



Michigan Department of Community Health

Newborn Screening News

Spring 2013

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

MICHIGAN HIGHLIGHTS

Improving Newborn Screening Rates within the Michigan Homebirth Community

Although the number of midwife deliveries is small relative to the birth cohort in Michigan, they often occur in the Amish and Mennonite populations, which have a higher incidence of several heritable disorders including phenylketonuria, maple syrup urine disease and glutaric acidemia type I. Compared to the overall newborn screen rate of 99.6% in the general population of Michigan births, approximately 65% of homebirths attended by midwives receive a newborn screen. When a screen is obtained for a homebirth, it is more likely to be collected late (after 36 hours of life) and slow to arrive in the state laboratory for testing (more than 4 days after specimen collection) compared to hospital births. Since the

time from birth to treatment initiation is critical for several disorders included in the newborn screening panel, failure to obtain a screen at all or in a timely manner can have devastating consequences. In response to these

concerns, the Michigan Department of Community Health (MDCH) Newborn Screening (NBS) Program applied for a 2013 Baby's First Test Challenge Award (www.babysfirsttest.org). The NBS Program was pleased to learn that the award has been granted to fund its quality improvement project. The project's three goals are to:

1. Increase understanding of barriers, experienced by both midwives and parents, to obtaining a newborn screen for infants born at home in order to identify strategies to increase participation.
2. Increase NBS education provided to midwives and interested community members in order to improve compliance with NBS Program recommendations.
3. Increase partnership relationships with midwives and local health departments in order to promote NBS for homebirths.

If you or someone you know has knowledge or experience with Michigan's homebirth community and would like to participate in a key informant interview, please contact Lois Turbett at 517-335-4181 or TurbettL@michigan.gov.

NBS Follow-up Program Contact Information

Phone: 517-335-4181

Email: newbornscreening@michigan.gov

Tracking NBS Specimens



Each hospital has its own in-house protocol regarding the collection and handling of NBS specimens. The Michigan NBS program provides recommendations

at www.michigan.gov/newbornscreening.

Various personnel and sites in a hospital may be involved in the NBS specimen collection process. For most hospitals, this process begins and ends in the nursery. In other hospitals, the NBS specimen/card may be moved around the birthing floor and hospital before it is packaged and ready for courier pick-up. This movement can cause specimens to be misplaced, not promptly left in the correct pick-up location or inappropriately mailed in lieu of using the courier.

To help keep track of specimens in-house, prior to courier pick-up, some hospitals have a sign-in sheet for the individuals placing the envelope in the NBS pick-up area. This is a recommended step to help prevent missing specimens.

Upon arrival at your hospital, the courier is required to scan the NBS envelope for tracking purposes. The tracking information confirms that the NBS envelope was picked up and can help the NBS program track missing specimens.

Lastly, it is important to maintain a sign-in sheet next to the NBS envelope pick-up area for the courier. The courier is to sign/initial and record the date and time of pick-up. Please make sure that both the in-house and courier tracking sign-in sheets are always present and in daily use.



COMING SOON! Revised BioTrust form

Based on survey responses from birthing hospital staff and parents, the BioTrust consent form, found on the back of the newborn screening card, has been revised. Expect to see new forms this spring!

 The new consent form will have a check box for parents to clearly mark their consent or decline regarding the use of their baby's blood spots for health research. Once the forms are in circulation, we will also ask that a **parent signature** be collected for both "yes" and "no" decisions.

Along with the new consent form, we have also made revisions to the BioTrust consent booklet. The booklet is now a brochure with reduced reading level to reach a larger number of parents. The new brochure provides more detail regarding the types of research using blood spots, facts regarding specimens collected prior to October 2010 and a checklist to ensure parents have completed all of the steps to learn about the BioTrust. We hope to have the consent brochure in circulation later this spring, after the current supply of BioTrust booklets is depleted. More details will be forthcoming. Please contact the BioTrust Coordinator at langboc@michigan.gov if you have any questions.

Spotlight on Unsatisfactory Specimens This issue: Capillary Tubes

The state laboratory received over 3,500 unsatisfactory specimens in 2012. Specimens that were layered, clotted, had serum rings or were damaged accounted for 65% of these unsatisfactory specimens. **Are you aware that the use of capillary tubes can result in an unsatisfactory specimen?** For this reason, the NBS Program strongly discourages the use of capillary tubes when collecting the newborn screen.

	<p>Note the swirl pattern that was caused when the capillary tube was used to "paint" the circle.</p>
	<p>This picture shows card damage from the capillary tube. It also caused the specimen to clot.</p>

Points to remember when collecting a NBS specimen:

- Wipe away the first drop of blood
- Apply *only* one large drop of blood to each preprinted circle
- Apply blood to *only* one side of the card
- Make sure the blood has soaked through to the other side

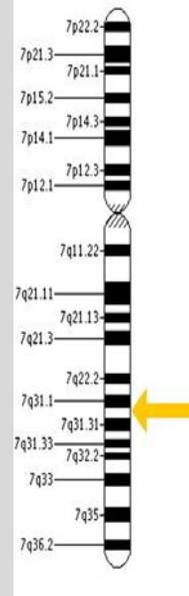
Unsatisfactory specimens can result in:

- 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
- Increased financial burden for the family if insurance declines to cover the cost of the repeat screen

Lois Turbett is available to work with staff in any hospital that requests help with specimen collection. She can be reached at (517) 335-4181 or via email at TurbettL@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.

