

Winter 2023



# Michigan Department of Health and Human Services Newborn Screening News

The Michigan Department of Health and Human Services (MDHHS) Newborn Screening (NBS) 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 third quarter of 2022, seven hospitals met all six of the NBS blood spot screening performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Henry Ford Jackson SCN    ➤ McLaren Port Huron SCN    ➤ ProMedica Hickman Hospital    ➤ Spectrum Health Zeeland
- Holland Hospital SCN    ➤ Munson Healthcare Charlevoix    ➤ Spectrum Health Ludington

### **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:**

- ✓ Save the Date NBS Conference
- ✓ Bloodspot Collection Resource
- ✓ CCHD Awareness Week
- ✓ Reluctant Parents: Communication Strategies
- ✓ Courier Flyer
- ✓ CCHD Reporting
- ✓ 2021 Annual Report Summary
  - Bloodspot
  - CCHD
- ✓ BioTrust Brochure Update
- ✓ Birth Defects Materials

During the third quarter of 2022, 31 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. Fifteen hospitals had 100% of CCHD results reported for newborns with a blood spot screen. Congratulations to the following hospitals on their impressive efforts:

- Bronson Battle Creek
- Huron Valley Sinai NICU
- McLaren Bay Region
- MyMichigan Alpena
- Oaklawn Hospital
- OSF St. Francis Hospital
- ProMedica Hickman Hospital
- Sparrow Hospital
- Spectrum Health Gerber Memorial
- Spectrum Health Ludington
- Three Rivers Health
- Trinity Health Muskegon
- Trinity Health St. Mary's
- Trinity Health St. Joseph Mercy Oakland
- UP Health System Bell

### **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% of 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 – Spring 2023 Newborn Screening Conference

The Newborn Screening Program will be hosting two virtual newborn screening conferences for hospital staff this spring. The trainings will cover a variety of topics including:

- Cystic fibrosis.
- Using performance metrics for quality improvement.
- Communication strategies for reluctant parents.
- Data reporting for pulse oximetry screening.
- BioTrust updates.

This free conference is highly recommended for hospital staff involved in NBS, especially NBS Coordinators and Lab Phlebotomy Managers. Nursing contact hours will be available.

**Save the Date:**  
**2023 Virtual MDHHS**  
**Newborn Screening Conferences**



**May 3, 2023**  
**May 31, 2023**  
 9:00 am - 2:30 pm

Registration details coming soon!  
 Nursing contact hours available.




## NBS Bloodspot Collection Guidance




A new quick reference tool is now available to help your team with the NBS bloodspot collection process. This resource includes three main sections: preparation, heel stick, and specimen collection.

Guidance on proper collection technique, specimen drying time, tips to improve blood flow, and comfort strategies are included.

This resource is located on our website at [Michigan.gov/NewbornScreening](https://Michigan.gov/NewbornScreening) under the “Resources for Hospitals and Health Professionals section.” [Click here for a direct link.](#)



### Newborn Screening (NBS) Bloodspot Collection Process

<b>Preparation</b> 	<ul style="list-style-type: none"> <li>• Heel-stick is the preferred method of specimen collection. Prior to collection, complete ALL information on the NBS card and verify identity of the infant.</li> <li>• Pain strategies include: swaddling and providing oral sucrose, non-nutritive suckling or breastfeeding during procedure.</li> <li>• Apply a warm compress to the heel for 3-5 minutes to promote blood flow. Commercial warming devices or a warm, moist towel or diaper can be used. Gentle massage of leg prior to procedure can also be helpful.</li> <li>• Position infant's leg lower than the heart. Gravity helps to increase venous pressure.</li> </ul>
<b>Heel Stick</b> 	<ul style="list-style-type: none"> <li>• Clean site area with alcohol prep and allow area to completely dry. Residual alcohol can interfere with test results and cause pain to infant.</li> <li>• Use sterile retractable 2.00 mm point lancet to make incision on lateral portion of infant's heel. The hatched area in photo shows the safe puncture area.</li> <li>• Wipe away the first large drop of blood to eliminate tissue fluids from interfering with sample quality.</li> <li>• Apply intermittent GENTLE pressure to heel, if needed, to form a large blood drop. Do not squeeze or milk the heel, as this can cause serum separation.</li> </ul>
<b>Specimen Collection</b> 	<ul style="list-style-type: none"> <li>• Gently touch a LARGE single drop of blood to the filter paper. Do not touch the heel to the filter paper. Apply blood to only one side of the filter paper (it does not matter which side is used).</li> <li>• Allow blood to soak through and completely fill circle with a single application of the LARGE blood drop. Check back of filter paper to confirm saturation.</li> <li>• Fill remaining circles. Remember, do not apply multiple drops to the same circle.</li> <li>• Apply appropriate dressing according to your institution's procedures.</li> <li>• Dry specimen for 3-4 hours in a horizontal position at room temperature. Ensure area is free of contaminants. Once dry, cover blood spots with the protective card flap and prepare for shipment to the lab.</li> </ul>

For additional Newborn Screening resources visit [Michigan.gov/NewbornScreening](https://Michigan.gov/NewbornScreening). Tip sheets to avoid unsatisfactory specimens are in the “Resources for Hospitals and Health Professionals” section.

