Michigan Department of Community Health

Newborn Screening News

Summer 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

Are You Throwing Money Away???

The cost of the first ("blue") and repeat ("pink") sample cards is $98.08 each. Did you know that you can return your cards for replacement if you are unable to use them? Reasons could include: card pieces are torn or separated, unsatisfactory specimen, wrong demographic information is entered or parental refusal. The *Newborn Screening Card Replacement Form* is located on the newborn screening website, www.michigan.gov/newbornscreening.

To complete this process: separate the top sheet of the NBS card from the filter paper, place any sheets that have blood on them in a biohazard bag, mail the completed card replacement form and the top sheets of the cards intended for replacement to the address on the form:

Michigan Department of
Community Health
Attention: Newborn Screening
4th Floor Lewis Cass Building
320 South Walnut
Lansing, MI 48913

Do not send these cards to the state laboratory!

Failure to send the cards to the Lewis Cass Building may result in you ***not*** receiving replacement cards!

Please Note:
Upcoming State Holidays

September 2 — Labor Day

NATIONAL HIGHLIGHTS

POMPE DISEASE RECOMMENDED BY SACHDNC

The Secretary's Discretionary Advisory Committee on Heritable Disorders in Newborns and Children recently recommended the addition of Pompe Disease to the National Recommended Uniform Screening Panel. MDCH will review the recommendation with the Michigan Newborn Screening Quality Assurance Advisory Committee for possible addition of this disorder to the newborn screening panel in 2014. Refer to the Newborn Screening News Fall 2012 issue for more details on Pompe Disease.

50th Anniversary of Newborn Screening

The Association of Public Health Laboratories (APHL) and the Centers for Disease Control and Prevention are sponsoring a traveling exhibit throughout 2013 celebrating the nation's 50 years of saving babies' lives through newborn screening.

The exhibit is working its way across the country and will be making an appearance in Michigan from September 9th through 20th. During the week of September 9th, the exhibit will be on display in a few of the Michigan Newborn Screening Medical Management centers—a great opportunity to visit and learn more about newborn screening. During the week of September 16th, the exhibit will be at the Capitol in Lansing, with visibility for legislators including a media event on September 18th.

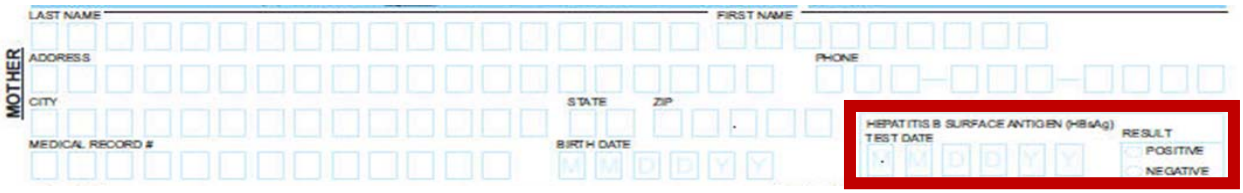
To learn more about Michigan's events, visit www.michigan.gov/newbornscreening. For more information about the national campaign, visit www.aphl.org.

NBS Follow-up Program Contact Information
Phone: 517-335-4181
Email: newbornscreening@michigan.gov

Michigan Department of Community Health
MDCH
Rick Snyder, Governor
James K. Haveman, Director

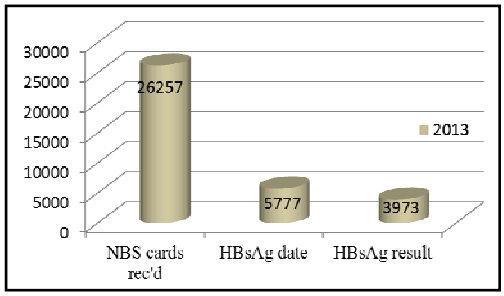
Mother's HBsAg Test Date and Result

The mission of the Perinatal Hepatitis B Prevention Program (PHBPP) is to identify hepatitis B surface antigen (HBsAg)-positive pregnant women during pregnancy so their infants, household and sexual contacts can receive the appropriate vaccination to prevent hepatitis B virus (HBV) transmission. If a woman with HBV (indicated as HBsAg-positive) is not identified prenatally, it is crucial that she is identified at delivery. When there is a breakdown in reporting, an infant is at risk and may become infected with HBV.



