MICHIGAN
Newborn
Screening

Michigan Department of Health and Human Services

Newborn Screening News

Spring 2017

The Michigan Department of Health and Human Services (MDHHS) Newborn Screening Follow-up Program works together with the State Newborn Screening Laboratory and coordinating centers to find and treat infants who need early medical care.

Timeliness Success for Metabolic Disorders

The goal of newborn screening is to identify infants at risk of having a disorder as quickly as possible, so that treatment can be initiated before symptoms begin and damage occurs. Many people and systems are involved to ensure that no delays occur throughout the NBS process. From hospital staff involved in filling out the NBS cards, collecting the specimens, and preparing the specimens for shipping to the courier service that is responsible for specimens arriving in the state lab the next business day, to the lab staff that processes and analyzes hundreds of NBS specimens per day to the follow-up staff that reports out results to providers to the follow-up coordinating centers and specialists who arrange for confirmatory testing and treatment initiation, it truly takes a village to keep the NBS Program running smoothly.

We wanted to highlight a success that shows the dedication of each and every person involved in NBS. In 2015, a total of 36 infants were diagnosed with classic galactosemia, profound biotinidase deficiency, amino acid disorders, organic acid disorders, or fatty acid oxidation disorders. **Every single one of those 36 infants had treatment initiated within the first six days of life!** This is a true success for the NBS system. Hospital staff were diligent in ensuring the screens were drawn and sent out in a timely manner. NBS lab and follow-up program staff tested the specimens and reported out the results to providers as soon as possible. The Children's Hospital of Michigan Metabolic Clinic staff worked with providers and families to initiate treatment before the infants reached one week of age. Every segment of the NBS process worked together to achieve the best possible outcomes for these affected newborns.

Thank you for all you do to ensure the NBS Program is a success for Michigan's newborns!

Annual Report 2015

Every year, the Newborn Screening (NBS) Program releases an annual report that provides detailed information about the previous birth year. These reports are available on the NBS Program website (www.michigan.gov/newbornscreening) and contain information on updates that occurred during that birth year, the number of babies screened overall, the number of babies identified with disorders on the NBS panel, performance metrics for each disorder including detection rate, false positive rate, and positive predictive value, and quality assurance information including the performance measures on the quarterly quality assurance reports and time to treatment by disorder.

In 2015, a total of 111,725 infants were screened in Michigan and 270 were diagnosed with one of the disorders on the NBS panel. Overall, one infant out of 414 screened confirmed with a disorder. Since the NBS Program began in 1965, almost 6,000 Michigan newborns have been identified with disorders through bloodspot screening. Congenital hypothyroidism and sickle cell disease are the most commonly identified disorders, affecting 94 and 64 infants born in 2015, respectively. In addition to disorders included on the panel, over 3,000 carriers were detected in 2015, with the majority being carriers for either sickle cell disease (2,717) or cystic fibrosis (296).

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MDHHS
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Improving Michigan’s CCHD Screening Data

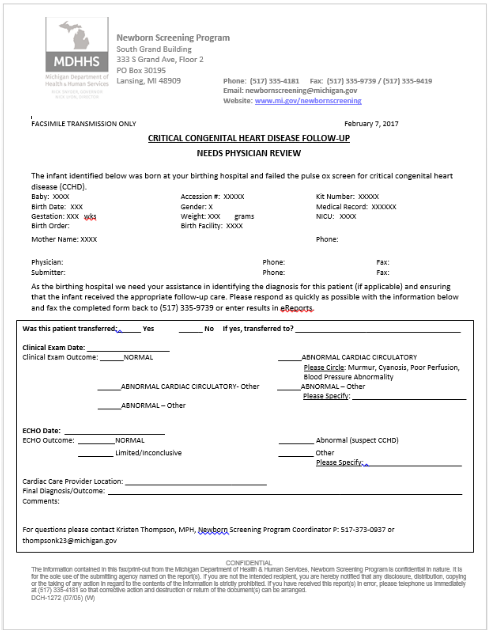
Over the past few months, newborn screening staff at The Michigan Department of Health and Human Services (MDHHS) have been working to improve hospital reporting of Critical Congenital Heart Disease (CCHD) screens. As a reminder, all CCHD screens should be reported to the state within 10 days of birth. While we believe most newborns are screened for CCHD during their hospital stay, less than 75% of non-NICU CCHD screens for newborns born in October 2016 were reported to the state by the end of November 2016. In order to improve reporting, our Newborn Screening Coordinator has started emailing hospitals with reporting levels under 75% to offer guidance.

We have received an overwhelming response from hospitals, many of which did not know that some of their CCHD screens were not being reported. We have also begun faxing birth hospitals a list of newborns for whom we have no CCHD screening information available along with a list of newborns who were noted as having missed their CCHD screen each month. If you receive one of these faxes, **please submit the unreported CCHD screening information in the same way that your hospital usually submits CCHD data to the state**.

As a result of these activities, we now have over 82% of CCHD screens for non-NICU babies born in October 2016 reported and over 85% of CCHD screens reported for non-NICU babies born in November 2016. Our intent is to improve CCHD reporting so that we can make sure all newborns receive appropriate follow up care after screening. We believe improving reporting will assist us in evaluating the current screening algorithm.

We also began a more thorough process for follow up of failed CCHD screens. If your hospital has a newborn who fails their CCHD screen, Kristen Thompson, our Newborn Screening Coordinator will be reaching out to you to determine the infant’s diagnosis. Follow-up will be done using a form that is faxed to the hospital, we ask that you fax the completed form back to (517) 335-9739 or enter results in eReports. Determining the infant’s diagnosis helps us to assess our CCHD screening false positive rate.

