



Michigan Department of Health and Human Services

Newborn Screening News

Winter 2017

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.

New Courier Service for Lower Peninsula

The NBS Program has contracted with STAT Courier to pick up your NBS bloodspot specimens beginning January 2, 2017. By now your hospital has been contacted and pickup times and locations have been mutually decided upon. Remember to instruct staff they should not place NBS envelopes in a basket or box designated for Quest or A1. You should already have a basket labeled STAT Courier. A courier log that includes the date, NBS envelope number(s) and a place for the courier to date and sign at the time of pickup should be kept at the pickup location. Keep this log for your records. STAT Courier will maintain an electronic log for their purposes and will not need copies of your logs.



Call Lois Turbett, 517-335-1966, if you need more information about this new courier service. Call STAT Courier directly at 888-592-7828 should you have courier concerns outside of NBS business hours.

Antibiotic Use Clarification

After receiving many questions about when to check the “Antibiotics” box on the NBS card during our centralized NBS training, we wanted to provide clarification. Antibiotics can cause a false elevation of a particular analyte (isovalerylcarnitine) on tandem mass spectrometry. When the laboratory scientists see that elevation, they look at the NBS card to see if “Antibiotics” has been checked. That helps them determine if the elevation could be caused by antibiotics rather than one of the disorders on the NBS panel. If the baby has been given antibiotics or if the mom had any antibiotics prior to or during delivery, please check “Antibiotics” on the NBS card. If you need clarification or have questions about this, please email newbornscreening@michigan.gov or call 1-866-673-9939.



NBS Follow-up Program Contact Information

Phone: 517-335-4181

Email: newbornscreening@michigan.gov

Sickle Cell Patients GET CONNECTED!

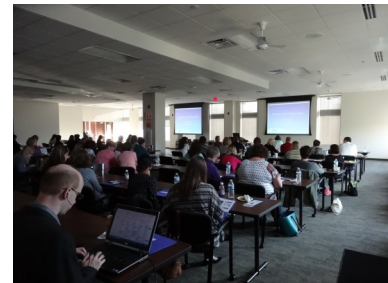


A major component of the national effort to enhance the overall quality of life for patients living with sickle cell disease is the new Get Connected, confidential, patient-powered registry housed at and managed by the Sickle Cell Disease Association of America (SCDAA). The registry supports the patient population by developing a more involved and knowledgeable community of individuals. The registry houses basic demographic information, and allows patients to keep their medical history secured and up-to-date in one electronic location. The registry provides a continuous stream of newsletters, community forums, and other industry-specific information. By maintaining a national patient registry where all patients can actively stay up-to-date on the sickle cell community and maintain their medical histories, the community will

become much stronger and unified in efforts to build better health care solutions for patients across the country. This resource may be invaluable to parents in understanding their baby's newborn screening diagnosis short and long-term. In addition, Get Connected allows the SCDAA to glean aggregate level data from patient entries, including capturing an overview of how many individuals living with sickle cell disease reside in the United States. This pertinent data can then be utilized to request substantial funding support for research and treatment. There is power in numbers and we want the Michigan sickle cell community to be well represented! Please refer your patients to www.GetConnectedscd.org to register for free.

2016 Newborn Screening Training

On Thursday, October 6th, 2016 the Newborn Screening Program hosted a centralized training in Lansing for hospital staff. The training included speakers on a variety of topics related to the newborn screening process. Beaumont Troy Hospital was spotlighted for their newborn screening best practices. Additionally, Genesys Regional Medical Center-Health Park, University of Michigan, and Alpena Regional Medical Center were highlighted for their Critical Congenital Heart Disease screening reporting best practices. There were 70 health professionals in attendance, representing 44 hospitals across Michigan. The Newborn Screening Program would like to thank those who presented, and those who attended the event.



In 2014, pulse oximetry screening for Critical Congenital Heart Disease (CCHD) was added to Michigan's Newborn Screening panel. Thanks to the dedicated staff at hospitals **225,115 infants have been screened and 10 have been diagnosed with a CCHD** as a result of screening since implementation in April 2014.



