

Fall 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 second quarter of 2021, six hospitals met all six of the NBS blood spot screening performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Bronson Methodist Hospital
- McLaren Thumb Region
- Munson Healthcare Charlevoix
- Aspirus Keweenaw Hospital
- Henry Ford Allegiance Health
- Metro Health Hospital

Performance Goals for NBS Blood Spot Quarterly Reports

1. Less than 2 percent of screens are collected >36 hours after birth.
2. Greater than 90 percent of screens arrive in the state laboratory by the appropriate day.
3. Less than 1 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. Greater than 90 percent 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:

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During the second quarter of 2021, 29 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. Five 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:

- Munson Healthcare Otsego Memorial Hospital
- Mid-Michigan Medical Center - Midland
- Holland Hospital
- McLaren Lapeer Region
- Spectrum Health Big Rapids 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 Fee Change

The Detroit Consumer Price Index increased 5.4% this year. To reflect this change, MDHHS applied a \$7.40 increase to the cost of each initial (blue) newborn screening card and a \$6.71 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 October 1, 2021, the cost for the initial newborn screening (NBS) card increased to \$144.50 (from \$137.10). The cost for the repeat (pink) cards changed to \$131.05 (from \$124.34). 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 newbornscreening@michigan.gov.

Michigan Birth Defects Registry and NBS Collaborative Partnership

The Newborn Screening Program has partnered with the Michigan Birth Defects Registry (MBDR) on a cooperative grant agreement through the Centers for Disease Control and Prevention that is titled “Advancing Population-Based Surveillance of Birth Defects.” The cooperative grant agreement aims to enhance the MBDR's data quality and work to improve health outcomes for Michigan residents. Component C of the cooperative agreement strictly focuses on Critical Congenital Heart Defects (CCHDs) and works to better link MBDR records with individual-level screening results and data.



A partnership already exists between the NBS and MBDR programs to conduct surveillance work, and this cooperative agreement will allow for development of a bidirectional reporting system for CCHDs. The programs will share records of infants with confirmed or reported CCHD cases to allow for improved identification and tracking of CCHD cases in Michigan. This collaborative partnership will also ensure that the MBDR has more complete data for CCHD cases, and it will allow for the NBS Program to better evaluate the effectiveness of pulse oximetry screening. Overall, this is a very exciting opportunity for two closely related programs within MDHHS to work together to improve data quality and completeness.



BIRTH DEFECTS
EDUCATION & OUTREACH
MICHIGAN DEPARTMENT OF HEALTH AND HUMAN SERVICES

Birth Defects Prevention Month is in January

Every 4 ½ minutes a baby is born with a birth defect. We know that not all birth defects can be prevented. But we also know that people of childbearing age can increase their chances of having a healthy baby by managing health conditions and by adopting healthy behaviors before and during pregnancy.

The Birth Defects and Education program would like to extend an opportunity for **free** educational outreach materials available to order. Topics include education on folic acid, preconception tips, and resources for families of infants and toddlers with special needs. The materials are available in English, Spanish and Arabic. Please visit <https://migrc.org/order-materials/> ordering page to submit your order.

Progress in research brings hope for new treatments and cures each day. Babies with birth defects are living longer and healthier lives. This is thanks to education, newborn screening, early diagnosis, special care and new medical treatments.



2019 NBS Annual Report Summary

Every year, the Newborn Screening (NBS) Program releases an annual report that provides detailed information about the previous birth year. These reports are available on the NBS Program website (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. The 2018 report is available now and the 2019 report will be finalized and posted fall 2021.



In 2019, a total of 106,126 infants were screened in Michigan and 267 (0.3%) were diagnosed with a disease on the blood spot panel. Overall, one infant out of 397 screened was diagnosed with one of the disorders. Since the NBS Program began in 1965, more than 7,000 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 126 and 60 infants born in 2019, respectively. The third most commonly diagnosed disorder is cystic fibrosis, with 15 cases diagnosed in 2019. X-linked adrenoleukodystrophy was added to the Michigan NBS panel in October 2019 and one case was detected in 2019.

2019 Critical Congenital Heart Disease (CCHD) Annual Report Summary

The 2019 CCHD Annual Report will be available in fall 2021. This report will give a general overview of the 2019 year in review, including NBS Program presentations and involvement in external groups, CCHD screening practices and methods, screening results, and quality assurance information. Some of the key points from 2019 include:

- NBS Staff involvement in a multitude of activities including committee meetings, hospital trainings, baby fairs, health summits, and conferences.
- The most common reason for not receiving a pulse oximetry screen is having an echocardiogram, followed by the infants being transferred between facilities.
- 99.9% of newborns who were administered a pulse oximetry screen passed.
- There were four confirmed CCHD cases that were detected after a failed pulse oximetry screen.
- An additional 14 secondary conditions were detected after the infants received a pulse oximetry screen.
- Pulse oximetry screening identified another 14 newborns with secondary hypoxic conditions.



