



Michigan Department of Community Health

Newborn Screening News

Summer 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.

MICHIGAN HIGHLIGHTS

SAVE THE DATE for NEWBORN SCREENING TRAININGS!!

Trainings will be provided this fall by the MDCH Newborn Screening Program at six regional sites throughout the Lower Peninsula. Topics will include NBS updates, improving specimen transit times, implications for healthcare providers and presentations on some of the NBS disorders. The full day training will include lunch with nursing contact hours available.

Training dates and sites:

September 23, 2014

**Covenant Healthcare
Saginaw**

September 29, 2014

**Spectrum Health United Hospital
Greenville**

September 30, 2014

**Munson Hospital
Traverse City**

Videoconferencing available for some hospitals

October 6, 2014

**Henry Ford Health System, One Ford Place
Detroit**

October 9, 2014

**University of Michigan Palmer Commons
Ann Arbor**

October 14, 2014

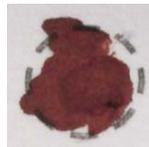
**Bronson Methodist Hospital
Kalamazoo**

All NBS coordinators, supervisors, nurse educators, lab personnel and others involved in the NBS process are encouraged to attend. Register today at <https://www.surveymonkey.com/s/nbsregistration>. For more information, visit the website at www.michigan.gov/newbornscreening or contact Lois Turbett at 517-335-1966 or turbettl@michigan.gov.

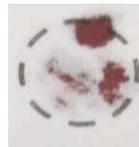
Spotlight on Unsatisfactory Specimens This issue: Quantity Not Sufficient (QNS)

Eight punches are required to run the initial set of NBS tests. Specimens with less than eight available punches are marked QNS.

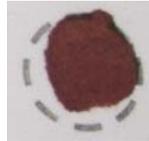
FRONT



BACK



Several small drops of blood were layered on one side of the filter paper preventing the blood from soaking through evenly to the back.



Remember to assess the quality of both sides of the specimen.



Four punches are made on two different spots to run the first set of tests. If all six spots look like the example on the right, there will not be enough blood for the initial tests.



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

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

Michigan Department
of Community Health



Rick Snyder, Governor
James K. Haveman, Director

NBS Follow-up Program Contact Information

Phone: 517-335-4181

Email: newbornscreening@michigan.gov

Hemoglobinopathies

MDCH Hemoglobinopathy Quality Improvement Program (MIHemQIP)

We are delighted to introduce Dominic Smith as the new Hemoglobinopathy Program Coordinator, who joined the Genomics and Newborn Screening team in April. Dominic will be involved with newborn screening follow-up activities related to sickle cell disease (SCD) and other hemoglobinopathies. In addition, her role is to go beyond NBS to encompass development of a broader public health program addressing sickle cell issues through the lifespan.

The Sickle Cell Disease Newborn Screening Surveillance Report to be released July 2014

MDCH recently completed an extensive data analysis and literature review to assess the burden of hemoglobin disorders on individuals of all ages identified through the newborn screening program. As a result, twelve hemoglobinopathy measures were developed and will be monitored over time: incidence, demographics, confirmatory diagnosis, antibiotic prophylaxis, patient education, immunizations, public insurance enrollment, transcranial doppler screening, hydroxyurea treatment, emergency department visits, inpatient hospitalizations, and outpatient visits. Data were obtained from birth certificate records, the Sickle Cell Disease Association, Michigan Chapter's aggregate data describing children and adults served through the center, immunization information from the Michigan Care Improvement Registry, and Medicaid and Children's Special Health Care Services claims. The report will describe the hemoglobinopathy measures calculated for Michigan, as well as comments about their significance and potential utility.

Sickle Cell Disease Strategic Plan Coming Soon

MDCH and partners are in the process of designing a comprehensive public health plan to address the needs of individuals (children and adults) with hemoglobinopathies, particularly SCD. This disease is characterized by a modification in the shape of the red blood cell from a smooth, donut-shape into a crescent or half-moon shape. The misshapen cells lack plasticity and can block small blood vessels, impairing blood flow. This condition leads to shortened red blood cell survival and anemia. Poor blood oxygen levels and blood vessel blockages in people with SCD can lead to chronic acute pain syndromes, severe bacterial infections, and necrosis (tissue death). The most common type of SCD is sickle cell anemia (Hemoglobin SS), Hemoglobin SC disease, sickle beta thalassemia (SB⁰) and sickle beta thalassemia plus (SB+). In 2013, Michigan Newborn Screening Program identified 52 newborns with sickle cell conditions (SS, SC disease, and S/Bthal) and an additional 2,773 newborns were identified as sickle cell disease carriers. Although life expectancy for individuals with sickle cell disease has increased significantly during the past 40 years, there is still a need to find new ways of addressing the disease burden. The plan is expected to be completed by December 2014.



