



Michigan Department of Community Health

Newborn Screening News

Fall 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

Newborn Screening Card Fee INCREASE

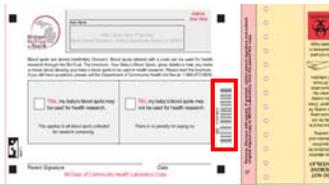
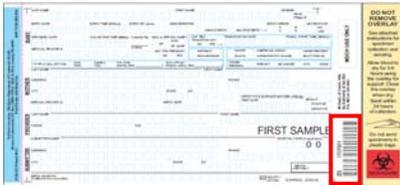
On October 1, 2014, the fee for the initial newborn screening card will increase from \$106.77 to \$125.36. The fee for the repeat (pink) cards will be \$117.29. The fee supports the Newborn Screening Laboratory, Follow-up and Medical Management programs. The fee is adjusted annually to reflect changes in the Detroit Consumer Price Index and to cover the cost of adding new disorders to the newborn screening panel.

The Detroit Consumer Price Index increased 1.3% adding \$1.39 to the cost of each newborn screening card. Critical Congenital Heart Disease (CCHD) screening was added to the NBS panel on April 1, 2014 adding \$4.50 to cover the cost of technical assistance to hospitals, data collection, follow-up, monitoring and evaluation of the effectiveness of screening. Pompe Disease, a lysosomal storage disorder, will be added to the newborn screening panel on October 1, 2014 increasing the fee an additional \$12.70. Screening for lysosomal storage disorders requires new screening technology, so initially the fee for Pompe Disease will be used to purchase new laboratory instruments, hire and train staff and establish new laboratory, follow-up, diagnostic and medical management protocols with screening expected to begin in the fall of 2015.

If you have questions regarding the fee, please contact the Newborn Screening Follow-up Program at (517) 335-4181.

Spotlight on Unsatisfactory Specimens - Cannot Identify

There are four parts of the NBS kit and each page contains the same unique number. Filter paper from another kit should **never** be used to collect the newborn's blood spot specimen since the numbers **will not** match and the specimen will be found unsatisfactory/cannot identify. A repeat specimen will be required. If pages from the kit come apart for any reason, use a new kit. The face sheet of the original kit can be submitted for card replacement.

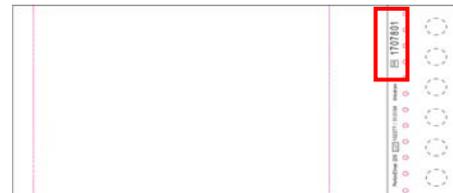


Points to remember when collecting the NBS specimen:

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
Nick Lyon, Director

NBS Follow-up Program Contact Information

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Email: newbornscreening@michigan.gov

Michigan Highlights from Sickle Cell Awareness Month



Governor Snyder Proclamation

Did you know Governor Snyder declared [September 2014 as Sickle Cell Awareness Month in Michigan](#)? Approximately 2,800 Michigan residents have sickle cell disease and 140,000 are trait carriers. This observance is particularly important this year given MDCH's focus on developing a public health strategic plan to address the burden of sickle cell disease across the lifespan of affected children and adults. The Sickle Cell Disease Association of America—Michigan Chapter (SCDAA-MI) and MDCH appreciate Governor Snyder's recognition and attention to this illness.

Sickle Cell Disease Association of America—Michigan Chapter

Many thanks to those who participated in the 1st annual Sickle Cell Disease & Myth Dispelling Walk on September 27th at the Detroit Zoo, organized by the SCDAA-MI. Participants were dressed in red t-shirts displaying myths about sickle cell disease—*"Do you have Sickle Cell Trait? ...it's in your genes"; "Sickle Cell: It's not just a Black Thing"; "I'm still here, living with Sickle Cell Disease"; "Living well with Sickle Cell" and "My Pain is Real"*. The walk provided an opportunity to raise awareness and money for patient care, social services and research to support people living with sickle cell disease. See you next year!

Focus Groups and Strategic Planning Meeting

Throughout the month of September, MDCH conducted five focus group meetings across Michigan with parents and individuals impacted by sickle cell disease. Discussion topics included utilization and accessibility of community resources, patient care satisfaction, daily barriers and burdens, and solutions to improve the quality of life for affected individuals. Information gleaned will inform the MDCH Sickle Cell Disease Strategic Plan.

To learn more about the MDCH Hemoglobinopathy Quality Improvement Program visit: www.michigan.gov/sicklecell.



Blood Spot Destruction

Sometimes BioTrust consent forms are returned to the state lab marked with a note to "destroy". Parents need to understand that the consent form cannot be used to make this request. The consent form is used to mark the parent's choice about allowing their newborn's blood spots to be used in health research. If a parent wants their newborn's blood spots destroyed, a separate *Directive to Destroy* form must be completed.

Notation on the below consent form is NOT sufficient for destruction of blood spots.

You can help parents fulfill this request by following a few quick and easy steps.