## Reminder: Updated BioTrust Brochures Available on NBSO

MDHHS's Newborn Screening Program made programmatic changes related to storage of blood spots. As of May 16, 2022, MDHHS no longer reserves one blood spot solely for parent or family use (the “parent spot”) following the completion of newborn screening.

Due to this revised policy, changes to the “After Newborn Screening- Your Baby's Blood Spots” brochure were necessary to remove references to the parent spot to accurately reflect MDHHS's retention policies. All families receive this brochure from the hospital as part of the BioTrust consent process. Ensuring that families have access to the most updated information about MDHHS's policies and the BioTrust program when completing the consent process is of the utmost importance to MDHHS.

As such, MDHHS requests that all hospitals immediately update their stock of the “After Newborn Screening- Your Baby's Blood Spots” brochure with the revised version. The revised brochures are available to order free of charge at [Michigan.gov/NBSOrders](https://Michigan.gov/NBSOrders). They are available in English, Spanish and Arabic. Once the revised brochures arrive, any outdated brochures must be discarded and replaced with the revised brochure.

Should you have any questions about the changes to the brochure or the ordering process, [please click here to email the newborn screening program](#) ([NBSOrders@michigan.gov](mailto:NBSOrders@michigan.gov)) or call 517-335-1400.



## Resources for Communicating with Reluctant Parents

Each week, the epidemiologist for the NBS Program completes a linkage between Michigan birth certificates and NBS records. The goal of this linkage is to find infants born in Michigan who may have a missed screen.

Utilizing this linkage, the NBS Program determined that 99.1% of infants born in Michigan in 2021 underwent a blood spot screen in the state. Some of the remaining 0.9% of infants were screened out of state or received palliative care only. However, over 500 Michigan infants born in 2021 (approximately 0.5% of all births) were not screened due to parent not permitting blood spot collection. While the majority of these infants were born in non-hospital settings, 0.2% of parents delivering at a hospital did not permit collection, accounting for approximately 200 babies.

Every year, approximately 300 babies in Michigan are diagnosed with a disorder identified through the newborn blood spot screen. This means that one out of every 340 infants screened in Michigan has a disorder on the NBS panel. With 500 Michigan newborns missing a screen due to parent refusal, there is potential every year for an infant to have a delayed diagnosis of a NBS-identifiable disorder. Although these numbers may seem small, newborns who do not receive an early diagnosis through newborn screening can suffer very serious health consequences—including disability and death.

Newborn screening and early treatment give affected babies the opportunity for the best possible health outcomes. When discussing screening with a reluctant parent, the following resources may be helpful:

- [List of disorders](#) on Michigan's panel – Parents may recognize or have a personal connection with one of the disorders on the list.
- [Directive to Destroy Residual Newborn Screening Blood Specimen form](#) - If parents are primarily objecting to having their child's specimen stored, this form can be filled out to have the remaining blood spots destroyed after screening is completed. Arabic and Spanish translations of the form are available.

If parents have additional questions or concerns, they may email [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov) or call 517-335-4181 to reach the Michigan NBS Program. NBS Program staff are happy to assist!

## Courier Flyer for Hospitals

*Receipt by Appropriate Day* is one of the measures selected by the NBS Program to ensure specimens arrive at the state laboratory by the appropriate day. The goal is that greater than 90% of screens are received by the appropriate day.

Our team has worked with hospitals to develop resources to help meet or exceed these measures. A flyer was created for Michigan hospitals to remind hospital staff of specific courier pick-up and cut-off times.

If you would like a hospital-specific courier flyer created for your staff, [please click here to email Lacey VanLoenen](#) ([NBSOrders@Michigan.gov](mailto:NBSOrders@Michigan.gov)) and request one for your team.

**Hospital Name**

Newborn Screening Specimen Pick-up Information

**Courier Pick-up Times:**

Monday – Friday	Sunday & Holidays
After XXXX	After XXXX

✓ Specimens must air dry for a minimum of three hours in a horizontal position.  
 ✓ Once dry, record the specimen on the log sheet and package for courier, prior to the scheduled pick-up time for the day.