BioTrust YouTube Video: NEW!

Recently, the BioTrust Program developed a YouTube video animating an infographic that walks families through their choices for blood spots after screening is complete. The video uses an easy-to-follow roadmap timeline to describe what happens to blood spots after testing and how parents can fill out the BioTrust consent form. Due to COVID-19, many hospitals are not doing in-person hospital tours. The YouTube video is a great resource to provide parents as part of a virtual hospital tour or birth education class so that expecting mothers will be informed and prepared to read the brochure and complete the BioTrust consent form upon arriving to the hospital. You can find the video at:



<https://www.youtube.com/watch?v=UMcvVskMaiY>

Physician Request Form for NBS Results

Obtaining newborn screening results is now easier for medical providers in Michigan. Previously, medical providers needed to obtain the parent or guardian's signature on a release of information form, unless that provider was listed on the NBS specimen card or as the provider of record in the Michigan Care Improvement Registry (MCIR). This requirement could often lead to delays in receiving results, particularly for specialists or out of state providers. The new NBS Report Request Form allows for the health care provider to sign the request form, certifying that they are providing medical care for the patient. The completed request form, along with a cover sheet from their office, can be faxed to the NBS Program at 517-335-9419 or 517-335-9739. This form does not replace the standard procedure of the NBS Lab sending results to the submitter via fax/mail. In addition, if the medical provider can access MCIR, that remains the best method for quickly obtaining NBS results.

The NBS Report Request Form can be found on the NBS website (Michigan.gov/NewbornScreening) by clicking on "Resources for Hospitals and Health Professionals".



MDHHS
Michigan Department of Health & Human Services
NEWBORN SCREENING PROGRAM

Phone: 517-335-4381
Fax: 517-335-9419 or 517-335-9739

NBS Report Request Form

Please be sure ALL FIELDS are filled in before faxing your request.
Fax this form, along with your cover page, to 517-335-9419 or 517-335-9739.

CHILD/PATIENT INFORMATION			
Child/patient name	First name	Last name	
Child/patient date of birth			Sex (circle one) F M
Birth facility/city			
Baby from multiple birth delivery	Circle one	Yes	No
Mother's name at time of patient's birth	Specify birth order (e.g., Twin 1, Twin 2, Triplet 1)		
Mother's alternate last name(s)	Last name		
PROVIDER INFORMATION			
Requestor's name	First name	Last name	
Facility name/city			
Health care provider's name	First name	Last name	
Health care provider's NPI#	Credential (MD, DO, NP, etc.)		
Direct phone number (x extension) of requester/provider			
Fax number where report is to be sent			

The requested document(s) contains confidential patient health information that is legally privileged. This information is intended only for the use of the individual or entity named above. Any unauthorized review, use, disclosure, or distribution of this communication(s) is expressly prohibited.

I certify the child listed above is my patient and hereby grant permission to the Michigan Department of Health and Human Services Newborn Screening Program to release the newborn screening record, including laboratory test reports of the child stated above, for diagnosis and treatment purposes only.

Signature of Health Care Provider _____ Date _____

Please return this completed document with your office fax cover page to the MDHHS Newborn Screening Program at 517-335-9419 or 517-335-9739.

To access this form visit www.michigan.gov/newbornscreening and select "resources for hospitals and health professionals"

Upcoming Holiday Schedule

Lower Peninsula Hospitals:

- Thursday, November 11, 2021 – holiday/Sunday schedule
- Thursday, November 25, 2021 – holiday/Sunday schedule
- Friday, November 26, 2021 – holiday/Sunday schedule
- Friday, December 24, 2021 – holiday/Sunday schedule
- Friday, December 31, 2021 – holiday/Sunday schedule
- Monday, January 17, 2022 – holiday/Sunday schedule

Upper Peninsula Hospitals:

- Thursday, November 11, 2021 – Normal Operations
- Thursday, November 25, 2021 – No UPS pickup
- Friday, November 26, 2021 – Normal Operations
- Friday, December 24, 2021 – Normal Operations
- Saturday, December 25, 2021 – No UPS pickup
- Friday, December 31, 2021 – Normal Operations
- Saturday, January 1, 2022 – No UPS pickup
- Monday, January 17, 2022 – Normal Operations



TECHNICAL ASSISTANCE

Angela Aldrich, NBS nurse consultant, is available to work with staff in any hospital that requests help with specimen collection. She can be reached by email at AldrichA1@Michigan.gov to answer your questions. Kristen Thompson, NBS Coordinator, is 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.