

Spring 2022



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

- Bronson Methodist Hospital
- Henry Ford Allegiance Health

#### **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:**

- ✓ Spring NBS Conference Registration
- ✓ Missing Blood Spot Specimens
- ✓ Adoption and the NBS Card
- ✓ Adoption and HBsAg Results
- ✓ MDHHS Baby Fair
- ✓ BioTrust FAQ Resources
- ✓ CCHD Follow-up Emails
- ✓ GAMT Deficiency Screening
- ✓ MPS II Recommendation

During the fourth quarter of 2021, 20 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. Ten hospitals had 100% of CCHD results reported for newborns with a blood spot screen.

Congratulations to the following hospitals on their impressive efforts:

- UP Health System - Bell
- Ascension Borgess - SCN
- ProMedica Coldwater Regional
- McLaren Lapeer Region
- Munson Healthcare Otsego Memorial
- UP Health System - Portage
- OSF St. Francis
- Ascension St. Joseph
- Three Rivers Health
- My Michigan Medical Center – West Branch

#### **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 blood spot 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](mailto:NewbornScreening@Michigan.gov)



**Save the Date:**  
2022 Virtual MDHHS  
Newborn Screening Conferences

**May 4, 2022**  
**May 17, 2022**

~9:00 am - 3:30 pm

Nursing contact hours are available!

To register, please go to:

<https://www.surveymonkey.com/r/NBSconference2022>

Topics include:

- Endocrine Disorders Highlight
- Improving Newborn Screening Specimen Quality
- Newborn Screening Card – Accuracy is Critical



**Register here:**

<https://www.surveymonkey.com/r/NBSconference2022>

### Missing Blood Spot Specimens

Every year, approximately 40-50 hospital births have a missed newborn blood spot screen, which delays potential identification of life-threatening disorders. Each week the NBS Program staff link electronic birth certificate (EBC) records to newborn screening specimens received. This process enables quick identification of infants with a Michigan birth certificate, but no record of a blood spot screen. Hospitals are alerted of these potentially missed newborn screens.



After the linkage, a manual review occurs for all infants not listed as deceased who show as having no blood spot on file. This includes a search of the NBS database and review of faxes received from hospitals documenting why a screen was not collected. If explanatory records are not found, NBS Program staff send a “No Record of Blood Spot Screen” fax to the designated NBS coordinator at the birth facility. A request is made for additional information regarding the reason for the missing blood spot, such as if the infant died before a screen was collected, infant was transferred out of state, name change due to adoption, etc. If the screen was truly missed, the NBS Program requests that the birth facility contact the family to return to have a screen collected as soon as possible.

Due to the critical importance of identifying affected infants and initiating treatment as quickly as possible, the NBS Program implemented the following process to ensure timely response. If acknowledgment that the screen was missed and/or a reason for no blood spot collection is received, the further actions in the timeline will end.

- Day One: Initial fax sent to birth facility’s NBS Coordinator.
- Day Two: NBS staff calls to ensure the fax has been received.
- Day Three: Second attempt fax is sent to NBS Coordinator.
- Day Five: MDHHS NBS nurse consultant calls NBS Coordinator to review case and gather information.
- Day Seven: Letters will be sent to the parents letting them know that the NBS Program has not received a screen for their infant and to the risk management area at the birth facility.

**It is ultimately the responsibility of the birth facility to ensure that all infants receive a newborn screen.**

Prevention of missed screenings is critical. Using a NBS specimen log is one method to track that collection takes place. Proactively informing the MDHHS NBS Program of reasons for not collecting a NBS can be completed utilizing the “Hospital Discharge Sheet”, which can be found at [Michigan.gov/NewbornScreening](https://Michigan.gov/NewbornScreening) under the *Resources for Hospitals and Health Professionals* section. If a parent will not permit collection, please fax the signed copy of your institution’s refusal form to the MDHHS NBS Follow-up Program at 517-335-9419 or 517-335-9739. Additional information about missing blood spots can be found in the updated Michigan Newborn Screening Guide for Hospitals.

## **Adoption and the NBS Card**

Accuracy and completeness of the contact information on the newborn screening card is critical for follow-up of abnormal results. The specimen submitter (hospital, outpatient lab, midwife) is legally responsible for the information placed in each section of the card. Confusion can occur when completing the card in the cases of closed adoption or surrendered infants. Birth parent information should NOT be placed on the NBS card for these situations. This ensures that identifiable information will not be inadvertently released in future requests for NBS results.