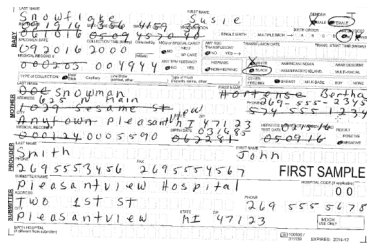
SAVE THE DATE! February 7-14 is Congenital Heart Defect Awareness week. Michigan's Newborn Screening Program will be doing several activities throughout the week to help raise awareness.

Spotlight on Unsatisfactory Specimens – Cannot Identify

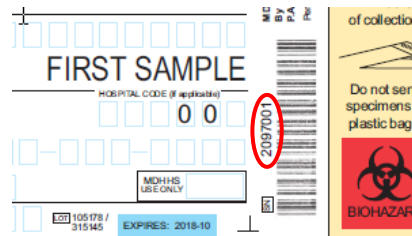
If the NBS Laboratory questions the identity of an infant, the bloodspot specimen will be determined unsatisfactory-cannot identify and a repeat specimen will be required. Identity is questioned when:

- Excessive use of ‘strickethroughs’ prevents NBS laboratory staff from accurately reading demographic information.
- The card (“kit”) number on the demographic sheet does not match the card number on the filter paper.
- Inaccurate or questionable information is provided on the NBS card.

Example of excessive use of strickethrough



Each NBS card has the same unique number on each page



Points to remember when collecting the NBS specimen:

1. Wipe away the first drop of blood
2. Apply *only* one large drop of blood to each preprinted circle
3. Apply blood to *only* one side of the card
4. Make sure the blood has soaked through to the other side

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



NBS Quarterly Reports and Stellar Performance

During the third quarter of 2016, six hospitals met all six of the NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Allegiance Health
- Spectrum Health Gerber Memorial
- Huron Medical Center
- Beaumont Hospital—Dearborn
- Beaumont Hospital—Trenton
- McLaren Port Huron—SCN

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.

In the News: False Negatives in Newborn Screening

The Milwaukee Journal Sentinel recently released a story called “The price of being wrong” (<http://projects.jsonline.com/news/2016/12/11/the-price-of-being-wrong.html>). The story discusses false negatives in newborn screening.

Our goal in Michigan, as with all state NBS programs, is to find the delicate balance between identifying all true disease cases through screening while minimizing the number of infants (and families) affected by false positive findings. Our laboratory and follow-up staff work closely with clinicians on our expert advisory committees to develop and evaluate screening cutoffs. In the event of a confirmed false negative case (a very rare event), concern raised by families or clinicians, or findings from published articles relevant to NBS, Michigan program staff routinely review screening performance metrics. This review is presented at the appropriate disease-specific advisory committee for discussion and recommendations.

The NBS Program educates primary care providers that newborn screening is a screen and should not replace clinical judgment, as noted on the NBS results mailer which contains the language “If there is a clinical concern, diagnostic testing should be initiated.” To maintain contact with their child’s primary care provider, we encourage all families to follow the recommended schedule of well-child visits.

We appreciate the concerns highlighted in the story and will continue to monitor our process in Michigan to encourage continuous quality improvement efforts that make the NBS experience as accurate as possible for Michigan’s newborns and their families.

Submitter Code: Please remember that staff members need to record the correct hospital submitter code on the newborn screening card. The last digit indicates the type of nursery: 0 means regular nursery, 1 means NICU, and 2 means SCN. The submitter code is used to make separate quarterly reports for each unit, so it’s important that we can correctly identify which unit submitted each specimen.

Phone Number: Please remember only one phone number per provider should be listed on the newborn screening card. Many requestors are using cell phone numbers or multiple different phone numbers for lines in provider offices and the laboratory is receiving new entries every day. Please have hospital staff clean up these lists and include one phone number per provider. Only include on the newborn screening card the doctor who is in charge of the baby’s care when the baby leaves the hospital.

Birth Weight: Please remember to record birth weight in **grams** on the first sample newborn screening card. Enter the current weight in grams on the repeat sample card.

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