Summer 2021

Michigan Department of Health and Human Services

Newborn Screening News

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.

NBS Quarterly Reports and Stellar Performance

During the first quarter of 2021, six hospitals met all six of the NBS blood spot screening performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Beaumont Hospital - Troy - NICU
- McLaren Port Huron - SCN
- Mercy Health Saint Mary's - NICU
- Munson Healthcare Cadillac
- Munson Healthcare Charlevoix
- Spectrum Health Lakeland Medical Center-St Joseph

Performance Goals for NBS Blood Spot Quarterly Reports

1. Less than 2% of screens are collected >36 hours after birth.
2. Greater than 90% of screens arrive in the state laboratory by the appropriate day.
3. Less than 1% of screens are unsatisfactory.
4. Greater than 95% of electronic birth certificates have the NBS card number recorded.
5. Greater than 90% of specimens have a returned BioTrust for Health consent form that is completed appropriately.
6. Greater than 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.

In this newsletter:

During the first quarter of 2021, 42 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. Five hospitals with the highest percent of CCHD results reported to the Newborn Screening Program on time are listed below. Congratulations to the following hospitals on their impressive efforts:

- Promedica Monroe Regional Hospital
- Mid-Michigan Medical Center – Midland
- UP Health System – Bell
- Henry Ford Wyandotte Hospital
- Ascension Providence Hospital – Southfield Campus

Performance Goals for CCHD Quarterly Reports

1. At least 90% of newborns with a blood spot screen have pulse oximetry screen results reported.
2. **At least 90% newborns with a blood spot screen have pulse oximetry screen results reported to the state less than 10 days after screen date.**
3. At least 90% of newborns with a bloodspot screen have pulse oximetry screen completed between 20 and 28 hours after birth.

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

Staff Highlights: New Newborn Screening Nurse Consultant and Quality Assurance Specialist

After serving as the nurse consultant with the Newborn Screening Program for the last 10 years, Lois Turbett has retired. We wish her all the best in retirement and thank her for her years of service!

We are delighted to introduce our new nurse consultant, Angie Aldrich. Angie has a nursing degree from the University of Michigan and a Master of Science in Nursing degree from Spring Arbor University. Angie spent 10 years at the Jackson County Health Department, first as a home visiting nurse in the Maternal Infant Health Program and later as the Director of Personal and Preventative Health. Angie has been the Quality Assurance Specialist for the NBS Program since spring 2020, so many of you are already know Angie. Angie's email is AldrichA1@Michigan.gov and her phone number is 517-335-1966. Welcome to this new role, Angie!

Becky Shaulis will be the new quality assurance specialist. Becky has a Bachelor of Science degree in biotechnology from Ferris State University and a Master of Science degree in molecular, cellular, and developmental biology from the University of Michigan. Becky has been the lead molecular scientist in the NBS lab since 2017. Becky is a fantastic addition to our team and looks forward to working with hospital staff involved in the newborn screening process. Becky's email is ShaulisR@Michigan.gov and her phone number is 517-335-8532. Welcome, Becky!

Congenital Adrenal Hyperplasia Cutoff Changes: Coming Summer 2021

For congenital adrenal hyperplasia (CAH) screening, Michigan's NBS Program uses 17-hydroxyprogesterone (17-OHP) cutoffs based on age at time of collection and birth weight for congenital hyperplasia (CAH) screening. Currently, three reference ranges are used: one for normal birth weight (≥2500 grams) and age at collection >12 hours; one for normal birth weight and age ≤12 hours; and one for low birth weight (<2500 grams). Following a false negative CAH case involving a mildly low birth weight infant, staff from the NBS Program evaluated the CAH screening algorithm to determine if changes were needed to improve performance metrics, particularly increasing sensitivity.

CAH screening data, including 17-OHP value, age at time of collection, birth weight, screening determination, and final diagnostic outcome, for Michigan births from 2010-2020 was analyzed. The results of the analyses were reviewed with Michigan's Pediatric Endocrine Advisory Council for input and guidance.

The screening algorithm that best balanced identifying newborns with CAH while minimizing false positives includes seven reference ranges based on time of collection and birth weight. This new screening algorithm will be implemented in summer 2021. The revised screening algorithm is anticipated to result in a similar number of positive screens per year compared to the current screening algorithm but shifts the majority of positive newborns from infants <1500 grams to infants >2500 grams. Due to this shift, NICUs will likely see a decrease in false positive screens for CAH among low birth weight newborns. The NBS Program will inform primary care providers of the algorithm change as well.

Reminder: Accurate Completion of the NBS Card Matters

The NBS Program relies on the accuracy of the demographic data provided on the NBS card. Some screening algorithms have different cutoffs based on age at time of specimen collection or birth weight, so the information provided can affect the screening outcome. Accurate and legible recording of the birth date, birth time, specimen collection date, specimen collection time, and birth weight is critical for making sure the correct screening outcome is selected!

Congenital Hypothyroidism:
Importance of Re-screening Same Sex Twins

Intellectual disability due to unrecognized and untreated primary congenital hypothyroidism (CH) can be prevented by detecting elevated thyroid stimulating hormone (TSH) values on the newborn screen (NBS) and starting treatment with levothyroxine within the first two weeks of life.

