Winter 2021







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 third quarter of 2020, seven 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 Trenton
- Beaumont Hospital Troy
- Henry Ford Allegiance Health
- McLaren Port Huron SCN
- ➤ McLaren Flint
- Mercy Health Saint Mary's NICU
- St. Joseph Mercy Ann Arbor

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:

- **MDHHS Virtual Baby Fairs**
- Common Card Errors Straddling the Midnight Hour
- **CCHD Hospital Guide**
- BioTrust for Health Alternate Consent Form
- **CHD Awareness Month**
- Birth Defects Awareness Month
- Sickle Cell Disease Activities

During the third quarter of 2020, 25 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. Timely reporting of the screen results is important, and the following hospitals reported over 98% of screens within 10 days!

- ProMedica Coldwater Regional > Ascension Providence Hospital, Hospital
- Munson Healthcare Cadillac
- McLaren Greater Lansing
- Southfield Campus
- ProMedica Monroe Regional Hospital

Performance Goals for CCHD Quarterly Reports

- 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.
- At least 90% of newborns with a bloodspot 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



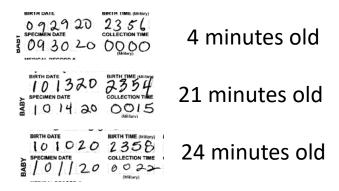
Michigan Department of Health and Human Services Hosts Two Virtual Baby Fairs

The Michigan Department of Health and Human Services (MDHHS) hosted virtual baby fairs for new and expecting parents on Wednesday, December 2 and Saturday, December 12. With COVID-19 cancelling all traditional ways in which MDHHS programs educate the public, MDHHS staff thought of new ways to educate new and expecting parents in a safe way. A group of programs from the department planned the first ever virtual baby fair. A total of 260 attendees across Michigan joined virtually to learn more about programs MDHHS has to offer support and guidance as they become parents. The Newborn Screening Program was one of nine presenting programs.



Common Card Errors - Straddling the Midnight Hour

The last performance metric on the quarterly Newborn Screening Quality Assurance Reports is: Less than one percent of specimens have errors in the demographic data (i.e. dates, times, birth weights, etc.). The following common card errors occurred by staff whose shift started on one date and ended on another.



Points to remember:

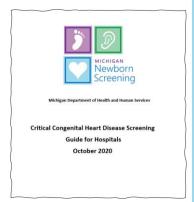
- 1. Make sure all the fields on the card are complete.
- 2. Check for errors and make necessary corrections before packaging the card for courier pickup.
- 3. Does the age in hours make sense?
- 4. Write the reason the specimen was collected early in the notes field of the card (transfer, RBC transfusion planned, parent request for early discharge, etc.).
- 5. Enter the birth weight (first sample) or current weight (repeat sample) in grams.
- 6. Write the gestational age on first sample cards.
- 7. Mark no if the baby was not transfused, even if it is not your practice to transfuse babies. Mark yes if the baby was transfused and include the most recent transfusion start date/time prior to the collection.

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. Increased burden on hospital staff and cost to the hospital.
- 4. Additional work for the primary care provider.
- 5. Inaccurate test interpretation due to age-dependent analyte cutoffs.

NEW: CCHD Hospital Guide

A new resource for newborn screening for CCHD is available to hospital staff. It is a one stop shop for everything you need to know about NBS for CCHD. Highlights include an overview of CCHD in Michigan, guidance for screeners, NICU protocol, common algorithm errors, submitting results to the NBS program, quality assurance, best practices, and other resources. The hospital guide is recommended for anyone taking the CCHD screen or teaching someone how to take it, as well as anyone who submits CCHD data to the state of Michigan. It is also a great reference for hospitals trying to evaluate their current CCHD protocols. If you have any questions, please contact Kristen Thompson, NBS Program Coordinator at ThompsonK23@Michigan.gov.



The hospital guide can be found here:

https://www.michigan.gov//documents/mdhhs/CCHD best practicesktdocx 706160 7.pdf

The BioTrust for Health alternate consent form is now available online in three languages: English, Spanish and Arabic

These forms can be used:

- In any situation where the original consent form attached to the NBS card is unavailable. An example of this
 could include if the form is separated from the card and accidentally thrown away.
- When asking families who speak Arabic or Spanish to complete the consent document.

Using this alternate form is simple! The top of the form has a demographics section that contains fields for names, birth date, birth location, and the NBS kit number. Copy the kit number from the blood spot card to ensure that the consent decision can be linked to the appropriate blood spot. Once the top section is complete, families can read through the BioTrust brochure, mark their decision, and sign the alternate consent form.