-  Instruct parents to mark "No" and sign the BioTrust consent form. Return this form to the state lab. *Blood spots will not be made available for research.*
-  Tell parents where to find a Directive to Destroy form. *The form is found on the BioTrust website (www.michigan.gov/biotrust) or by calling toll free 1-866-673-9939.*
-  Instruct parents to complete and return the Directive to Destroy form to the state lab along with a copy of their child's birth certificate and their proof of identity. *After receipt, blood spots will be destroyed in the state lab and parents receive a confirmation letter.*

The BioTrust consent brochure also explains to parents that blood spots collected after July 1984 are part of the BioTrust and may also be destroyed. Parents or individuals over 18 years may follow the last two steps outlined above to request destruction of these spots. Please encourage any individual to contact the BioTrust Coordinator for additional details: Carrie Langbo, langboc@michigan.gov or 517-335-6497.



CCHD Data Submission

Reminders for those hospitals submitting their CCHD data by **uploaded file to the secure State of Michigan ftp site:**

- Files need to be submitted once a week
- Please check the files for errors before submission
- There are still quite a number of linking errors occurring, meaning the CCHD data file could not be linked up to the newborn screening blood spot card. We cannot guarantee all the linking errors can be resolved. The linking errors are usually due to:
 - ◊ Mother's first name not matching. *Even one letter difference will result in no match.*
 - ◊ Mother's last name not matching. *Even one letter difference will result in no match.*
 - ◊ Baby's birth date not matching.
 - ◊ Newborn screening kit number is incorrect.
 - ◊ On a multiple birth, the birth order is missing.
- Most of the linking errors are occurring in records with missing newborn screening kit numbers. The newborn screening kit number field was made an optional field because a number of hospitals indicated they would not be able to provide this information.



Reminders for those hospitals submitting their CCHD data by the **web based module eReports:**

- When entering your pulse ox readings, it is best to wait until the baby you are entering the information on is found with the Specimen Search query. This ensures all the demographics data is directly from the newborn screening blood spot card.
- Before hitting the SUBMIT button, make sure your hospital is selected as the Submitter. If you start typing in your hospital name in the Submitter field it should pop up.



NBS Quarterly Reports and Stellar Performance

During the second quarter of 2014, three hospitals met five of six of the NBS performance goals. Due to the phasing in of CCHD screening this quarter, we excluded that goal to identify stellar performers. We would like to congratulate the following hospitals on their impressive efforts!

- **Metro Health Hospital**
- **St. Joseph Mercy Hospital Pontiac**
- **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 by the appropriate day
3. <1% of screens are unsatisfactory
4. >95% of electronic birth certificates have the NBS card number recorded
5. >90% of specimens have a returned BioTrust for Health consent form that is completed appropriately
6. >90% of newborns with a dried blood spot have pulse oximetry screening results reported

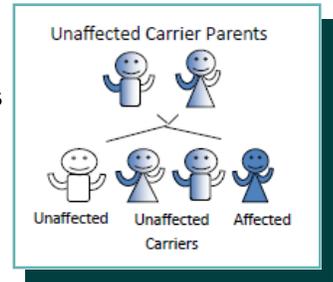
We hope you will be able to use information in the quarterly reports to improve your part of the NBS system. If you have any questions, please call the NBS Follow-up Program at 1-517-335-4181.



NBS Carrier Detection



While trying to find newborns with a genetic disorder, current newborn screening methods also have the ability to detect some babies who are simply *carriers*. For example, newborns who inherit one abnormal sickle cell gene and one normal gene are carriers described as having *sickle cell trait*. These children will not have the signs of sickle cell disease seen in those who inherit two abnormal copies of the sickle cell gene but some people with sickle cell trait have experienced adverse responses to intense exercise and extreme dehydration. This has led to important discussions regarding the need for athletes to understand any genetic risk for participation in sports including their sickle cell carrier status. Current NBS methods allow Michigan to detect nearly all newborns with sickle cell disease and sickle cell trait.



In order to find newborns with cystic fibrosis (CF), Michigan's current NBS methods also identify some newborns who may simply be *carriers*. Newborns who inherit only one abnormal CF gene and one normal gene are carriers while those who inherit two abnormal genes have CF. To distinguish between being a carrier and having the disease CF, follow-up is done with a sweat chloride test and possibly more genetic testing. Current NBS methods allow Michigan to detect nearly all newborns with CF but only about 7% of Caucasian CF carriers. While the purpose of NBS is to find newborns with disease, parents should also understand their child could be identified as a carrier for certain disorders.



Important Reminders!

NEW Card Ordering System UPDATE!

The anticipated go-live date for the web-based application to purchase newborn screening cards or order educational materials has been pushed back and is tentatively scheduled for later this fall. The system will require payment (either by e-check or credit card) prior to the shipment of any newborn screening cards. Hospital purchasing departments will be notified of the new procedure.

The webpage for ordering cards and materials 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 urquhart1@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