In monozygotic twins, there is a risk of missing a diagnosis of CH in one of the twins based on initial NBS as there is fetal blood mixing in multiple births[1]. The American Academy of Pediatrics[2] and European Society for Pediatric Endocrinology[3] both recommend a second screen for all monozygotic twins at two weeks of life so as reduce risk of missed diagnosis of CH. In Michigan, a recent analysis of NBS data since 2017 showed that approximately 35% of same sex twins received a second screen.

Michigan's Pediatric Endocrine Advisory Council strongly recommends a serum TSH or second newborn screen for all same sex twins at two weeks of life so as reduce risk of missed diagnosis of CH. Michigan's NBS Program staff will be working with birth hospitals and primary care providers to explain the importance of this recommendation and implement measures to increase the percent of same sex twins with serum TSH or second newborn screen.

References:

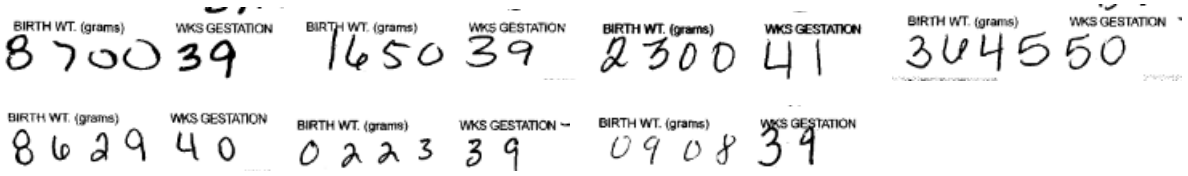
1. Rebecca Perry *et. al.*, Discordance of monozygotic twins for thyroid dysgenesis: implications for screening and for molecular pathophysiology. J Clin Endocrinol Metab. 2002;87(9):4072-7.
2. Update of Newborn Screening and Therapy for Congenital Hypothyroidism. American Academy of Pediatrics, Susan R. Rose, *et. al.,* and the Section on Endocrinology and Committee on Genetics, American Thyroid Association, Rosalind S. Brown, *et. al*., and the Public Health Committee and Lawson Wilkins Pediatric Endocrine Society. Pediatrics. 2006;117(6):2290-2303.
3. Juliane Léger *et. al.*, Clinical Practice Guideline. European Society for Paediatric Endocrinology Consensus Guidelines on Screening, Diagnosis, and Management of Congenital Hypothyroidism. J Clin Endocrinol Metab. 2014; 99(2):363–384.

Innovations in Newborn Screening Interoperability (INBSI) Resource Center and Learning Collaborative

The Michigan Newborn Screening (NBS) Program has been accepted to participate in the Innovations in Newborn Screening Interoperability (INBSI) Resource Center and Learning Collaborative which began April 2021. The Health Resources and Services Administration and Altarum have worked together to develop this collaborative, to enhance interoperability between state newborn screening programs and health care providers to improve processes for screening and reporting results in a timely manner. The Michigan NBS Program will receive personalized readiness assessments and implementation roadmaps for dried bloodspot, CCHD and EHDI screening to help expand electronic data exchange of NBS data with health care providers. The INBSI collaborative will provide the NBS Program with an opportunity to reprioritize steps needed for implementing HL7 messaging at more hospitals in Michigan for NBS. If your hospital is interested in implementing HL7 messaging for CCHD, blood spot orders or receiving results, please email Kristy Karasinski, NBS Follow-up Consultant, at KarasinskiK@Michigan.gov.

Common Card Errors – Implausible birth weight and gestational age

The last performance metric on the quarterly *Newborn Screening Quality Assurance Notification* is: *Less than one percent of specimens have errors in the demographic data (i.e. dates, times, birth weights, etc.).* The following common card errors occurred when staff entered a birth weight that is unlikely based on the gestational age entered or the gestational age is not plausible.



Points to remember:

1. Make sure all the fields on the card are complete.
2. Check for errors and make necessary corrections before packaging the card for courier pickup.
3. Enter the birth weight (first sample) or current weight (repeat sample) in grams.
4. Write the gestational age on first sample cards.
5. Does the birth weight align with the gestational age?
6. Is the gestational age plausible?

Card errors can result in:

1. Infant distress caused by an entry error that led to an unnecessary repeat specimen.
2. Additional work for NBS laboratory and follow-up staff.
3. Inaccurate test interpretation due to age-dependent analyte cutoffs.

Upcoming Holiday Schedule

Lower Peninsula Hospitals:

- Monday, September 6, 2021 – holiday/Sunday schedule

Upper Peninsula Hospitals:

- Monday, September 6, 2021 – no UPS pickup

TECHNICAL ASSISTANCE

Angela Aldrich, NBS nurse consultant, is available to work with staff in any hospital that requests help with specimen collection. She can be reached by email at AldrichA1@Michigan.gov to answer your questions. Kristen Thompson, NBS Coordinator, is 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 Michigan.gov/NewbornScreening.