



Newborn Screening News

Fall 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 2nd quarter of 2018, five hospitals met all six of the NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Beaumont Hospital—Troy
- Huron Valley-Sinai Hospital NICU
- Spectrum Health Ludington Hospital
- Otsego Memorial Hospital
- Three Rivers Area Hospital

Performance Goals for NBS Quarterly Reports

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

Meet our new staff:

In this newsletter:

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Shawn Moloney is the Newborn Screening Operations Coordinator. Shawn received her bachelor’s degrees from Michigan State University and is currently pursuing her Master of Public Health at Michigan State University as well. Shawn worked as a Laboratory Scientist at the Newborn Screening Laboratory and a Laboratory Coordinator at MSU before starting with the NBS Program in July. Shawn will be working with the NBSO and courier systems. Her email address is MoloneyS1@michigan.gov.

Shelby Atkinson is the new Genomics and Newborn Screening Research Coordinator. Shelby received her undergraduate degree in genetics from Michigan State University and is a recent graduate of the MSU Master of Public Health program. In her new position, she will coordinate the BioTrust for Health activities, including the parental consent process. In addition, she will work with researchers who are using the leftover blood spots for use in approved health research. Her email address is AtkinsonS2@michigan.gov. Please contact her if you need any technical assistance for the BioTrust consent process.

NBS Follow-up Program Contact Information
Phone: 517-335-4181
Email: newbornscreening@michigan.gov



Spinal Muscular Atrophy is Added to the Recommended Uniform Screening Panel

On July 2, 2018 the Secretary of Health and Human Services accepted the recommendation of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) to add spinal muscular atrophy (SMA) to the Recommended Uniform Screening Panel (RUSP). SMA, an autosomal recessive motor neuron disease, is the leading genetic cause of death in infancy. Detection of SMA through newborn screening will allow for early treatment with the FDA-approved drug Spinraza to give patients the best chance for improved clinical outcomes. In light of the Secretary's endorsement, the Michigan Newborn Screening Program has begun its process to review adding SMA to Michigan's newborn screening panel. An Ad Hoc SMA Advisory Committee has been established to provide clinical expertise as recommendations are reviewed by the NBS Technical and Quality Assurance Advisory Committees later this year. Any recommendations regarding the addition of SMA will be forwarded to the MDHHS director and legislature for consideration and final approval.

Reconciling Newborn Screening Results

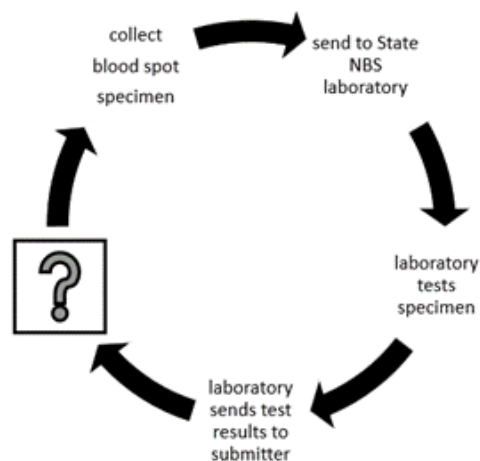
Many members of the healthcare team are involved in the newborn screening (NBS) process. Each member is likely to understand his or her role, but most are unaware of what happens once their task is finished. Reconciling NBS results is an important part of the hospital's NBS process that helps to assure that every newborn has received a blood spot screen.

The NBS Program releases the final report to the submitter after all testing has been completed, usually one week after the specimen has been received. Unless the newborn has been placed in foster care or released for adoption, the final report is uploaded to the Michigan Care Improvement Registry (MCIR) approximately two to three weeks after the specimen has been received. Hospitals and primary care providers who have been granted permission may access NBS results from MCIR.

Each hospital determines where it wants to receive the final report. These are two potential options for how a hospital may reconcile NBS results:

- Option A: Mother baby unit (MBU) keeps the yellow submitter copy. The NBS laboratory faxes the final report to the MBU. The MBU makes sure that each yellow copy has a matching final report. If two weeks have passed and there is no final report to match to a yellow copy, a staff person looks for the results in MCIR or faxes NBS Follow-up staff at 517-335-9739 or 517-335-9419.
- Option B: MBU, special care nursery (SCN) or neonatal intensive care unit (NICU) send the yellow submitter copy to their hospital laboratory. The NBS laboratory faxes the final report to the hospital laboratory. The hospital laboratory makes sure that each yellow copy has a matching final report. If two weeks have passed and there is no final report to match to a yellow copy, a staff person looks for the results in MCIR or faxes NBS Follow-up staff.

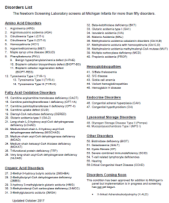
Some hospitals do not have a process for reconciling NBS results. Though they receive the final report and scan it into the newborn's electronic medical record, there is no method in place to make sure that results have been received for every newborn who has had a blood spot specimen collected. This could leave some newborns at risk if they left the hospital without having received a newborn screen; or, the screen was collected but misplaced and not sent to the NBS laboratory. Please ensure your hospital has a method in place to confirm that a final report has been received for every newborn. If you need assistance reconciling NBS results, please contact Lois Turbett, NBS nurse consultant, by phone (517-335-1966) or email (turbettl@michigan.gov).



