



Newborn Screening News

Winter 2019

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

- Beaumont Hospital—Troy
- Mid Michigan Medical Center Gratiot
- Hillsdale Hospital
- Munson Healthcare Cadillac Hospital
- McLaren Port Huron—SCN
- St. Joseph Mercy Hospital
- St. Mary Mercy Hospital—Livonia

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.

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Newborn Screening Online Courses

Online courses that cover the three components of newborn screening (blood spot, hearing, and heart) are available to complete by accessing <https://training.mihealth.org/>. There is no cost to take these courses. Once you register, you can use your user name and password to take *Newborn Screening – Michigan*, *Newborn Hearing Screening – 2015*, and *Critical Congenital Heart Disease*.

How to Submit Expired Cards for Replacement

Please be aware that some first and sample repeat cards are due to expire in January 2019. After January 31, 2019, do not use these cards because they will be unsatisfactory. To receive replacement cards, fill out the “Newborn Screening Card Replacement Form” (Appendix 6 of the NBS Guide for Hospitals) and mail the form and white face sheet(s) to:

Attention: Newborn Screening
333 S. Grand Ave., 2nd Floor
PO Box 30195
Lansing, MI 48909

NBS Follow-up Program Contact Information

Phone: 517-335-4181

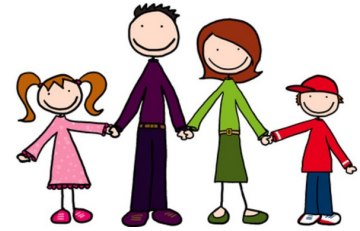
Email: newbornscreening@michigan.gov



Care Coordination Training Coming Spring 2019

The Newborn Screening Program, in partnership with the Family Center for Children and Youth with Special Health Care Needs, will be offering a Care Coordination: Empowering Families learning opportunity in the spring of 2019. The purpose of this one-day training is to help parents learn:

- How to work with a medical home
- Techniques to organize information and find reliable resources
- How to navigate health care and information systems
- Skills to increase communication and coordination among multiple providers
- How to plan for the transition to adult care
- Ideas for coping with stress and finding peer support
- Ways to advocate for improving care



This training is available to any Michigan parent (biological, step, foster, adoptive or kinship) or legal guardian of a child who has been diagnosed or identified through newborn screening. Participants who attend the full day and complete the evaluation will receive a \$50 gift card to offset time, mileage and childcare costs. Lunch will be provided.

The Newborn Screening staff will notify partners and provide flyers to promote this educational opportunity for families. If you would like to receive a flyer, please email newbornscreening@michigan.gov.

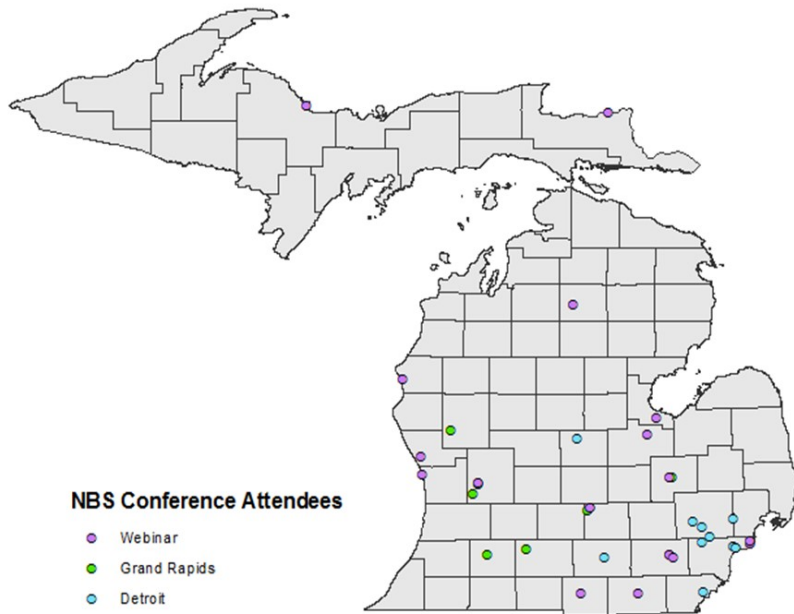
Tips for Encouraging Reluctant Parents to Accept Blood Spot Screening

Thank you for the feedback we received from those of you who attended our October NBS conferences in Detroit and Grand Rapids. Many of you provided great tips on how to interact with parents who have questions about accepting blood spot screening. These are some of the suggestions you offered:

- Education
 - ◇ Provide educational materials prior to delivery.
 - ◇ Use the materials to answer questions parents may have.
 - ◇ Ask a pediatric hospitalist to talk to the parents.
- Disorders screened
 - ◇ Explain how quickly healthy-appearing newborns can become sick if they have a disorder.
 - ◇ Describe how early treatment can prevent intellectual disability, severe adverse health outcomes, or death.
 - ◇ Point out that in most cases there is no known family history of a disorder detected through NBS.
 - ◇ Give real-life examples of how early identification of a disorder improved the lives of some babies.
- Blood spot collection
 - ◇ Review all of the steps involved in blood spot collection.
 - ◇ Provide comfort measures to help the newborn during the process.
 - ◇ Let the parents know how the blood spot specimen is tested and when they can expect results.
- Parental distrust of storing residual blood spot specimens
 - ◇ Describe how blood spots are stored at the Michigan Neonatal Biobank and the steps taken to protect their newborn's privacy.
 - ◇ Review the BioTrust brochure and consent form; show parents where to mark their decision.
 - ◇ Offer to help parents complete the *Residual Newborn Screening Blood Spot Directive* form if their reluctance is due to the state storing their newborn's residual blood spots.

The Newborn Screening Conference Recap

The NBS Program hosted two conferences in October 2018, one in Detroit at Harper Hospital and one in Grand Rapids at Mercy Health Saint Mary's. Both conferences could also be attended remotely via webinar. In total, 81 health professionals from 35 different hospitals attended the conferences. The map below displays the hospitals which had representation at the conferences. Topics covered at the conferences included program updates, new disorders, the Michigan BioTrust for Health, NBS educational materials, and screening for critical congenital heart disease.



Sickle Cell Disease - Pain Management Course Continuing Education - 1.50 Nursing Contact Hours

We invite nurses, nurse practitioners, physicians, health educators, public health professionals, and other healthcare professionals to take our newly developed Sickle Cell Disease – Pain Management online course. Learners will obtain enhanced knowledge of sickle cell disease, pain management assessment and treatment, and enhanced skills in prevention strategies.

Course Link: <https://courses.mihealth.org/PUBLIC>

Course ID: SCD-01-2018

For questions contact Dominic Smith at smithd82@michigan.gov or 517-373-5818.

2017 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 (www.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.

In 2017, a total of 109,740 infants were screened in Michigan and 304 (0.3%) were diagnosed with a disease on the blood spot panel. Overall, one infant out of 361 screened was diagnosed with one of the disorders. Since the NBS Program began in 1965, more than 6,500 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 121 and 64 infants born in 2017, respectively. In addition to disorders included on the panel, more than 3,000 carriers were detected in 2017.

Thank you for all you do to ensure screens are collected and sent in a timely manner to allow for early identification and treatment initiation for affected infants!

Michigan BioTrust Brochure

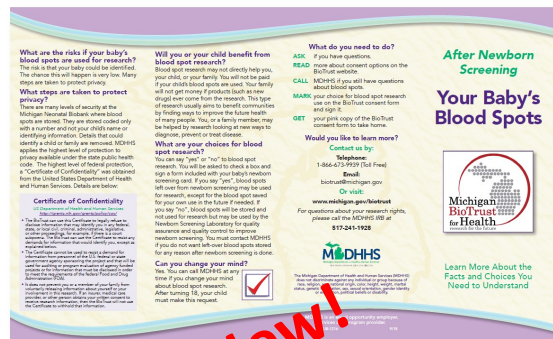
The Michigan BioTrust for Health brochure was updated in October 2018. These updates include changes to overall look of the pamphlet as well as the content within that describes the BioTrust program. Design elements have been updated to match other newborn screening educational materials.

The BioTrust's Community Values Advisory Board (CVAB) provides the Michigan Department of Health and Human Services (MDHHS) with advice about opportunities for ongoing community awareness and education. The CVAB reviewed the changes to the BioTrust brochure and helped identify additional sections where edits could be made to better describe how the BioTrust works. The changes made are intended to help new families better understand the Michigan BioTrust for Health program.

The changes to this brochure do not affect how it is used. All families should receive a copy of the BioTrust brochure before they mark their decision on the BioTrust consent form found on the back of the newborn screening card.

The new BioTrust brochures are available to order online through the NBS Online ordering system. If you already have stock of an older version of the BioTrust brochure, they DO NOT need to be disposed of. Please feel free to use up your remaining brochures before placing an order for updated materials.

If any questions arise regarding the Michigan BioTrust for Health or the new BioTrust brochure, please contact the BioTrust coordinator, Shelby Atkinson, at atkinsons2@michigan.gov or at 517-335-6497.



Upcoming Holiday Courier Schedule:

Lower Peninsula Hospitals:

Monday, Feb. 18, 2019 – Sunday/holiday 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