### **Key points to remember in cases of closed adoption or surrendered infant:**

#### **Baby section:**

- List the infant's name as "Baby Doe" or the hospital generated name that is used in the hospital's medical record. If your hospital generates a name for the infant, placing this on the card will help identify the infant if we need to contact your team with a question or to report an abnormal screen.
- If the date of birth is unknown, use the surrender date and time.

#### **Mother section:**

- Mark the appropriate circle for the information provided. This may be adoptive parent, foster parent, or adoption agency.
- Name and contact information should reflect who will be caring for the infant upon release. If the adoption or foster parent information is not available, please place the name and contact information for the adoption agency.
- Mother's medical record, birth date, and Hepatitis B Surface Antigen results can be left blank for these cases.

#### **Notes section:**

- Additional information should be placed in the notes section, as needed. For example, noting that this is a closed adoption or safe surrender will ensure that this is clearly recorded in our system.

#### **BioTrust Consent:**

- Only the parent or legal guardian can sign the consent form. The birth mother could sign the consent form while she remains the legal guardian. However, the future adoptive parent may wish to select a different option.
- An option is to return the NBS specimen without the BioTrust consent form. Then send the form and brochure home with the family and/or adoption agency caring for the infant. Once legal guardianship is established, that person can make the BioTrust decision and return the form to MDHHS.

#### **Changes After Card Submitted:**

- If the NBS card has already been sent to MDHHS with birth mother's information and then the decision is made to place the infant into closed adoption or safe surrender, please notify us immediately and request that the birth mother's information is removed from our system.
- You can fax this information using the "Hospital Discharge Sheet" found in the Michigan NBS Guide for Hospitals (Appendix 7) or call the NBS Follow-up Program at 517-335-4181.

If you have further questions about these cases, please contact Angie Aldrich, NBS Nurse Consultant, at 517-335-1966.

## Adoption and the Hepatitis B Surface Antigen Field

Documentation of Hepatitis B Surface Antigen (HBsAg) results on the “Mother Section” of the newborn screening card is necessary to ensure that every infant born to a woman who is HBsAg-positive receives prompt treatment. Confusion may occur when filling out the NBS card for an infant placed into adoption.

The Newborn Screening Guide for Hospitals has been updated to clarify how to document a birth mother’s hepatitis B surface antigen (HBsAg) screening test date and result under the Mother’s Name section for cases where this section is being completed for an adoptive parent, foster parent, or adoption agency. Under the **Hepatitis B Surface Antigen (HBsAg)** section - The birth mother’s HBsAg results would not be documented under this section. **However, if the birth mother’s HBsAg result is positive, please contact the Perinatal Hepatitis B Prevention Program at 517-242-8319.**

Under **Mother’s Name** section - we have updated the guide with an (\*) after the sentence “Please provide the contact information for the adoptive parent, foster parent, or adoption agency in place of the mother’s information.\* (Refer to the HBsAg section on how to document the birth mother’s HBsAg test date and result).

## MDHHS Baby Fair

The NBS Program is excited to share an opportunity for new and expecting parents across the state of Michigan! In partnership with 14 other Michigan Department of Health and Human Services (MDHHS) programs, the NBS Program hosts a virtual baby fair twice a year. Our next round of baby fairs will be held June 14 from 6:30 p.m. to 8:30 p.m., June 15 from 9 a.m. to 11 a.m., and June 22 from 9:00 a.m. to 11:00 a.m. Please pass this save the date along to anyone you feel may be interested in participating or distributing the flyer.

The MDHHS virtual baby fair is FREE. Parents can learn how to be better prepared for their best adventure yet! They will have an opportunity to learn about available resources, important health and safety information and ask questions to MDHHS staff.

MDHHS is excited to be able to offer a safe and convenient way for parents to get the important information they need! If you have any questions, or would like a shareable version of the flyer, please email [ThompsonK23@Michigan.gov](mailto:ThompsonK23@Michigan.gov).

### REGISTER NOW!

Michigan Department of Health and Human Services  
Virtual Baby Fair

Are you a new or expecting parent? Join us for a virtual baby fair to learn how to be better prepared for your best adventure yet! Learn about resources available to you, important information, and ask questions to experts.

Tuesday, June 14, 2022 from 6:30-8:30 p.m.  
Wednesday, June 15, 2022 from 9:00-11:00 a.m.  
Tuesday, June 28, 2022 from 9:00-11:00 a.m.

Registration:  
<https://mdhhsvirtualbabyfairsummer2022.eventbrite.com>

#### Participating MDHHS Programs:

- Newborn Screening
- BioTrust for Health
- Infant Safe Sleep
- Childhood Lead Poisoning Prevention Program
- Women, Infants, & Children (WIC)
- Vital Records
- Unintentional Injury Prevention
- Immunizations
- Early Hearing Detection and Intervention
- Maternal Infant Health Program
- Michigan Home Visiting Initiative
- Birth Defects Education and Outreach
- Breastfeeding Support
- Children’s Special Healthcare Services
- Eat Safe Fish



**MDHHS** Scan here to register!

For more information please contact Kristen Thompson  
[ThompsonK23@Michigan.gov](mailto:ThompsonK23@Michigan.gov)  
517-284-4992





## FAQ Documents Available Online for the Newborn Screening and BioTrust Programs

Throughout the newborn screening and BioTrust consent processes, families may have questions for staff about what types of screening are done and what their choices for blood spots are after testing is complete. MDHHS is committed to ensuring that parents can access answers to their questions and maintains an online Frequently Asked Questions (FAQs) document that parents can be directed to while at the hospital. These questions are an excellent resource for staff to share with families when questions go beyond the scope of provider knowledge. MDHHS also encourages staff to be familiar with the answers to these questions to aid in the parental education of these programs.

Below is a direct link to a document containing frequently asked questions for both Newborn Screening and BioTrust program activities. Additional FAQs for the BioTrust can be found on the BioTrust webpage under the “Frequently Asked Questions” tab. The homepage can be found at [www.Michigan.gov/BioTrust](http://www.Michigan.gov/BioTrust).

If families have questions that cannot be answered by staff or the FAQ documents, families can contact the newborn screening and BioTrust programs directly by phone at 1-866-673-9939 or send email to [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov)

## Critical Congenital Heart Disease (CCHD) Follow-up:

### Monthly notification of no information and missed screens are now being emailed!

On a monthly basis, the NBS Program notifies hospitals of newborns without pulse oximetry results or reported as having a missed pulse oximetry screen for CCHD. In the past, the NBS Program sent these notifications via fax. Beginning October 2021, notifications are now sent via email to the nurse coordinator and any known IT contacts. If you are not receiving these emails or would like to add pertinent staff to the contact list, please contact Kristen Thompson at [ThompsonK23@Michigan.gov](mailto:ThompsonK23@Michigan.gov).



### What does a “no information” screening notification mean?

If you receive an email titled “no information” for CCHD screening, this serves as your hospital’s notification that the NBS Program has not received pulse oximetry screening information on the newborns listed. The program is asking that you submit this screening data using your normal reporting method. Please **do not reply back** to the email with the CCHD screening results. If you are unsure of how your hospital reports this data to the NBS Program, you will need to contact your hospital’s IT department. You can also report pulse oximetry results using the online reporting module, eReports. If you are interested in getting registered for eReports, contact Kristen Thompson at [ThompsonK23@Michigan.gov](mailto:ThompsonK23@Michigan.gov).

### What does a “missed” screening notification mean?

If you receive an email titled “missed” for CCHD screening, this is a list of newborns your hospital reported as having a missed pulse oximetry screen for CCHD. Please confirm if the CCHD screen was truly missed. If it was, proceed using your hospital’s internal policies. The NBS Program recommends notifying the child’s PCP that the pulse oximetry screen was not completed. If the CCHD screen for that child was completed, please report the screening results using one of the methods listed above.

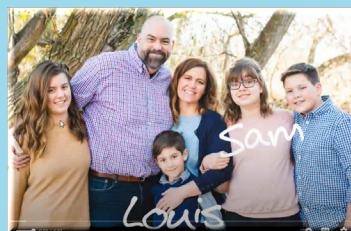
*Please note, newborns without pulse oximetry screen results impact your hospital’s performance on the CCHD quarterly quality assurance report, so please report results after notification.*

## Guanidinoacetate methyl transferase (GAMT) deficiency

GAMT deficiency is an inborn error of metabolism that affects creatine synthesis. When the guanidinoacetate methyltransferase enzyme is damaged, creatine cannot be synthesized and guanidinoacetate (GAA) accumulates. This creates a shortage of creatine in the body and excessive amounts of GAA, which is a neurotoxin. Creatine is an essential metabolite for the brain, heart and muscle. When the body does not get enough creatine and has extra GAA, it can cause developmental delay, speech problems, seizures and behavior issues such as autism and hyperactivity. Lack of early treatment can lead to lifelong cognitive impairments which may be severe. Treatment for GAMT deficiency consists of correcting the creatine deficiency and reducing GAA levels in the body and brain through dietary and medical interventions. Treatment is most effective if started early in life before symptoms arise.

