



# Michigan Department of Community Health

# Newborn Screening News

## Spring 2014

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

### **In the News: Tragic Consequences Due to Newborn Screening Specimen Delays**

The Milwaukee Journal Sentinel recently won several awards for its “Deadly Delays” series of articles that reported on NBS specimen transit delays among various U.S. hospitals. The link is provided at the end of the article. The journal highlighted several cases of babies who became critically ill because their screens were late arriving to the lab for testing. After a Freedom of Information Act request from the Milwaukee Journal Sentinel for hospital level information on NBS, twenty-six states, including Michigan, released data on transit time and unsatisfactory specimens. Please refer to the Newborn screening programs, state by state link at the end of the article for further information on how your hospital compares with others in Michigan.

A key factor to the success of NBS is getting the sample to the laboratory for testing as quickly as possible. Except for some unforeseen circumstances, such as weather delays, most specimens could arrive to the State of Michigan Newborn Screening Laboratory no later than the baby’s fourth day of life. Your hospital’s quarterly report lets you know the number of first sample specimens collected after 36 hours of life and the number of specimens arriving to the lab more than three days after collection.

With your help we can make sure every baby has the best chance at early diagnosis and treatment! Follow these tips to help improve specimen transit times for your hospital.

- Schedule the collection as close to 24 hours as possible (but not a minute before!). Remember: Collecting a 24-hour screen at 4 a.m. is better than collecting a 36-hour screen at 4 p.m.
- Dedicate staff during each shift to package dried specimens for send-out.
- Maintain a specimen log on the floor that includes the kit number and the date/time the specimen was sent to your courier pick-up location.
- Know if your hospital has Saturday OR Sunday pick-up.
- Know your courier pick-up location and time.
- If the baby needs to be transferred to another hospital, collect an early screen prior to transfer.
- If you are a receiving hospital, make sure the screen was collected by the transferring hospital. Collect a 24-hour screen if needed.

Deadly Delays article link—<http://www.jsonline.com/watchdog/Deadly-Delays-Watchdog-Report-newborn-screening-program-231927171.html>

State by state link— <http://www.jsonline.com/watchdog/deadly-delays-newborn-screening-programs-state-by-state-228834411.html#!/nation/has-data/michigan/>

## **Do You Know Your Courier Service Provider(s)??**

Hospitals in the Upper Peninsula continue to have Monday-Saturday courier pick-up service provided by UPS. All but one hospital in the Lower Peninsula have Monday-Friday courier service provided by Quest. Some Lower Peninsula hospitals have Saturday pick-up by Quest while the majority have Sunday pick-up by A1 International. Please e-mail [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov) if you need detailed information about your hospital’s NBS courier service, including pick-up days, times and locations within your building.

### **NBS Follow-up Program Contact Information**

Phone: 517-335-4181

Email: [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov)

Michigan Department  
of Community Health



Rick Snyder, Governor  
James K. Haveman, Director



# APRIL IS...

## Primary Immunodeficiency Diseases Awareness Month



Severe Combined Immunodeficiency Disorders (SCID) are the most severe type of Primary Immunodeficiency Diseases (PIDD). Babies born with a primary immune deficiency have a very difficult time fighting off infections that are typically minor for other people.

Since October 2011, the Michigan Department of Community Health has detected 34 newborns with serious immunodeficiency, including SCID (3) and some other primary (14) and secondary (17) immunodeficiency disorders. Follow-up care is given by leading children's hospitals like Children's Hospital of Michigan, C.S. Mott Children's Hospital and Helen DeVos Children's Hospital.

These conditions are often inherited and present from birth. There are more than a dozen different genetic causes. About nine out of ten times, the cause can be determined. Affected babies need early diagnosis and treatment, most often cord blood transplant, to survive.

Michigan was among the first states to implement SCID screening. Ongoing quality improvement efforts by MDCH means that fewer babies have a false positive screening result. Prompt referral can save a life!

Find out more about the MDCH Newborn Screening Program:  
[www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening)

Learn more about primary immune deficiency:  
<http://primaryimmune.org/>

### Spotlight on Unsatisfactory Specimens This issue: Clotted

The State Laboratory received over 3,000 unsatisfactory specimens in 2013. One reason for an unsatisfactory specimen is clotting. This can be caused by:

- touching the same circle on the filter paper to a blood drop several times;
- using both sides of the filter paper to collect the blood;
- using capillary tubes to "color" or "dot" the circle.



Points to remember when collecting the NBS specimen:

1. Wipe away the first drop of blood
2. Apply *only* one large drop of blood to each preprinted circle
3. Apply blood to *only* one side of the card
4. Make sure the blood has soaked through to the other side
5. The 6th spot on the card is optional

Unsatisfactory specimens can result in:

- Infant distress caused by the need for a repeat specimen collection
- 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

### NEW Card Ordering System UPDATE!

The anticipated go-live date for the web-based application to purchase newborn screening cards or ordering training materials is tentatively scheduled for mid-May. The system will require payment (either by e-check or credit card) prior to the shipment of any new screening cards.

All customers, for security purposes, will be required to establish a State of Michigan Single Sign-On account via [www.michigan.gov/business](http://www.michigan.gov/business). Initial validation processes as well as detailed instructions regarding web navigation will be provided once finalized.

♥ Mandated CCHD screening by pulse oximetry began April 1, 2014. If your hospital still needs assistance with data submission to MDCH please contact Keri Urquhart, CCHD Nurse Educator at [urquhartk1@michigan.gov](mailto:urquhartk1@michigan.gov)

Lois Turbett is available to work with staff in any hospital that requests help with specimen collection or transit issues. She can be reached toll-free at (866) 673-9939 or by email at [TurbettL@michigan.gov](mailto:TurbettL@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.



## Retirement Announcement — Carole Flevaris

Congratulations to Carole Flevaris, the Newborn Screening Follow-up Coordinator, for her five years of dedicated work for the Newborn Screening Program and over twenty years with the State of Michigan. Please send any questions to [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov) for any help with courier or transit information.

## Problem with Repeat (Pink) Newborn Screening cards

The image shows a portion of a newborn screening card. The field 'BIRTH WT. (grams)' is circled in red. Other visible fields include 'BIRTH TIME (Military)', 'COLLECTION TIME (Military)', and a 'NO' checkbox.

A misprint has been detected on pink cards distributed since Fall 2013. Please note that on the new Repeat Specimen cards the field, “Birth Weight” is requested when instead it should be “Current Weight”. As always, continue to complete the fields as labeled. The pink cards will be corrected, reprinted and replaced within the next few months. All incoming pink cards (Lot # 102277) are being reviewed for age appropriate weight until these cards have been removed from circulation.

**Please remember to write the birth and current weight in grams.**

## Single or Multiple Birth?

The image shows a portion of a newborn screening card. The 'SINGLE BIRTH' and 'MULTIPLE BIRTH' radio buttons are circled in red. Other visible fields include 'BIRTH ORDER' with options A, B, C, and D.

Please remember to mark “single birth” or “multiple birth” on the card. This field is important for distinguishing between these types of babies.



## NBS Quarterly Reports and Stellar Performance

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

**Beaumont Hospital-Troy  
Holland Hospital  
Metro Health 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 ≤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. >90% of specimens have a returned BioTrust for Health consent form that is 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 1-517-335-4181.

## 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](mailto:newbornscreening@michigan.gov) or visit our website at [www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening)