



Newborn Screening News

Summer 2018

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 2018, three hospitals met all six of the NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- **Beaumont Hospital—Troy**
- **Lakeland of Niles**
- **St. Joseph Mercy Hospital—NICU**

Performance Goals for NBS Quarterly Reports

1. <2 percent of screens are collected >36 hours after birth
2. >90 percent of screens arrive in the state laboratory by the appropriate day
3. <1 percent of screens are unsatisfactory
4. >95 percent of electronic birth certificates have the NBS card number recorded
5. >90 percent of specimens have a returned BioTrust for Health consent form that is completed appropriately
6. < 1 percent of specimens have errors in the birth date/time and/or specimen collection date/time on the NBS card

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.

NBS Quarterly Reports and Stellar Transit Performance

Between April 2017 and March 2018, 11 hospitals had 98 percent or more of their specimens arrive at the state lab by the appropriate day. These hospitals went above and beyond in ensuring their infants received screening results as soon as possible. We would like to congratulate the following hospitals on their transit timeliness!

- **Beaumont Hospital—Troy**
- **Huron Medical Center**
- **McLaren Port Huron-SCN**
- **McLaren Flint**
- **McLaren Northern Michigan Hospital**
- **Michigan Medicine**
- **Munson Healthcare Charlevoix Hospital**
- **Spectrum Health United Hospital**
- **St. John River District Hospital**
- **St. Joseph Mercy Hospital**
- **Sturgis Hospital**

Reminder for Repeat Cards

Remember to completely fill out the information on the repeat cards, especially the collection date and time. Some analytes have different cut-offs based on the infant's age, so it is very important for the NBS laboratory to have accurate information. If the NBS laboratory is not able to determine an infant's age at time of specimen collection, it will default to the most conservative cut-off. Please help ensure the NBS laboratory has the most accurate information possible and completely fill out the repeat cards!

NBS Follow-up Program Contact Information

Phone: 517-335-4181

Email: newbornscreening@michigan.gov

Newborn Screening Education before Birth

The Michigan Newborn Screening Program began testing for phenylketonuria (PKU) in 1965. Since then, over 50 conditions have been added to the screening panel, and roughly 250-280 babies are detected with rare conditions each year. Despite the growth and success of the program, some new Michigan mothers are still unaware of newborn screening and its importance to their baby's health.

The NBS Program has begun surveying parents of newly-diagnosed infants to learn more about their experiences learning about their child's NBS result and having their child's diagnosis confirmed. A common theme emerging is that mothers wished they would have known more about newborn screening before giving birth. Parents feel being informed about newborn screening during the prenatal period helps to learn more about conditions and how to handle the possibility of an abnormal result. Actively engaging mothers in conversations about newborn screening during prenatal visits can be an effective way to inform them about what to expect.

Recently, the NBS Program developed an infographic that uses an easy-to-follow roadmap timeline to describe what happens at each event throughout the newborn screening process. NBS Program staff will be promoting use of this infographic with child birth educators and other groups working with expectant parents. Providing mothers with an informational sheet to take home allows them to review it at their own pace and follow-up with questions prior to giving birth. Our goal is that expecting mothers will be informed and prepared for newborn screening.

This infographic can be ordered online at no-cost through NBSO, the online ordering system for NBS cards and educational materials. If you have suggestions for groups that may be interested in using this infographic or have any other questions about the new infographic, please email newbornscreening@michigan.gov.



New CCHD Quarterly Report

A new CCHD-specific quarterly report is now being sent to birth hospitals. NICUs and SCNs receive these reports for informational purposes, but the NBS Program understands that pulse oximetry screening will differ for that population and may not be appropriate for all infants. The NBS Program will not hold NICUs and SCNs to the same goals as those for regular nursery units. Newborns in NICUs or SCNs are not included in calculating State totals or percentages.

Three metrics are included in the CCHD quarterly report, and the goal of 90 percent for each metric was set by NBS Program staff. The first metric is percent of newborns with pulse oximetry screen results reported to the NBS Program. Overall, 92 percent of babies in regular nurseries with blood spot screens had pulse oximetry screen results reported in the first quarter of 2018, meeting the goal of 90 percent. The second metric relates to timely reporting of pulse oximetry screening results. Statewide, 57 percent of newborns had screening values reported within 10 days of the screen. The last metric tracks timely completion of the pulse oximetry screen. The Michigan algorithm requests a screen completed as close to 24 hours of life as possible. For this last metric, any screens completed between 20-28 hours after birth are considered timely. Approximately 80 percent of newborns in regular nurseries throughout Michigan had a pulse oximetry screen completed between 20-28 hours of life.

The CCHD report also includes information on pulse oximetry screening results and compliance errors for the unit.

A total of 10 hospitals met all three CCHD screening metrics for the first quarter of 2018!

