



Michigan Department of Community Health

Newborn Screening News

Winter 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

IMPORTANT CHANGES TO THE COST OF THE NEWBORN SCREENING RETEST CARD

Beginning January 1, 2013 the MDCH Newborn Screening Program will charge a fee for all pink retest cards. The fee will be \$98.08 which is the same fee charged for the blue initial test cards. This change has become necessary for several reasons including: increased program costs due to laboratory testing and implementation of new guidelines; follow-up and medical management costs for the care of infants who have a positive newborn screening result; and a marked increase in the number of unsatisfactory specimens received by the NBS laboratory.

The Michigan Newborn Screening Program has never charged for retests, so it is with regret that this change is now necessary to maintain financial viability and quality of the program. Our staff will continue to offer technical assistance to help minimize the number of retests for infants in your hospital.

All specimens on pink retest cards that were not purchased and are received by the MDCH Newborn Screening Laboratory after January 1, 2013 will be tested and the submitter will be billed \$98.08 per card for the cost of testing.

Additional information on this important change is available at www.michigan.gov/newbornscreening.



Please Note: Upcoming State Holidays

January 21— Martin Luther King, Jr. Day
February 18— Presidents' Day

NBS Follow-up Program Contact Information

Phone: 517-335-4181

Email: newbornscreening@michigan.gov

Spotlight on Unsatisfactory Specimens This issue: LAYERED

The state laboratory received 3,578 unsatisfactory specimens in 2012. Of those, 1,505 (42%) were deemed unsatisfactory due to layering (examples shown below). NBS tests are standardized based on a single layer of blood. Layering can result in either false positive or false negative determinations.

Points to remember when collecting a 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:

- 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 any hospital staff that request help with specimen collection. Contact Lois by phone toll-free: (866) 673-9939 or by email: TurbettL@michigan.gov.

Michigan Department
of Community Health



Rick Snyder, Governor
James K. Haveman, Director



Spotlight on Survey Results

Critical Congenital Heart Disease hospital survey results

The Newborn Screening Program recently sent out a survey to all the birthing hospitals in the state. The purpose was to gain a better understanding of how hospitals are addressing pulse oximetry screening for Critical Congenital Heart Disease (CCHD) in their birthing centers, and what MDCH can do to help implement hospital screening programs.



Seventy-one hospitals (84%) responded to our survey and of those, almost 60% are currently screening for CCHD in their birthing centers, and another 32% are developing screening programs. As MDCH continues to build partnerships with the birthing centers, our goal is to have every hospital screening for CCHD as a part of routine newborn care.

The survey addressed potential barriers to implementing a screening program. The main concerns included follow-up care and the purchasing of new equipment. Currently 47% of the hospitals surveyed have the capability to administer a pediatric echocardiogram with 34% of them being able to read the results. More than half of the hospitals (56%) transfer infants out for diagnosis and treatment for CCHD.

For more information on Michigan’s CCHD Newborn Screening Demonstration Program, visit www.michigan.gov/cchd

Unsatisfactory NBS specimen survey results

Following a marked increase in the number of unsatisfactory NBS specimens (Figure 1), laboratory and follow-up staff from the Michigan Newborn Screening (NBS) Program created a workgroup to explore possible reasons for the increase and devise quality improvement strategies. A survey was developed to learn about each hospital’s NBS procedures in order to determine how many hospitals follow the recommendations found in the Clinical Laboratory and Standards Institute (CLSI) publication *Blood Collection on Filter Paper for Newborn Screening Programs; Approved Standard—Fifth Edition*. A link to the electronic survey was sent to hospital NBS coordinators in the fall of 2012. Responses from hospitals with low rates of unsatisfactory specimens were compared with those of hospitals with higher rates.

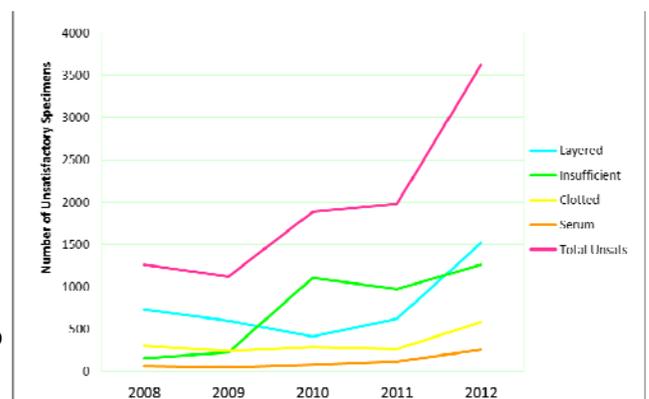


Figure 1. Number of Unsatisfactory Specimens, by Type, Michigan, 2008-August 2012

A total of 52 hospital staff members completed the survey. Overall, the majority of the CLSI guidelines are followed. The most frequently followed guidelines are: the yellow protective flap covers the filter paper while the demographic information is entered; the heel warmer is removed immediately before blood collection; and alcohol is used to cleanse the incision site, which is then allowed to air dry. The following opportunities for improvement were identified: hospital staff should wear gloves when entering demographic information to avoid specimen contamination; heel warmers should be used routinely and kept in place for at least three minutes to promote adequate blood flow and reduce the likelihood of collecting an insufficient quantity of blood; and, only one large drop of blood should be applied to each preprinted circle to avoid layering.

