



Michigan Department of Health and Human Services

Newborn Screening News

Summer 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.

Recall Affects Cystic Fibrosis Screenings

It is not uncommon to hear of recalls for food or parts for automobiles and toys, but we have recently experienced one of the most significant recalls to impact the Newborn Screening (NBS) Program in over 50 years. On March 31, 2016, the MDHHS NBS Laboratory was notified of a voluntary recall by Hologic, the company manufacturing a component of the molecular assay used as a 2nd tier test for cystic fibrosis (CF) newborn screening. Our laboratory uses an immunoreactive trypsinogen (IRT) assay as the 1st tier screen for CF. Specimens with elevated IRT (≥ 96 th daily percentile) then undergo a 2nd tier screen for CF gene mutations.

Approximately 20 NBS programs were impacted by this nationwide recall. Michigan was able to respond quickly because of an existing emergency preparedness plan that included a formal collaboration with Florida's Department of Health. Since March 28th, about 100 specimens per week requiring 2nd tier testing for CF gene mutations are being sent to the Florida NBS Laboratory while work is underway to establish a new CF molecular assay in Michigan. The new assay will include the same expanded panel of 60 CF gene mutations currently used in Florida—20 more mutations than Michigan's previous panel. For more details regarding the recall response and a list of the mutations detected using the expanded mutation panel, please visit our website (www.michigan.gov/newbornscreening). Michigan families continue to benefit from the hard work and dedication of NBS Program staff not only in our state but also in Florida, and we are very appreciative of their efforts!

Newborn Screening Update on MPS I and X-ALD

On February 16, 2016 the US Secretary of Health and Human Services approved the addition of mucopolysaccharidosis type I (MPS I) and X-linked adrenoleukodystrophy (X-ALD) to the Recommended Uniform Screening Panel. Both of these conditions were also recently added to Michigan's newborn screening panel, after receiving approval by the MDHHS director and passing legislative review.

Both MPS I and X-ALD are inherited multisystem disorders associated with progressive neurologic decline and early death. Identification through newborn screening, however, will give affected children the best chance to benefit from early treatment. The Michigan Newborn Screening Program is currently working with its advisory groups and medical management coordinating centers on protocols to ensure appropriate follow-up for infants with positive newborn screening results. Screening will begin once FDA approved laboratory technology becomes available. MPS I will use the same laboratory platform as Pompe disease, with screening for both conditions expected to begin later this year. A commercially available tandem mass spectrometry kit to screen for X-ALD is anticipated in 2017.

NBS Follow-up Program Contact Information

Phone: 517-335-4181

Email: newbornscreening@michigan.gov

CCHD Screening & Reporting- HL7 Update

A Health Level Seven (HL7) national standard has been developed for critical congenital heart disease (CCHD) pulse oximetry results and several hospitals throughout the state are starting to take advantage of this real-time reporting option for CCHD screening.

Earlier this year, **Alpena Regional Medical Center** was the first hospital in the state to submit CCHD data in real-time utilizing the secure Health Information Exchange (HIE) infrastructure. Once the screening is complete and entered into the hospital's electronic medical record, the system generates an HL7 message with the results and sends it to the Great Lakes Health Connect (GLHC), a Michigan Health Information Network (MiHIN) participating organization. From there, MiHIN forwards it to the Newborn Screening Program. The HL7 message for CCHD screening, is just one of 130 million messages sent through the secure HIE infrastructure since it went live in 2012.



CCHD Screening Done
Data entered into EMR
and HL7 message created



HL7 message transfers from the EMR to secure HIE infrastructure and then into one of the MiHIN networks; from there it transfers into the MDHHS Data Hub directly into the NBS CCHD Database.

Through the use of HL7 messaging, hospitals can improve their reporting of CCHD screens **AND** receive *meaningful use credit* for reporting CCHD pulse oximetry results.