PerkinElmer, "Sickle Cell Image." Viacord for PerkinElmer.

June 19th: World Sickle Cell Day

In the year 2008, the General Assembly of the United Nations adopted a resolution which determines sickle cell disease as a public health problem and one of the world's foremost genetic disease, requiring heightened awareness and activism, diagnosis and management. World Sickle Cell Awareness Day provides an opportunity to increase understanding of SCD and how the disease affects individuals and families worldwide.

Important Changes to NBS Quarterly Reports

From the second quarter of 2014 on, your NBS quarterly report measures will change. Two measures will be removed, and two new measures will be included.

The courier measure ($\geq 90\%$ of screens arrive in state laboratory ≤ 4 days after collection) and the batching measure ($< 2\%$ of envelopes are batched) will be removed and replaced with a measure related to specimens being received on or before the appropriate day. A database has been created with the specimen pickup time for Monday-Friday and the weekend day and time for every birthing unit in the state. Since hospitals are advised to dry specimens for at least 3 hours and time may be needed to prepare specimens for shipping, we allowed for a 5-hour cushion between collection time and the earliest possible pickup time. We then developed hospital-specific cutoffs for determining whether specimens were received in the state laboratory by the appropriate day based on collection time and each hospital's courier pickup times. The goal for the new measure is that $> 90\%$ of screens arrive in the state laboratory by the appropriate day.

Effective April 1, 2014, MDCH has implemented mandated screening of all Michigan newborns for critical congenital heart disease (CCHD) using pulse oximetry with electronic reporting of screening results to the state NBS Program. We have added a new measure and set a goal of 90% of newborns with a dried blood spot screen having pulse oximetry screening results reported.

The following table indicates which measures we are focusing on and the performance goal that we have set for each measure.

Measure	Performance Goal
Late Screens	Less than 2% of screens collected greater than 36 hours after birth
Receipt by Appropriate Day	Greater than 90% of screens arrive in state laboratory by the appropriate day
Unsatisfactory Screens	Less than 1% of screens are unsatisfactory
NBS Card Number	Greater than 95% of electronic birth certificates have the NBS card number recorded
Returned BioTrust for Health Consent Forms	At least 90% of specimens have a returned BioTrust for Health consent form that is completed appropriately
Reported Pulse Oximetry Screening Results	At least 90% of newborns with a dried blood spot screen have pulse oximetry screening results reported



NBS Quarterly Reports and Stellar Performance

During the first quarter of 2014, five hospitals met all six NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Bell Memorial Hospital
- Charlevoix Hospital
- William Beaumont Hospital-Troy
- Holland Hospital
- Metro Health Hospital

Performance Goals for NBS Quarterly Reports during the first quarter of 2014

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.



Important Reminders!



1st Annual National Sickle Cell Walk with the Stars – August 30, 2014

To learn more visit, <http://www.sicklecellnationalwalk.com/>

1st Annual Sickle Cell Walkathon @ The Detroit Zoo – September 27, 2014

This event is presented by the Sickle Cell Disease Association, Michigan Chapter.

To learn more visit, <http://www.scdami.org/>

NBS Lab Renovations



This summer the Newborn Screening Laboratory is in the midst of a major renovation project. It will accomplish two objectives within a single disruption of the laboratory. One objective is to reorganize the existing space to enhance the existing unidirectional flow procedures and preparation for possible expansion of molecular screening capacity. This carries out the recommendation from a Molecular Assessment Program review conducted in 2012 by laboratorians from the Association of Public Health Laboratories, Centers for Disease Control and Prevention, and other state newborn screening laboratories. The other objective is part of a Department of Technology, Management and Budget project to upgrade building controls and increase energy efficiency throughout the building.

The renovations will be done in separate five week phases so that testing will continue without interruption. Three work spaces will be completely emptied and rebuilt for new instrumentation and more efficient use of work space. When finished in November, the laboratory will be better able to provide quality testing for Michigan newborns.

NEW Card Ordering System UPDATE!

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

A site will be accessible directly as well as through a link from the newborn screening website. Initial validation processes as well as detailed instructions regarding web navigation will be provided once finalized.

TECHNICAL ASSISTANCE

Lois Turbett 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 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