For a more detailed summary of the survey findings, please visit the NBS website (www.michigan.gov/newbornscreening) and click on “Documents, Forms, and Reports”.

Hemoglobin H Disease



Michigan began screening for Hemoglobin H disease, one of the alpha thalassemia disorders, in 2011. To date, seven cases of Hemoglobin H Disease have been diagnosed. The predominant hemoglobin in newborns is fetal hemoglobin (HbF), which is comprised of a tetramer formed by two alpha and two gamma chains. HbF is gradually replaced with adult hemoglobin (HbA) as the baby gets older. HbA is comprised of a tetramer formed by two alpha and two beta chains. Four genes regulate the production of alpha chains while two genes regulate the production of gamma and beta chains. If there are one, two or three alpha gene deletions or mutations, this causes fewer alpha chains to be produced. When this happens, there are more HbF gamma chains than HbF alpha chains. The excess of gamma chains form a tetramer called Hemoglobin Bart's, which is detected by newborn screening. As more HbA is produced, an excess of beta chains is created which forms a tetramer called Hemoglobin H.

The Newborn Screening Laboratory screens for alpha thalassemia by evaluating the percent of fast hemoglobin in newborn dried blood spots. The presence of Hemoglobin Bart's indicates that one or more of the four genes that produce the alpha chains are dysfunctional, causing alpha thalassemia. Low levels of Bart's are often clinically insignificant. High levels of Bart's most often indicate that three of the alpha chains are dysfunctional. The clinical manifestations of this disorder are variable but most patients have chronic hemolysis, moderate anemia and develop some degree of splenomegaly. Patients may require transfusions and iron chelation therapy.

Hemoglobin H disease with hemoglobin Constant Spring

Hemoglobin H disease with hemoglobin Constant Spring is typically more severe than the more common form of Hemoglobin H Disease. This occurs when there are two alpha gene deletions and a third Constant Spring mutation. The clinical manifestations of this disorder include moderate anemia, splenomegaly, and possible transfusion dependence.



NBS Quarterly Reports and Stellar Performance

During the third quarter of 2012, four hospitals met all seven NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

**Huron Valley-Sinai Hospital
McLaren Greater Lansing Hospital
William Beaumont Hospital-Troy
Zeeland Community 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. >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!

The MDCH Newborn Screening Follow-up Program looks for missing newborn screens by comparing birth certificate records to the NBS database. Quite often missed screens are due to parental refusal, hospital transfer or a name change. You can help by faxing the following information to NBS Follow-up:

- ⇒ Signed parent refusals
- ⇒ Hospital transfer information
- ⇒ Infant's legal name as it will appear on the birth certificate

Please fax this information to (517) 335-9149 or (517) 335-9739

Have You Inventoried Your Educational Materials?



Every parent should receive a NBS brochure and BioTrust Consent booklet. Hospitals normally receive one copy of each for every NBS card. Often additional orders for educational materials are placed, resulting in large hospital inventories. You now have the option to continue receiving educational materials with each NBS card or ordering them on demand. We've collected ordering preferences from almost all hospitals, but if you haven't given MDCH your preferences, please contact Kidist Dimore at: dimorek@michigan.gov. Please ensure you know where this material is delivered in your hospital and keep track of the inventory. To order materials please contact Val Klasko at 517-241-5583 or email: MDCH-NBScards@michigan.gov

Courier Transit Supplies

With the beginning of the New Year, 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 and the MDCH NBS Laboratory to ensure prompt delivery of all specimens.

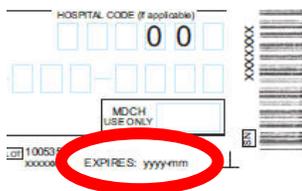
Weekend NBS specimens



Remember if you do not have Saturday pickup, place late Friday and all Saturday NBS specimens into a NBS envelope and leave it in the pick-up basket/area. Place all Sunday NBS specimens in a separate NBS envelope and drop it in the same pick-up basket/area. These envelopes will be ready for Sunday pick-up by the A-1 International Courier/Star Courier.

Expired Cards

Always check for the expiration date on the NBS card. The newer NBS cards have an expiration date printed in the lower right corner of the card. If there is no expiration date on the card, the card is expired. Please refer to the [Michigan Newborn Screening Guide](#) for information on how to replace these cards.



The Save Babies Through Screening Foundation, Inc. is offering a free newborn screening educational DVD for both professionals and parents. One Foot at a Time is a comprehensive DVD that can be ordered in English and Spanish. Order by calling toll-free at 1-888-454-3383 or visiting their website at www.savebabies.org. This website and the new video are valuable educational tools for nurse educators, phlebotomists, newborn screening coordinators and parents.

The information presented augments the Michigan Newborn Screening video, also available free of charge by request to newbornscreening@michigan.gov

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