About 7% of the cases are identified at delivery through the use of the NBS card. On the NBS card, under the ***MOTHER*** section, it is extremely important that the hospital complete mom's HBsAg test date and result. If the card is marked HBsAg-positive, the card will be copied and forwarded to the PHBPP for review. If these cards are not marked properly, we may not identify the HBsAg-positive woman and her baby may not receive the hepatitis B vaccine and the hepatitis B immune globulin (HBIG) at birth which will help protect the baby from getting HBV.

The graph to the right depicts the first quarter of 2013. There were 26,257 NBS cards received by MDCH. Out of these cards, 5,777 (22%) indicated mom's HBsAg date of testing and 3,973 (15%) indicated mom's HBsAg test result.



More care ***MUST*** be taken to fully complete the NBS cards and especially to indicate mom's HBsAg test date and result. These babies are depending on us! For additional information, please contact the PHBPP at 517-335-8122 or 313-456-4432, or go to www.michigan.gov/hepatitisB for the latest information on the PHBPP.

Spotlight on Unsatisfactory Specimens
This issue: Insufficient

The state laboratory received over 3,500 unsatisfactory specimens in 2012. Specimens that had an insufficient amount of blood applied accounted for almost one-third of those unsatisfactory specimens. The lab needs to make 13 punches to allow for initial and repeat testing. Remember that ideally, one full spot is left for future use by the parent. Sometimes no blood is leftover when testing is completed on insufficient specimens.

Points to remember when collecting a NBS specimen:

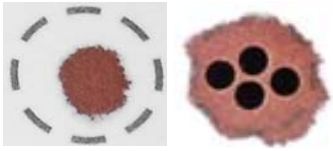
- Wipe away the first drop of blood
- Apply *only* one large drop of blood to each preprinted circle
- Apply blood to *only* one side of the card
- Make sure the blood has soaked through to the other side

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 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.

The spot above was insufficient because the blood did not soak through to the back of the card. Be sure to examine both sides to assess specimen quality.



Punches made for the first set of tests are preset. If a circle is not completely filled in with blood, the lab will need to spend extra time making individual punches.

Phenylketonuria (PKU)

This year marks the 50th anniversary of newborn screening in the United States. One could say that the journey began in 1934 when Norwegian biochemist and physician, Ivar Asbjorn Folling, described an inherited metabolic disorder characterized by severe intellectual impairment, motor problems and skin abnormalities. Affected individuals excreted phenylpyruvic acid in their urine and the disorder came to be known as phenylketonuria (PKU).

In the early 1950s, German pediatrician and inborn errors of metabolism researcher, Horst Bickel, and his colleagues at the Birmingham University Children's Hospital, developed a formula low in phenylalanine (Phe). These doctors were able to demonstrate that by following a low Phe diet, children with PKU had fewer symptoms, though they remained intellectually disabled. The researchers learned later that children should begin a low Phe diet soon after birth to prevent the devastating outcomes of the disease.

During the 1950s, diagnosing infants with PKU was delayed because they did not excrete high enough concentrations of phenylpyruvic acid in their urine to give a positive test result. Presented with the challenge to develop a test that would allow early identification of children with PKU, Dr. Robert Guthrie created a bacterial inhibition assay (BIA) that could detect elevated levels of Phe in whole blood on special filter paper. In 1961, Dr. Guthrie and his lab began a successful pilot project to screen infants for PKU using the BIA and in 1963, Massachusetts became the first state to mandate screening of all newborns for PKU. By 1965, 34 states, including Michigan, had implemented newborn screening. Mississippi was the last state to mandate newborn screening in 1985.

PKU is an autosomal recessive disorder. Both parents must carry a mutation in the phenylalanine hydroxylase (PAH) gene in order to pass on PKU to their infant. PAH mutations reduce the activity of phenylalanine hydroxylase, an enzyme that helps to convert the essential amino acid phenylalanine to tyrosine. Over time, high Phe levels cause the symptoms associated with PKU. Today, children diagnosed with PKU as newborns who follow a strict low Phe diet and have regular monitoring of their blood Phe levels can expect to live normal, productive lives.

