



Newborn Screening News

Winter 2020

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 2019, four hospitals met all six of the NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Bronson Methodist Hospital
- Holland Hospital—SCN
- Huron Valley-Sinai Hospital
- Huron Valley-Sinai Hospital—NICU

Performance Goals for NBS Quarterly Reports

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

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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Instructions for Replacing Expired Cards

Please check your inventory for cards with an expiration date of January 2020. Unused expired cards can be returned for replacement by completing the *Newborn Screening Card Replacement Form*. This form can be found in Appendix 6 of the Newborn Screening Guide for Hospitals. The Guide is available at www.Michigan.gov/NewbornScreening and then clicking on *Resources for Hospitals and Health Professionals*.

Staff Highlight: Newborn Screening Operations Coordinator

Lacey VanLoenen began as the Newborn Screening Operations Coordinator in December 2019, but she is not a new face to newborn screening. Lacey has worked as a Newborn Screening follow-up technician since 2017. In her new role, Lacey is responsible for overseeing the courier operations for STAT and UPS, as well as working with NBSO, the online ordering system for newborn screening cards and educational materials. Lacey is a certified medical assistant and recently received her bachelor's degree. Lacey's email address is VanloenenL1@michigan.gov.

NBS Follow-up Program Contact Information
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Email: newbornscreening@michigan.gov



Spotlight on Unsatisfactory Specimens: Quantity Not Sufficient and Insufficient

The NBS Program expects that less than one percent of blood spot specimens are unsatisfactory for testing. During 2013, the unsatisfactory specimen rate climbed to an average of 2.5 percent. The NBS Laboratory took pictures of all unsatisfactory specimens received during 2013 and 2014. Lois Turbett used these pictures to provide feedback to hospitals with high unsatisfactory specimen rates. That, along with the addition of a sixth circle to the NBS card, resulted in an average unsatisfactory specimen rate of 1.1 percent in 2015 and 2016. Unfortunately, the unsatisfactory specimen rate doubled to 2.2 percent in 2019.

The NBS Laboratory makes nine card punches for the first set of tests and often needs additional punches to validate results. Because of this, the laboratory requires 15 punches to allow for initial and additional testing. The laboratory will mark the specimen quantity not sufficient (QNS) if there are fewer than nine available punches.



A satisfactory blood spot will yield four, sometimes five punches.



If all six blood spots are like this, there will not be enough blood available to run all the initial tests. [See summer 2014 newsletter for this comparison.]

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 one side of the card *only*.
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.

Lois Turbett 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 TurbettL@michigan.gov to answer your questions. 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.

Brochures: A new look and additional languages available!

The Newborn Screening Program recently made updates to the color of the background on all brochures. The prenatal brochure will now have a light green background, the general newborn screening brochure will keep the tan background, the critical congenital heart disease brochure will have a light blue background, and the BioTrust brochure will have a gray background.

The Newborn Screening and BioTrust Roadmap and the brochure for expectant parents are now available in Spanish and Arabic.

To order any newborn screening educational resources, visit www.michigan.gov/nbsorders.



Surveillance for Sickle Cell Disease

About 100,000 Americans have sickle cell disease (SCD), which is most common among people of African descent. SCD was added to Michigan's Newborn Screening panel in 1987. Since then, over 2,000 newborns with SCD have been identified and referred for early treatment initiation.

In 2018, legislation authorizing the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act was signed. It authorized the award of grants for three broad purposes: collecting and maintaining data on SCD health outcomes and carrying out various public health activities that include education and training of health professionals at the community, local, and state levels; supporting local and state laboratories that conduct tests to detect SCD; and evaluating best practices for the prevention and treatment of complications for SCD.

The MDHHS Genomics & Genetic Disorders Section was recently awarded a Centers for Disease Control and Prevention (CDC) cooperative agreement to develop a surveillance system to collect data on the issues faced by people living with SCD. Currently, only two states – California and Georgia – work with CDC to collect population-based, comprehensive health information about people with SCD. This funding brings together nine states partnering to build the framework and road map to gather unique data and conduct in-depth analysis to better understand the needs and improve the health of this vulnerable population.