Suggestions for Educating and Encouraging Parents about Newborn Screening

Many parents may feel nervous or anxious about having a newborn screening dried blood spot test performed. Although our goal is to educate about newborn screening in the prenatal period, not every parent will arrive at the hospital knowing that the newborn screen will be collected or be familiar with the importance of newborn screening. Or, they may be aware of newborn screening and have some reservations. Since newborn screening is mandated by Michigan's public health code, we wanted to provide some suggestions that may help educate and encourage parents about newborn screening.

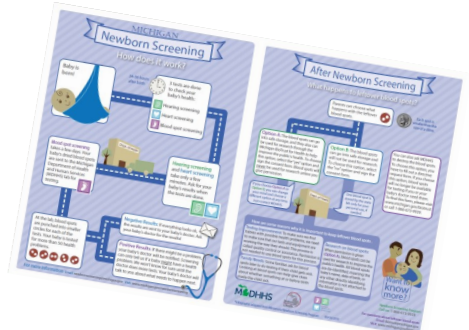
- Go to the Michigan Newborn Screening Program website (www.michigan.gov/newbornscreening)
 - ◆ Click on "List of Disorders and Fact Sheets"
 - ◇ A one-page document of all the disorders on the NBS panel can be printed. Although many of the disorders are rare, parents may have heard of some of the more commonly-identified disorders, such as hypothyroidism, sickle cell disease, or cystic fibrosis. Seeing this list of disorders may help parents understand why it is so critical for their newborn to be screened.
 - ◆ Click on "General Information for Families"
 - ◇ Under "Family Resources", click on "FAQ: Newborn Screening and the BioTrust for Health"
 - This three-page document contains questions that we receive most frequently from parents. It explains why newborn screening is important and what happens to the blood spots after newborn screening is completed.
 - ◆ Click on "Resources for Hospitals and Health Professionals"
 - ◇ Under "Forms", click on "Residual Newborn Screening Blood Spot Directive"
 - Parents can fill out this one page form and submit it to have their newborn's remaining blood destroyed after newborn screening is completed. Parents will need to submit this form, along with a copy of the child's birth certificate (or hospital certificate of live birth) and a copy of one parent's ID (driver's license, state-issued identification card, or passport). Having the ability to ensure the remaining blood is destroyed may help parents feel more comfortable with newborn screening.
- Minnesota's Newborn Screening Program created a 7-minute YouTube video highlighting a family that was going to refuse newborn blood spot screening. Nurses encouraged the parents to have the screen collected, and the newborn was diagnosed with a disorder on the NBS panel. Watching this video may provide a visual example of how newborn screening saves lives. The video can be found here: <https://www.youtube.com/watch?v=Q7oEz6pmhPA>.



These are our suggestions, but we're excited to learn more about what has worked for you. If you have suggestions, please email Lois Turbett, nurse consultant for the Newborn Screening Program, at turbettl@michigan.gov. Look for more ideas in a future newsletter when we will compile information that we received through email and through discussions at the October conferences!

Newborn Screening Road Map for New Parents

The Newborn Screening Program is happy to introduce a new resource for parents. This two page infographic, explains how the newborn screening process works and outlines the parents choices for the leftover blood spots. The program is hoping to promote use of this document by hospital and prenatal educators. Please email newbornscreening@michigan.gov if you have any ideas how we can reach this group within your hospital or to request copies of the document. It will be available to order in NBSO soon.



Reporting CCHD Screening Results: Pulse Ox Not Completed

The Newborn Screening Program collects individual-level data on the pulse oximetry screening for critical congenital heart disease (CCHD). The data is needed to be able to assess the efficacy of the screen and ensure that infants who fail their screen are receiving appropriate follow-up care. It is important that the data we receive is complete and accurate. We have noticed that occasionally when an infant has been transferred to a different hospital before a screen can be conducted, the hospitals will write “transfer” in the other category. In doing this, that screen is being labeled as a “missed” screen versus a “transfer”. This will cause unnecessary follow-up and will impact your hospital’s quarterly report numbers. Instead, under the “Pulse Ox Not Completed” drop down, select “transfer”. Thank you for all you do to promote accurate reporting at your facility!

Expired Cards

Please check your inventory for first and repeat sample cards that are due to expire in January 2019 and use those cards first. The expiration date on these cards is highlighted with pink or blue shading. The expiration date is located in the lower right-hand corner of the NBS card. Cards may be used through the last day of the month in which they expire.

Samples collected after the expiration date will be found unsatisfactory and a repeat screen will be requested.

Unsatisfactory specimens can result in:

- Infant distress caused by the need for a repeat specimen collection
- Additional work for hospital and NBS staff
- Unnecessary burden on parents who have to bring their baby back for a repeat screen
- Delayed valid test results that could have a negative impact on the health of the baby
- Increased cost to the hospital

Upcoming Holiday Courier Schedule:

Lower Peninsula Hospitals:

Monday, Nov. 12 – holiday schedule
Thursday, Nov. 22 – holiday schedule
Friday, Nov. 23 – holiday schedule
Monday, Dec. 24 – no pickups
Tuesday, Dec. 25 – holiday schedule
Monday, Dec. 31 – no pickups
Tuesday, Jan. 1 – holiday schedule
Monday, Jan. 21 – holiday schedule

Upper Peninsula Hospitals:

Friday, Nov. 23 – UPS will pick up
Monday, Dec. 24 – UPS will pick up
Tuesday, Dec. 25 – no UPS pickup
Monday, Dec. 31 – UPS will pick up
Tuesday, Jan. 1 – no UPS pickup

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