Because there is not a second copy of the alternate form, please make a copy of the signed form for the family to keep for their records. The alternate consent can then be sent back to the Newborn Screening Laboratory through the courier system. We suggest that the unit print out copies of these three forms and keep them somewhere on the floor for easy access.

The BioTrust alternate consent forms can be located on the newborn screening website under the "Resources for Hospitals and Health Professionals" page. Direct links can also be found below:

English:

https://www.michigan.gov/documents/mdch/BioTrust Alternate Parental Consent Form 10 2014 487693 7.p

Spanish:

https://www.michigan.gov/documents/mdhhs/MDHHS-5842 Spanish 695421 7.pdf

Arabic:

https://www.michigan.gov/documents/mdhhs/MDHHS-5842 Arabic 695418 7.pdf

For questions related to the BioTrust consent process, contact Shelby Atkinson at AtkinsonS2@michigan.gov or at 517-335-6497.

February 7-14 is Congenital Heart Disease Awareness Week!

In 2019, 96,516 babies in Michigan were screened for critical congenital heart diseases (CCHD). Of those, four were diagnosed with a CCHD and sixteen were diagnosed with another previously unrecognized hypoxic condition after a failed pulse oximetry screening.

Thank you for helping to ensure that every baby born in Michigan has the opportunity to be screened for CCHD.

Our program is a success because of the hard work of people like you!



January is National Birth Defects Prevention Month

The MDHHS Birth Defects Education and Outreach program is joining the National Birth Defects Prevention Network (NBDPN) to raise awareness of birth defects and to promote strategies that can reduce the risk of birth defects and their complications.

Birth defects affect 1 in every 33 babies born in the United States and are a leading cause of infant mortality. Babies who survive and live with birth defects are at an increased risk for developing many lifelong physical, cognitive, and social challenges.

This year's theme is "Best for You. Best for Baby." Although not all birth defects can be prevented, the healthcare community can help all women who could become pregnant or are pregnant to lower their risk of having babies with birth defects. This includes encouraging them to follow some basic health guidelines throughout their reproductive years:

- Be sure to take 400 micrograms (mcg) of folic acid every day.
- Book a visit with your healthcare provider before stopping or starting any medicine.
- Become up-to-date with all vaccines, including the flu shot.
- Before you get pregnant, try to reach a healthy weight.
- Boost your health by avoiding harmful substances during pregnancy, such as alcohol, tobacco, and other drugs.

January is a perfect time to call additional attention to the importance of folic acid in preventing certain birth defects. The United States Public Health Service recommends that all women of childbearing age consume 400 micrograms (400mcg or .4mg) of folic acid daily to prevent up to 50 - 70% of neural tube defects, such as spina bifida and anencephaly.

The MDHHS Birth Defects Education and Outreach program has free resource materials available on their website (Michigan.gov/birthdefectsinfo) to assist you in raising awareness of birth defects as a public health issue in your hospital and communities. You can make a difference in the lives of Michigan families. If you have questions or would like more information, please contact Courtney Miller at millerc47@michigan.gov.



Sickle Cell Disease Updates:

The University of Michigan, in partnership with the Michigan Department of Health and Human Services (MDHHS), was granted a three-year cooperative agreement from the CDC to implement the Michigan Sickle Cell Data Collection (MiSCDC) Program. This funding will allow collection of information on every individual living with sickle cell disease in the state of Michigan to study long-term trends in diagnosis, treatment, and healthcare access. The overall purpose of the proposed project is to foster the elimination of health disparities among those living with SCD through increasing SCD-related partnerships across Michigan, implementing standardized methods for SCD surveillance, and communicating findings to stakeholders in the SCD community.



Reminder:

The Sickle Cell Disease - Pain Management Course is still available for online learning. Course number SCD-01-2018 provides a complete overview of sickle cell disease, pain prevention, assessment, and management. The course offers 1.5 nursing contact hours upon successful completion that can be used to meet the pain credit requirement for several disciplines of Michigan healthcare providers.

https://www.mihealth.org/#Learn

Select the mihealth.org button.

Upcoming Holiday Courier Schedule:

Lower Peninsula Hospitals:

Monday, February 15 – holiday/Sunday schedule Monday, May 31 – holiday/Sunday schedule

Upper Peninsula Hospitals:

Monday, February 15 – UPS will pick up Monday, May 31 – no UPS pick up



TECHNICAL ASSISTANCE

Kristen Thompson, NBS Coordinator, is also available to work with hospitals on CCHD pulse oximetry screening and reporting and can be reached at 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