Based upon a recent ruling from the Centers for Medicare and Medicaid Services, hospitals are required to select three public health measures to **comply with the Meaningful Use public health measures**. One of these measures is reporting to a Specialized Registry. Submitting electronic HL7 pulse oximetry reports to the MDHHS Newborn Screening Program meets the definition of submitting to a Specialized Registry.

HL7 reporting of CCHD pulse oximetry results benefits your hospital in many ways:

- ✓ Reduces staff time
- ✓ Decreases reporting errors
- ✓ Allows for real time reporting of CCHD results
- ✓ Helps pave the way for HL7 messaging for newborn screening card demographics and results reporting which is coming in the future!

If you are interested in more information about HL7 reporting of CCHD screening data and the Specialized Registry Meaningful Use objective, please contact the Newborn Screening Meaningful Use help desk at NBS.Help@altarum.org, 734-302-4933, or visit www.michiganhealthIT.org.

Newborn Screening Program receives APHL NewSTEPS 360 Grant Award for Implementing HL7 Messaging

Michigan's NBS Program was one of 20 state programs selected to receive funding from the Newborn Screening Technical Assistance and Evaluation Program (NewSTEPS 360). NewSTEPS 360 is a collaboration between the Colorado School of Public Health and the Association of Public Health Laboratories (APHL) and funded by the Health Resources and Services Administration. The NBS Program will receive funding over a three year period to improve NBS turnaround time through implementation of HL7 messaging.

A subset of Michigan hospital systems was identified via an online survey as having high interest in development of HL7 messaging capability for submission of NBS test orders and receipt of results. Through this grant, the NBS Program will provide a financial incentive for each hospital system that has agreed to use Health Information Technology for electronic submission of NBS demographic data, test orders and Critical Congenital Heart Disease pulse oximetry screening results to MDHHS. By working with these hospital systems to onboard HL7 messaging, the goal is to monitor and improve the following quality indicators: accuracy of data submitted for test orders, time between specimen collection and specimen receipt in the NBS laboratory, and time until NBS results are reported to the submitting hospital, provider or parent.

This grant provides opportunity to improve turnaround time for result reporting. Use of HL7 messaging will reduce the number of data entry errors and decrease manual data entry for both NBS Program and hospital staff.



Dear NBS Coordinators - We need your help!

Dr. Beth Tarini, a health services researcher at the University of Iowa (formerly at University of Michigan), is working with the Michigan Department of Health and Human Services to identify ways to maximize the efficiency of the collection, processing and transport of NBS samples. As part of this project, Dr. Tarini is interested in learning from the NBS coordinators about the different ways that hospitals collect, process and transport the NBS samples. Given your expertise with your hospital's process, your perspective is critical. In the next few weeks, Dr. Tarini will be emailing you a link to a short survey about your hospital's processes. If you have any questions, please email Dr. Tarini at btarini@umich.edu or beth-tarini@uiowa.edu.



NBS Quarterly Reports and Stellar Performance

During the 1st quarter of 2016, nine hospitals met all six NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Charlevoix Hospital
- Community Health Center Branch County
- McLaren Greater Lansing
- McLaren Port Huron
- Munson Mercy Healthcare Cadillac
- Spectrum Health Butterworth Campus
- Spectrum Health Zeeland Hospital
- St. Mary Hospital-Livonia
- Sturgis Hospital

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!

Specimen Pick Up Schedule for Labor Day (Sept. 5th) :

The State NBS Laboratory and follow-up **will be open** on Labor Day, however, there will be no specimen pick up by UPS (Upper Peninsula Hospitals) or Quest Diagnostics (Lower Peninsula Hospitals).



NBS Follow-Up has moved!



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***The NBS Laboratory has not moved.**

Newborn Screening Centralized Training

The NBS Program will be holding a training for hospital staff and midwives on Thursday, October 6th, 2016 in Lansing. This day-long training will include speakers on a variety of topics related to the NBS process. Nursing CEUs and a webinar option will be available. Look for more detailed information about the trainings and registration information later this summer!

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 turbett@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.

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