- **Beaumont Hospital Farmington Hills**
- **Beaumont Hospital Wayne**
- **Beaumont Hospital Dearborn**
- **Beaumont Hospital Trenton**
- **Beaumont Hospital Troy**
- **Bronson Methodist Hospital**
- **McLaren Port Huron Hospital**
- **ProMedica Coldwater Regional Hospital**
- **Providence Hospital**
- **St. John River District Hospital**

Additional Steps in Following Up on Missed Screens

Since 2007, NBS Program staff have linked birth certificate and NBS records every week. The purpose of that linkage is to find infants with a Michigan birth certificate and no record of a blood spot screen, so hospitals can be alerted of a potentially missed newborn screen. Every year, approximately 40-50 hospital births have a missed newborn blood spot screen.

All birth certificates are linked through a matching algorithm, and a file is created of infants without a blood spot screen identified. No follow-up is performed for infants listed as deceased on the birth certificate, but additional follow-up for all other infants in that file is performed by a NBS technician. The technician manually searches through the NBS database for the screen and reviews faxes from hospitals documenting why a screen was not collected. If appropriate records are not found, the NBS technician faxes a form to the designated NBS coordinator at the birth facility to alert that the NBS Program has no record of a blood spot screen for that infant and to request additional information, such as if the infant expired before a screen was collected, infant was transferred out of state, name change due to adoption, etc. If the screen was truly missed, the NBS Program requests that the birth facility contact the family to return and have a screen collected as soon as possible. If several screens are missing, the NBS nurse consultant will become involved since this may indicate an issue with transporting specimens from the hospital to the state laboratory.

Due to the critical importance of identifying affected infants and initiating treatment as quickly as possible, the NBS Program implemented additional steps to the follow-up process to ensure timely response.

1. The day after the initial fax is sent to a birth facility, the NBS technician calls to ensure the fax has been received.
2. If no additional information is provided by the birth facility, a second fax is sent.
3. If no additional information is provided by the birth facility, the NBS nurse consultant calls the designated NBS coordinator to inform that letters will be sent to the parents letting them know that the NBS Program has not received a screen for their infant and to the risk management area at the birth facility if no documentation is returned.

Keeping a NBS log will help respond to these faxes. More information about NBS logs can be found in the [Fall 2017 newsletter](#).

Please alert your staff to the importance of these faxes about potentially missed screens and ensure your facility has steps in place to respond to these faxes as quickly as possible!

2016 NBS Annual Report Summary

Every year, the NBS Program releases an annual report that provides detailed information about the previous year. These reports are available on the NBS Program website (www.michigan.gov/newbornscreening) and contain information on updates that occurred during that 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.

In 2016, a total of 111,685 infants were screened in Michigan and 258 (0.2 percent) were diagnosed with a disease on the blood spot panel. Overall, one infant out of 433 screened was diagnosed with one of the disorders. Since the NBS Program began in 1965, more than 6,200 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 93 and 56 infants born in 2016, respectively. In addition to disorders included on the panel, nearly 3,000 carriers were detected in 2016.

New NBS Quarterly Quality Assurance Report Metric

Last quarter, a new metric was added to the NBS hospital quarterly reports. The new metric “NBS cards with incorrect dates/times” aims for less than 1 percent of specimens to have errors in the birth or collection date/time fields on the NBS card. Since some of the cut-offs for the disorders on the NBS panel depend on the age of collection, it is crucial that these fields are filled out correctly. For the 1st quarter of 2018, 2.8 percent of all first specimens had errors in the birth or collection date/time fields on the NBS card. When a date/time error is suspected, the NBS lab calls hospitals to verify the information on the NBS card. This can be a time-consuming process, thus cutting down on these errors will save time for both the lab and hospital staff. Please reach out to Isabel Hurden, NBS Epidemiologist, at hurdeni@michigan.gov, if you have any questions about the new quarterly report metric.

Save the Date: 2018 Newborn Screening Conference

Tuesday, October 9, 2018—Harper Hospital Detroit

Wednesday, October 24, 2018—Mercy Health St. Mary’s Hospital Grand Rapids

Registration and additional information will be distributed at a later date.

Upcoming Holidays:

Lower Peninsula Hospitals:

STAT **will** pick up your specimens following the **Sunday pickup** schedule on the following holidays:

- Labor Day, Monday, September 3
- Thanksgiving Day, Thursday, November 22
- Friday, November 23
- Christmas Eve, Monday, December 24
- Christmas Day, Tuesday, December 25
- New Year’s Eve, Monday, December 31
- New Year’s Day, Tuesday, January 1



Upper Peninsula Hospitals:

There will be no UPS pickups on the following holidays:

- Labor Day, Monday, September 3
- Thanksgiving Day, Thursday, November 22*
- Christmas Eve, Monday, December 24
- Christmas Day, Tuesday, December 25
- New Year’s Eve, Monday, December 31
- New Year’s Day, Tuesday, January 1

*UPS **will** pick up on Friday, November 23

TECHNICAL ASSISTANCE

Lois Turbett, NBS nurse consultant, is available to work with staff in any hospital that requests help with specimen collection. She can be reached toll-free at (866) 673-9939 or by email at turbettl@michigan.gov to answer your questions. 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 www.michigan.gov/newbornscreening