancements Grant Awardees

The MDHHS – Public Health Genomics Section is pleased to announce the awardees of a new funding opportunity titled, "Sickle Cell Clinic Expansion and Enhancements." The purpose of these three-year grants is to offer new resources to providers to increase patient access to quality multidisciplinary health care and improve care coordination, as well as establish preferred provider networks that focus specifically on sickle cell disease (SCD).



The 3 awardees each receiving \$100,000 include:

Henry Ford Health System (HFHS): HFHS will focus on assuring a smooth transition of patients from pediatric to adult care, as well as work to assure improved access to other specialty and treatment management services, such as orthopedics, pain management, and allied services.

Michigan State University (MSU): MSU will work to establish a lifespan sickle cell center in Lansing within their Inherited Blood Disorder Service. This clinic will be staffed by a multi-disciplinary team and will be available to both pediatric and adult patients with SCD.

University of Michigan (UM): UM will work to improve adherence of healthcare providers to national guidelines and increasing its patient/caregiver adherence to preventative care including appointments and disease-altering treatments/medications.

Our hemoglobinopathy quality improvement staff look forward to sharing program outcomes as this work continues to evolve, so you can learn more about the lifelong importance of identifying babies with sickle cell disease through newborn screening.

Provider Education Opportunities

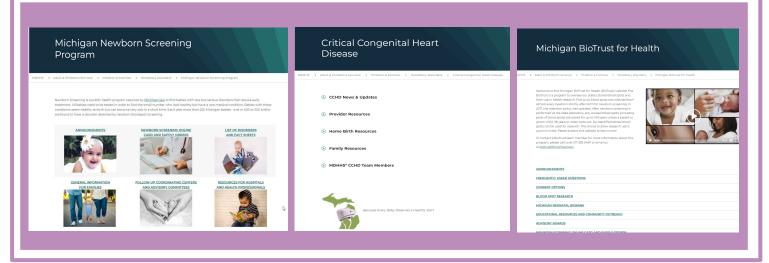
Provider events allow us to educate healthcare professionals involved with the NBS process. NBS staff are available to present at Grand Rounds or other educational sessions. If you know of any opportunities for the NBS Program to speak to healthcare professionals involved with the screen, please click herealthcare professionals involved with the screen, please click herealthcare professionals involved with the screen, please click herealthcare professionals involved with the screen, please click herealthcare professionals involved with the screen, please click herealthcare professionals involved with the screen, please click herealthcare professionals involved with the screen, please click herealthcare professionals involved with the screen, please click herealthcare professionals involved with the screen, please click herealthcare professionals involved with the screen, please click herealthcare professionals involved with the screen of the professionals involved with the professionals involv

For more program information, please visit the following MDHHS websites:

Michigan.gov/newbornscreening

Michigan.gov/CCHD

Michigan.gov/biotrust



Upcoming Holiday Schedule

Lower Peninsula Hospitals:

• Monday, September 5 – Holiday/Sunday schedule

Upper Peninsula Hospitals:

Monday, September 5– UPS will be closed for Labor Day



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). 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.