The Michigan Sickle Cell Initiative for Population-based Surveillance team will spend the next year working with the Children's Hospital of Michigan, University of Michigan, Detroit Medical Center and Hurley Medical Center to develop and implement strategies to collect vital information about SCD.

Critical Congenital Heart Disease: Common Algorithm Errors

In 2018, 742 babies were screened improperly according to the approved screening algorithm for critical congenital heart defects (CCHD). Most concerning are the infants who failed their first screen and were unnecessarily rescreened and those who did not have a necessary rescreen completed. In 2018, 63 babies were discharged from the hospital before a CCHD was ruled out. It is extremely important to follow the screening algorithm with every infant. A rescreen needed or failed screen result means that the baby had low levels of oxygen in the blood. This finding can have many causes. Clinical follow-up is needed to determine if a CCHD or other condition is present. Because the harmful effects of a CCHD can develop shortly after birth, follow-up assessments must be completed as soon as possible to determine if the infant has a cardiac problem. Please make sure that you and your staff review the approved screening algorithm for CCHD, which can be found on our website at www.Michigan.gov/cchd.

Pulse Oximetry Algorithm Noncompliance in Michigan, 2018	
Reason	Number (N)
Human Error (<70 Saturation Value) 1st Screen	13
Unnecessary Rescreen	680
Failed First Screen	14
Passed First Screen	666
Rescreen Not Complete	41
Second Rescreen Not Complete	8
Total	742



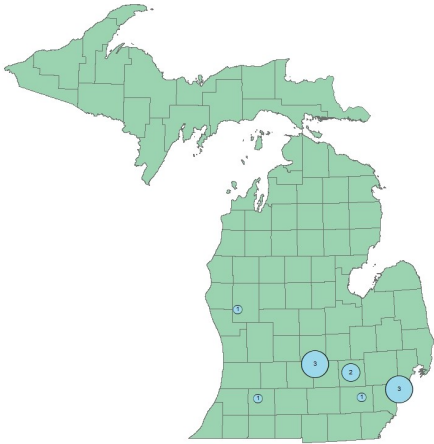
February 7-14 is Congenital Heart Disease Awareness Week!

Thank you for helping to ensure that every baby born in Michigan has the opportunity to be screened for critical congenital heart disease. Our program is a success because of the hard work of people like you!

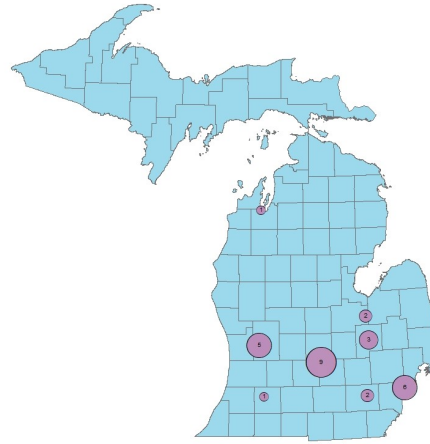
Newborn Screening Program Educational Efforts

Providing education to providers and the public to increase awareness about newborn screening is a focus of the Newborn Screening Program. Program staff have been attending events throughout Michigan to provide information about newborn screening to clinical providers, expectant parents, and new parents. In 2018 and 2019, Newborn Screening Program staff attended 11 events for the public, including events like festivals and baby fairs, as well as 29 provider events and presentations. If you know of any events that would be a good fit for newborn screening, please email newbornscreening@michigan.gov.

NBS Public Events, 2018-2019



NBS Provider Education Events and Presentations, 2018-2019



Upcoming Holiday Courier Schedule:

Lower Peninsula Hospitals:

Monday, February 17 – holiday/Sunday schedule

Upper Peninsula Hospitals:

Monday, February 17 – regular schedule



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