Cystic Fibrosis (CF)

Through newborn screening, babies with cystic fibrosis (CF) can be identified before they develop significant complications. Doctors can begin necessary therapies early to promote good lung function, better nutrition and the best opportunity for a healthier life. Michigan uses a two-tiered approach to CF newborn screening combined with diagnostic sweat testing to find babies with CF. First, the level of a pancreatic enzyme, referred to as IRT, is measured. *If the IRT is elevated*, a test is run on the same blood spot sample to look for 40 common mutations in the CFTR gene (gene associated with CF). Over 1500 CFTR mutations are known, but most states like Michigan only screen for a portion that are more often responsible for causing CF. An infant's newborn screen is interpreted as positive if one or two CFTR mutations are detected. A follow-up sweat test in one of Michigan's five CF Centers is performed to confirm whether a baby has CF or is simply a carrier. Sometimes more than one sweat test or further genetic testing is necessary to provide a diagnosis.



Researchers are still learning about the CFTR gene and the effect different mutations have on the resulting health for a child with CF. A new website (www.cftr2.org) is now available for parents and physicians to see how others with the same CFTR mutations have fared. Information from people with 160 different mutations has been compiled on the CFTR2 website. In addition, researchers are currently looking at how children with particular mutations respond to various medications. One mutation, G551D, has already been shown responsive to a particular drug, Kalydeco, and new trials are underway to look at children with the most common CFTR gene mutation, delta F508. The Cystic Fibrosis Foundation (www.cff.org) is a great resource for you and your patients to stay well-informed about all advances in detecting and treating CF.



NBS Quarterly Reports and Stellar Performance

During the first quarter of 2013, five hospitals met all seven NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

**Huron Medical Center
Huron Valley-Sinai Hospital
McLaren Greater Lansing Hospital
Port Huron Hospital
William Beaumont Hospital-Troy**

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 ≤4 days after collection
3. <1% of screens are unsatisfactory
4. <2% of envelopes are batched (i.e., contain screens with collection dates >2 days)
5. >95% of electronic birth certificates have the NBS card number recorded
6. >95% of specimens have a returned BioTrust for Health consent form
7. >90% of returned BioTrust for Health consent forms are completed appropriately

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 1-866-673-9939.



Important Reminders!

Guidelines for Packaging and Courier Services



Once NBS specimens dry, hospital staff packages the specimens for courier pick-up. This daily task is often performed by various employees. Due to hospital staff turn-over, assignment changes, holiday and vacation schedules, different staff may be assigned to NBS packaging responsibilities. It is important that all hospital staff responsible have ongoing training for the packaging and transit of NBS specimens.

Early Specimens

If you receive an EARLY specimen notification for a specimen drawn at <24 hours of life, please review promptly. If there was an error in recording a specimen Birth Date/Time or Collection Date/Time, please make the appropriate corrections at the bottom of the notification and fax them to 517-335-9773 as soon as possible. Accurate reporting of screening information on the NBS card will prevent unnecessary rescreening.

**Note: If your records indicate this specimen was collected at => 24 hours please provide the following information and fax back to 517-335-9773 so that we may correct our records on this infant.*

Birth Date: _____ Birth Time: _____ Collection Date: _____ Collection Time: _____
(Military) (Military)

Name of person completing this form: _____

**** PLEASE DO NOT FAX PAGES FROM THE MEDICAL RECORD ****

Time Saver Tips

Please review these helpful tips provided by the Michigan NBS program. Following these guidelines will reduce the risk of errors and lead to prompt diagnosis of NBS disorders. For additional recommendations, visit www.michigan.gov/newbornscreening.

1. Use a customized hospital stamp/sticker for filling out the address information on the NBS envelope and card.
2. Always have a designated pick-up area for the NBS envelopes. Keep a copy of the courier's contact information in this area.
3. Learn your courier's name, contact information and daily pick-up time.
4. Share your contact information with your courier so you can be easily contacted in case of any delays. Upper Peninsula hospitals using UPS may track NBS specimens and troubleshoot problems online or by calling the preferred customer hotline.



Please Note: Upcoming State Holidays

May 27 — Memorial Day
July 4 — Independence Day

Celebrate Newborn Screening's 50th Anniversary!!

Let us know if you plan on honoring this occasion at your hospital. Next issue will provide details of the events planned by the Michigan NBS program.

Courier Transit Supplies

Please remember to order your Newborn Screening envelopes by contacting Val Klasko at 517-241-5583 or email: MDCH-NBScards@michigan.gov. It is important to use the preprinted white MDCH NBS envelopes as they contain a UPC code that allows for tracking by the courier to ensure prompt delivery of all specimens.

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