NBS Quarterly Reports and Stellar Performance

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

Botsford General Hospital
Holland Hospital
Huron Valley-Sinai Hospital
Port Huron Hospital
Spectrum Health Butterworth Campus
William Beaumont Hospital-Troy

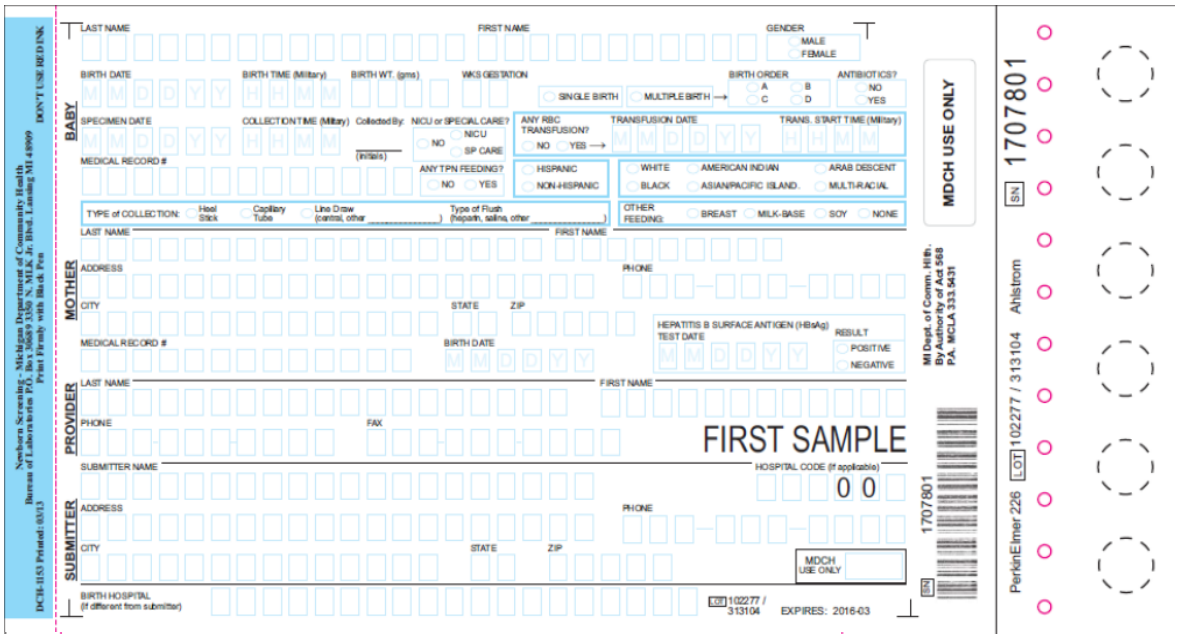
Performance Goals for NBS Quarterly Reports

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!

A New Look to the Newborn Screening Card



A sixth circle has been added to the NBS card for optional use. The State Laboratory requires that you apply blood to a minimum of five circles. The sixth circle should be used if you believe there is an insufficient amount of blood on the other five circles.

⇒ The collection time should be entered in military time. For example, if the specimen was collected at 1:23 p.m., the collection time is 1323.

⇒ It is acceptable to apply a preprinted hospital label that includes the hospital name, address, phone number and the appropriate hospital code. Please ensure that the sticker is not placed above the perforation.

⇒ In order to expedite the transit of NBS envelopes to the MDCH State laboratory, please place NBS specimen cards in the envelopes provided by the NBS program and only use the appropriate courier services. Please encourage staff to put an X over the postage square located in the upper right corner of the white NBS envelope as a reminder postage is not necessary. Homebirth attendants receive prepaid envelopes from the NBS program.

Demographic Change Requests

The Newborn Screening Program will ONLY correct information and provide corrected laboratory reports if the incorrect information is related to interpretation of test results. The data fields below indicate information that should be submitted to be changed if entered on the newborn screening card incorrectly. Please fax corrections for these fields to 517-335-9773

Corrected information that may be submitted:

Weight
Birth Date / Time
Multiple Birth / Birth Order
Antibiotics
NICU or Special Care
TPN
Specimen Collection Date / Time
Transfused and Transfusion Date / Time

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