As another part of our evaluation efforts, we are linking CCHD records to Michigan Birth Defect Registry data to determine the CCHD screening results of infants who were diagnosed with a CCHD. With so many screens unreported, it is difficult to evaluate the effectiveness of the CCHD screening program. With your help, we hope to continue to improve reporting so that we can better evaluate and improve the program.



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CRITICAL CONGENITAL HEART DISEASE FOLLOW-UP

NEEDS PHYSICIAN REVIEW

The infant identified below was born at your birthing hospital and failed the pulse ox screen for critical congenital heart disease (CCHD).

Baby: XXXX
Accession #: XXXXX
Kit Number: XXXXX
Birth Date: XXX
Gender: X
Medical Record: XXXXXX
Gestation: XXX wks
Weight: XXX grams
NICU: XXXX
Birth Order:
Birth Facility: XXXX
Mother Name: XXXX
Phone:

Physician: Phone: Fax:
Submitter: Phone: Fax:

As the birthing hospital we need your assistance in identifying the diagnosis for this patient (if applicable) and ensuring that the infant received the appropriate follow-up care. Please respond as quickly as possible with the information below and fax the completed form back to (517) 335-9739 or enter results in eReports.

Was this patient transferred: ______ **Yes** ______ **No** **If yes, transferred to?** ______

Clinical Exam Date: ______
Clinical Exam Outcome: ______NORMAL
______ABNORMAL CARDIAC CIRCULATORY
Please Circle: Murmur, Cyanosis, Poor Perfusion, Blood Pressure Abnormality
______ABNORMAL CARDIAC CIRCULATORY- Other
______ABNORMAL – Other
Please Specify: ______
______ABNORMAL – Other

ECHO Date: ______
ECHO Outcome: ______NORMAL
______ Abnormal (suspect CCHD)
______ Limited/Inconclusive
______ Other
Please Specify: ______

Cardiac Care Provider Location: ______
Final Diagnosis/Outcome: ______
Comments:

For questions please contact Kristen Thompson, MPH, Newborn Screening Program Coordinator P: 517-373-0937 or thompsonk23@michigan.gov

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DCH-1272 (07/05) (W)

Thank you for all your CCHD screening and reporting efforts. If you have questions about your hospital’s CCHD reporting rates, or would like help improving them, please contact Kristen Thompson at ThompsonK23@michigan.gov.

HL7 Reporting: NBS Bloodspot Orders, Results & CCHD Reporting

A Health Level Seven (HL7) national standard has been developed for NBS bloodspot orders, receiving NBS results and critical congenital heart disease (CCHD) pulse oximetry results. This technology allows for electronic submission of NBS demographic data and bloodspot test orders that are currently handwritten on the card, as well as returning NBS results to your hospital electronically. Submitting electronic HL7 messages for CCHD pulse oximetry results not only can improve the timeliness, quality and consistency of reporting but it can also make a hospital eligible for meaningful use credit from the Centers for Medicare and Medicaid Services.

If you are interested in more information about HL7 reporting of NBS bloodspot orders, receiving NBS results or submitting CCHD pulse oximetry results, please contact Kristy Tomasko at tomaskok@michigan.gov or visit https://michiganhealthit.org/public-health/newborn-screening/ for detailed information on how to implement HL7 messaging at your hospital.

NBS Quarterly Reports and Stellar Performance

During the forth quarter of 2016, seven hospitals met all six of the NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- **Allegiance Health**
- **Beaumont Hospital—Troy**
- **Charlevoix Hospital**
- **Holland Hospital**
- **Huron Medical Center**
- **McLaren Central Michigan**
- **Spectrum Health United Hospital**

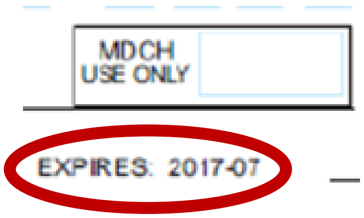
Performance Goals for NBS Quarterly Reports

1. <2% of screens are collected >36 hours after birth
2. >90% of screens arrive in the state laboratory 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 517-335-4181.

Spotlight on Unsatisfactory Specimens - Expired Cards

Please check your inventory for first and repeat sample cards that are due to expire on July 31, 2017 and use those cards first. The expiration date on these cards is not highlighted. Most of the cards you have been using lately do not expire until January 31, 2019. Those cards have an expiration date highlighted in blue (first sample) or pink (repeat sample). The expiration date is located in the lower right-hand corner of the NBS card. Cards may be used through the last day of the month in which they expire. Samples collected after the expiration date will be found unsatisfactory and a repeat screen will be requested.



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

Submitter Code: Please remember that staff members need to record the correct hospital submitter code on the newborn screening card. The last digit indicates the type of nursery: 0 means regular nursery, 1 means NICU, and 2 means SCN. The submitter code is used to make separate quarterly reports for each unit, so it's important that we can correctly identify which unit submitted each specimen.

Phone Number: Please remember only one phone number per provider should be listed on the newborn screening card. Many requestors are using cell phone numbers or multiple different phone numbers for lines in provider offices and the laboratory is receiving new entries every day. Please have hospital staff clean up these lists and include one phone number per provider. Only include on the newborn screening card the doctor who is in charge of the baby's care when the baby leaves the hospital.

Birth Weight: Please remember to record birth weight in **grams** on the first sample newborn screening card. Enter the current weight in grams on the repeat sample card.

TECHNICAL ASSISTANCE

Lois Turbett, NBS nurse consultant, 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. Kristen Thompson, NBS Coordinator is also available to work with hospitals on CCHD pulse oximetry screening and reporting, and can be reached at thompsonk23@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