Michigan plans to screen all newborns for GAMT deficiency in the second half of 2022 and will be the third state in the United States to screen for GAMT deficiency. GAMT deficiency screening will be completed using the dried filter paper blood spots collected as part of the current newborn screening process. Michigan's Newborn Screening Laboratory will use a tandem mass spectrometry method to measure the analytes guanidinoacetate and creatine to screen for GAMT deficiency.

**GAMT Deficiency Story: The Power of Newborn Screening.** See the dramatic difference newborn screening can have for children with GAMT Deficiency.



This video features a Utah family's story of two children with living with GAMT deficiency.

Watch the video here! <https://youtu.be/sw0zRq6kZ0>

## Mucopolysaccharidosis Type II Recommended for the RUSP

On February 10, the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) voted to recommend the addition of mucopolysaccharidosis type II (MPS II) to the Recommended Uniform Screening Panel (RUSP). The recommendation will now be forwarded to the US Department of Health and Human Services Secretary for final approval.

MPS II, or Hunter syndrome, is an X-linked lysosomal storage disorder affecting approximately 1/100,000 to 1/170,000 male births. It is caused by a deficiency of the lysosomal enzyme iduronate-2-sulfatase, responsible for breaking down large sugar molecules called glycosaminoglycans (GAGs). The accumulation of GAGs in the cells leads to progressive organ dysfunction, skeletal deformities, cognitive impairment, neurodegenerative disease in many, and shortened life expectancy. Although there is no cure for MPS II, enzyme replacement therapy (idursulfase) is effective in improving somatic symptoms and prolonging survival. Early identification and treatment give boys with MPS II the best chance at improved outcomes.

Newborn screening for MPS II is performed by measuring iduronate-2-sulfatase activity in dried blood spots. Screening has already been successfully implemented in Illinois and Missouri, with other states expected to follow once the condition is officially added to the RUSP. The Michigan Newborn Screening Program will be initiating next steps with its advisory committees to consider the addition of MPS II to Michigan's panel. Michigan currently screens for two other lysosomal storage disorders, Pompe disease and mucopolysaccharidosis type I, which were added in 2017.



## Provider Education Opportunities

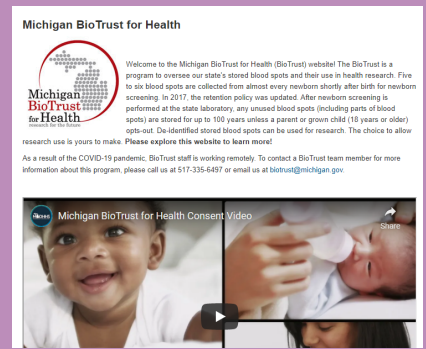
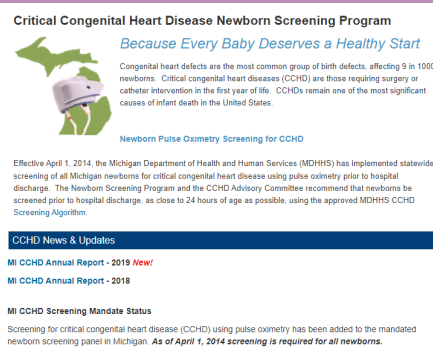
Provider events allow us to educate healthcare professionals involved with the NBS process. NBS staff are available to present at Grand Rounds or other educational sessions. If you know of any opportunities for the NBS Program to speak to healthcare professionals involved with the screen, please email [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov), and we would be happy to participate!

**For more program information, please visit the following MDHHS websites:**

[Michigan.gov/newbornscreening](http://Michigan.gov/newbornscreening)

[Michigan.gov/CCHD](http://Michigan.gov/CCHD)

[Michigan.gov/biotrust](http://Michigan.gov/biotrust)



## Upcoming Holiday Schedule

### Lower Peninsula Hospitals:

- Monday, May 30 – Holiday/Sunday schedule
- Monday, June 20 – Holiday/Sunday schedule
- Monday, July 4 – Holiday/Sunday schedule

### Upper Peninsula Hospitals:

- Monday, May 30 – UPS will be closed for Memorial Day
- Monday, June 20 – UPS will not be affected by Juneteenth
- Monday, July 4 – UPS will be closed for the 4<sup>th</sup> of July



## 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](mailto:AldrichA1@Michigan.gov). 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](mailto: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](mailto:NewbornScreening@Michigan.gov) or visit our website at [Michigan.gov/NewbornScreening](http://Michigan.gov/NewbornScreening).