



Newborn Screening News

Winter 2016

The Michigan Department of Health and Human Services (MDHHS) Newborn Screening Follow-up Program works together with the State Newborn Screening Laboratory to find and treat infants who need early medical care.

REWIND 2015: 50th Anniversary of Newborn Screening

Hospital and Legislator Fact Sheets

Michigan's NBS History Booklet

Family story boards

Press Releases

- January 15: [Congenital Hypothyroidism Highlighted During January to Increase Awareness](#)
- February 27: [MDCH supports Rare Disease Day, recognizes importance of Newborn Screening](#)
- April 24: [MDHHS supports World Primary Immunodeficiency Week: State promotes awareness, importance of newborn screening](#)
- May 14: [Newborn Screening Key for Detecting Cystic Fibrosis Early in Life](#)
- September 17: [MDHHS celebrates 50 years of Michigan's Newborn Screening Program](#)

On September 16, the Newborn Screening Program held a Newborn Screening Symposium with a variety of presentations about the past, current and future of Michigan's NBS program. To view the presentations and for more information on the events that took place throughout 2015, please visit www.michigan.gov/newbornscreening.

Educational events

Educational opportunities were offered throughout 2015 for providers and parents. Newborn screening was represented at 11 events targeting providers and 5 baby fairs educating parents and families.

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



MDHHS Develops Sickle Cell Disease Strategic Plan

We are pleased to announce the release of our 3-year public health strategic plan developed to address the needs of individuals (children and adults) with hemoglobinopathies, particularly sickle cell disease, across the lifespan. The state plan is the result of many months of collaborative efforts by nearly 100 individuals ranging from focus group participants, hematologists, pediatricians, workgroups and committee members, reviewers, individuals living with sickle cell disease, and caregivers. A joint departmental effort with the Lifecourse Epidemiology & Genomics Division, the Family & Community Health Division, and Children's Special Health Care Services provided the impetus and staff needed to accomplish this project.

Newborn screening for sickle cell disease began in 1987 and is one of the most prevalent disorders detected by the program. While researchers and providers have come a long way in terms of understanding the disease and providing treatment for children, adults with the condition continue to face many challenges, including access to proper care. The disease has a dramatic impact on the lives of over 2,800 residents and their families. For many, daily living can consist of illness, pain, time-consuming trips to the emergency department, stigmatization, and a compromised quality of life. The strategic plan addresses challenges by responding to gaps in education, services, and healthcare barriers identified throughout the planning process. The following priorities and goals within the plan will promote integration and expansion of sickle cell disease services and resources within existing public health programs and emphasize the need to enhance patients' clinical experience.

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Education & Awareness: Develop a statewide multi-level messaging and communication strategy to increase awareness of sickle cell disease, disease-modifying medical therapies, and sickle cell trait.

Transition: Develop and implement strategies for improving transition from pediatric to adult care.

Provider Shortage: Increase availability of primary and specialty care providers who treat all aspects of sickle cell disease with an emphasis on increasing providers for adults.

Psychosocial/Mental Health Support: Increase recognition of the need to address psychological issues and provide mental health support.

Medication Adherence: Develop protocols for improving medication adherence in accordance with the National Heart, Lung and Blood Institute's Evidence-Based Management of Sickle Cell Disease Guidelines.

Day Treatment Clinics: Improve acute care in the emergency room or alternative settings.

Research: Establish a Michigan sickle cell disease consortium to coordinate public health research efforts within the State of Michigan.

To access the strategic plan visit http://www.michigan.gov/documents/mdhhs/MDHHS_Final_SCD_Strategic_Plan_504325_7.pdf.
Email Dominic Smith at smithd82@michigan.gov if you would like to be involved with efforts to assist this population or to receive additional information.

Recommended Additions to the Michigan Newborn Screening Panel

The Michigan Newborn Screening Quality Assurance Advisory Committee recently recommended that mucopolysaccharidosis type I (MPS I) and X-linked adrenoleukodystrophy (X-ALD) be added to the Michigan newborn screening panel. The recommendations follow those of the federal Advisory Committee on Heritable Disorders in Newborns and Children to add both diseases to the Recommended Uniform Screening Panel, with final approval pending by the Secretary of Health and Human Services.

MPS I (a lysosomal disorder) and X-ALD (a peroxisomal disorder) are inherited progressive, multisystem diseases that vary in age of onset and severity of symptoms. Both conditions have early onset forms that follow a similar clinical course of rapidly progressive neurologic decline and childhood death. Since symptoms are usually not evident at birth, early diagnosis through newborn screening offers affected children the best chance to benefit from early treatment.

The recommendations to add MPS I and X-ALD to the Michigan newborn screening panel have been approved by the MDHHS director and must undergo legislative review before being adopted into the state's newborn screening statute. Statewide screening can then be implemented once FDA approved laboratory technology becomes available and the validation and population studies are completed. Meanwhile, the Newborn Screening Program will be working with its advisory groups and medical management coordinating centers to develop protocols to ensure that infants who screen positive receive appropriate referrals, diagnostic testing, and treatment.

Thank you, Hospital Staff!

As part of the Newborn Screening Celebration events, the Michigan Department of Health and Human Services along with the Michigan Health and Hospital Association recognized seven hospitals for outstanding performance in newborn screening. The hospitals listed below met or exceeded all six performance metrics during the first six months of 2015. We'd like to thank all birthing hospitals for their hard work and commitment to keeping Michigan babies healthy through newborn screening.

*Left: Representative McBroom accepting the award on behalf of Dickinson County Healthcare System, Nick Lyon, MDHHS Director, and Dr. Gary Roth, MHA Representative
Center: Holland Hospital*



*Right: McLaren Port Huron
Left: Mid-Michigan Medical Center—Midland
Center: Spectrum Health Gerber Memorial
Right: Spectrum Health Zeeland Hospital
Bottom Center: Samantha; diagnosed through NBS
Bottom Right: Beaumont Hospital—Troy*



NBS Quarterly Reports and Stellar Performance

During the third quarter of 2015, ten hospitals met all six of the NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Allegiance Health
- Beaumont Hospital—Troy
- Huron Medical Center
- McLaren Port Huron—SCN
- Spectrum Health Gerber Memorial
- Beaumont Hospital—Farmington Hills
- Holland Hospital
- McLaren Port Huron
- Spectrum Health Butterworth Campus
- St. Mary 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 1-517-335-4181.



Important Reminders!

Michigan Newborn Screening Online Card and Supply Orders

We are pleased to announce the successful launch of the NBS Online Ordering System (NBSO)! As of October 1st hospitals have been required to place all NBS card orders through NBSO which can be accessed at <http://www.michigan.gov/nbsorders>. It is quick and easy to use. After you enter the site, click on NBSOnline Web Store – Order NOW!. First-time users will need to register. Once registered, anyone can place an order for educational materials and NBS envelopes. Orders requiring payment ie NBS cards must be paid by eCheck or credit card at the time of purchase. For more instruction on using NBSO, please refer to the *NBSO Registration and Order Guide*, available at www.michigan.gov/nbsorders.

Still have questions? Contact Valerie Ewald, NBSO Administrator at nbsorders@michigan.gov or call 517-335-8887.

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. Keri Urquhart, CCHD nurse educator, is also available to work with hospitals on CCHD pulse oximetry screening and reporting, and can be reached at urquhartk1@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