



Michigan Department of Health and Human Services

Newborn Screening News

Fall 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.

Removal of two disorders from Michigan's NBS Panel

Effective September 30, 2017, two metabolic disorders, short-chain acyl-CoA dehydrogenase deficiency (SCAD) and isobutyryl-CoA dehydrogenase deficiency (IBD), were removed from Michigan's newborn screening (NBS) panel. When these conditions were added to Michigan's panel in 2005 due to expanded screening using mass spectrometry, they were included as secondary targets on the federal recommended uniform screening panel. After expert review, these conditions were found to have minimal to no clinical consequences and therefore no tangible benefits from detection through NBS. Consequently, the Quality Assurance Advisory Committee recommended the removal of these two disorders from Michigan's NBS panel which was implemented in 2017.

Sickle Cell Disease Pain Management CME Course Coming Soon!!!

The Michigan Department of Health and Human Services (MDHHS) Hemoglobinopathy Quality Improvement Program is pleased to announce the development of a Pain Management for Patients with Sickle Cell Disease online CME course for nurses. This course will aim to enhance the learner's knowledge to assess, intervene, evaluate, and document sickle cell disease pain and its management. The need for this course was identified in the MDHHS public health strategic plan for children and adults with hemoglobinopathies, particularly sickle cell disease, across the lifespan. The strategic plan is the result of many months of collaborative efforts by nearly 100 individuals ranging from focus group participants, hematologists, pediatricians, nurses, public health practitioners, and individuals living with sickle cell disease. For many with the condition, daily living consists of illness, pain, time-consuming trips to the emergency department, stigmatization, and a compromised quality of life. Timely, appropriate, and respectful pain management can relieve pain, reduce hospitalizations, and decrease the development of chronic pain symptoms. Stay



tuned to learn more when the course is rolled out!

Sickle Cell Disease Strategic Plan:

www.michigan.gov/sicklecell

Congratulations to Children's Hospital of Michigan for their national recognition on timeliness for metabolic disorders!

You may remember that we mentioned in a previous newsletter that in 2015, a total of 36 infants were diagnosed with classic galactosemia, profound biotinidase deficiency, amino acid disorders, organic acid disorders, or fatty acid oxidation disorders. Every single one of those 36 infants had treatment initiated within the first six days of life! The Association of Public Health Laboratories and NewSTEPS will be highlighting this story on their website in September. We would like to thank everyone involved in ensuring the NBS Program is a success for Michigan's newborns!



NBS Follow-up Program Contact Information

Phone: 517-335-4181

Email: newbornscreening@michigan.gov



RICK SNYDER, GOVERNOR | NICK LYON, DIRECTOR

NBS for Lysosomal Storage Disorders is Underway!

Effective August 7, 2017, the Newborn Screening Laboratory began screening for two lysosomal storage disorders: Pompe disease, also called glycogen storage disease type II (GSD II), and mucopolysaccharidosis type I (MPS I), also called Hunter syndrome. While Michigan-specific cutoffs are being validated and software changes are implemented, only positive screening results will be reported. Notices will be sent to providers before screening results for these disorders will be added to the NBS mailer for all newborns. Michigan is one of nine states currently screening or implementing screening for these disorders. In Michigan, babies with positive screens will be referred to the Children’s Hospital of Michigan, Detroit Medical Center or the University of Michigan Medical Center (Michigan Medical) for follow-up. The program is estimating 3-4 affected Michigan babies each year will be detected and referred for early treatment through newborn screening. Information and resources for parents and providers can be found at:

www.michigan.gov/newbornscreening.



Newborn Screening Courier Log

Date	Envelope Number(s)	Courier Name (print)	Courier Signature	Pickup Date/ Military Time	Staff Signature

Once a week the NBS Program looks for missed bloodspot screens by linking the NBS and birth certificate records. Earlier this year the NBS Program discovered through this linking process that 21 NBS bloodspot specimens were missing from two large hospitals. Both hospitals conducted an investigation and found that the courier envelopes that contained the missing specimens had been placed in the wrong location. The NBS Program expects each STAT courier to find a staff member and confirm there are no envelopes for pickup whenever the basket is empty. Both of these hospitals should have specimens picked up every day but neither courier checked with a staff member to confirm there were no envelopes ready for pickup.

Each hospital should keep a courier log that contains enough information to locate missing newborn screens. Contact Lois Turbett at TurbettL@michigan.gov for a sample courier log. The NBS envelope number(s) should be on Lower Peninsula logs and the UPS tracking number (usually starts with 1Z05V0R4) should be on Upper Peninsula logs.

Newborn Screening Card Fee Change:

On October 1, 2017, the cost for the initial newborn screening card increased to \$125.83 (from \$125.16). The cost for the repeat (pink) cards changed to \$117.69 (from \$117.11). The fee supports the Newborn Screening Laboratory, Follow-up, and Coordinating Centers. The fee is adjusted annually to reflect changes in the Detroit Consumer Price Index and to cover the cost of adding new disorders to the newborn screening panel.

The Detroit Consumer Price Index increased 1.1% this year. To reflect this change, MDHHS applied a \$1.38 increase to the cost of each initial (blue) newborn screening card and a \$1.29 increase to the cost of each repeat (pink) card purchased. The fee was revised to include additional funding to support a new 60-allele second tier test for cystic fibrosis and screening for Mucopolysaccharidosis Type 1 and a cost reduction associated with use of digital microfluidics technology to screen for Pompe disease.

If you have questions regarding the fee, please contact the Newborn Screening Follow-up Program at 517-335-4181.



NBS Quarterly Reports and Stellar Performance

During the 2nd quarter of 2017, ten hospitals met all six of the NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- **Beaumont Hospital—Troy**
- **McLaren Central Michigan**
- **Henry Ford Allegiance Health**
- **Mid-Michigan Medical Center Gratiot**
- **Huron Medical Center**
- **Lakeland of Niles**
- **Mid-Michigan Medical Center Midland**
- **Otsego Memorial Hospital**
- **McLaren Port Huron**
- **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.

Holiday Pick-up Schedule:

Lower Peninsula Hospitals:

- STAT **will** pick up your NBS specimens on Friday, November 10 (state observed Veterans' Day) following the **Sunday pickup schedule**
- STAT **will** pick up your specimens on Thursday, November 23 (Thanksgiving Day) following the **Sunday pickup schedule**
- STAT **will** pick up your specimens on Friday, November 24 following the **Sunday pickup schedule**
- Because Christmas falls on Monday, STAT **will** pick up your specimens on Saturday, December 23 and Monday, December 25 (Christmas Day) following the **Sunday pickup schedule**. STAT **will not** pick up specimens on Sunday, December 24.
- Because New Year's Day falls on a Monday, STAT **will** pick up your specimens on Saturday, December 30 and Monday, January 1 (New Year's Day). STAT **will not** pick up specimens on Sunday, December 31 (New Year's Eve).

Upper Peninsula Hospitals:

- UPS **will** pick up your NBS specimens on Friday, November 10 (state observed Veterans' Day).
- UPS **will not** pick up your specimens on Thursday, November 23 (Thanksgiving Day)
- UPS **will not** pick up your specimens on Monday, December 25 (Christmas Day)
- UPS **will not** pick up your specimens on Monday, January 1 (New Year's Day)

NBS Laboratory and Follow-up staff will be working on Friday, November 24; Sunday, December 24; and Sunday, December 31.

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 appropriate 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