**Monday – Friday**  
 Specimens collected **before** XXXX should be ready for courier pick-up the same day.  
 Specimens collected **after** XXXX should go out the next scheduled courier pick-up day.\*

**Sunday – Holidays**  
 Specimens collected **before** XXXX should be ready for courier pick-up the same day.  
 Specimens collected **after** XXXX should go out the next scheduled courier pick-up day.\*

\*It is okay to send specimen early, if you ensure it is completely dried, logged, and packaged before the courier arrives!

Remember ...

- This is not just a card...these are babies!
- Every time you hold a newborn screening card, you hold a baby's life in your hands!
- Timely transportation of the newborn screening cards could be a matter of life and death!

No courier service on Saturdays, except for an occasional holiday adjustment.  
 Watch the Newborn Screening newsletter and emails for holiday schedule changes.

## **Reporting Pulse Oximetry Results to the Newborn Screening Program**

Hospitals are required to electronically submit CCHD screening data to the Michigan Newborn Screening (NBS) Program within 10 days of the screen being taken.

Michigan has three options for hospitals to utilize to securely report CCHD data electronically to the state:

- eReports.
- File Transfer Service (FTS).
- Health Level 7 (HL7) messaging.

### **eReports**

eReports is an online reporting module hosted through the MiLogin interface for reporting CCHD data to the NBS Program. Results can be entered one record and instantly link with records from blood spot and hearing screening. eReports can also be used in combination with FTS or HL7 messaging to correct errors or report screening information for individual patients as needed.

❑ To register for eReports, [click here to reach Kristen by email](#) (ThompsonK23@Michigan.gov).

### **File Transfer Service (FTS)**

❑ FTS is a semi-automatic transmission process for reporting CCHD screening data to the NBS Program. This method does not require individual patient data entry like eReports does. Using this method, hospitals report regular (usually weekly) files with CCHD screening information for babies born at their hospital. If your hospital has an interest in FTS, [click here to reach Kristen by email](#) (ThompsonK23@Michigan.gov).

### **Health Level 7 (HL7) Messaging**

HL7 messaging is another way the NBS Program can receive CCHD screening results. Several hospitals in Michigan implemented this method of real time reporting CCHD pulse oximetry screening results. HL7 reporting benefits hospitals by reducing staff time on manual reporting options, decreasing reporting errors, and reporting results faster to the NBS Program.

The NBS Program is also working on developing HL7 messaging for the NBS card demographics and result reporting. Hospitals that have implemented HL7 messaging for reporting pulse oximetry screening results will have much of the necessary structure in place to implement these other NBS messages.

If you are interested in more information about HL7 reporting of CCHD pulse oximetry screening data, [click here to reach Kristy Karasinski by email](#) (karasinskik@michigan.gov).



### **Critical Congenital Heart Disease Awareness**

February 7-14 is Congenital Heart Disease Awareness Week!

In 2021, 94,384 Michigan babies were screened for Critical Congenital Heart Disease (CCHD) through pulse oximetry. Three were diagnosed with a CCHD and nine were diagnosed with another hypoxic condition as a result of the failed screen.

Thank you for helping to ensure that every baby born in Michigan has the opportunity to be screened for critical congenital heart disease. Our program is a success because of the hard work of people like you!



### **2021 NBS Annual Report Summary**

Every year, the Newborn Screening (NBS) Program releases an annual report that provides detailed screening information about the previous birth year. These reports are available on the NBS Program website ([www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening)) and contain information on updates that occurred during that birth year, the number of babies screened overall and the number 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 reports and time to treatment by disorder.

In 2021, a total of 102,965 infants were screened in Michigan and 304 (0.3%) were diagnosed with a disease on the blood spot panel. Overall, one infant out of 339 screened was diagnosed with one of the disorders. Since the NBS Program began in 1965, more than 7,700 Michigan newborns have been identified with disorders on the NBS blood spot panel. Congenital hypothyroidism and sickle cell disease are the most commonly identified disorders, affecting 144 and 39 infants born in 2021, respectively. The third most diagnosed disorder is cystic fibrosis, with 24 cases diagnosed in 2021.

### **2021 Critical Congenital Heart Disease (CCHD) Annual Report Summary**

The Michigan Newborn Screening Program is continually working with hospitals to ensure that all babies are receiving the required pulse oximetry screen to ensure that CCHD cases are identified and that interventions are started as quickly as possible for affected infants.

The 2021 CCHD Annual Report includes NBS Program presentations and involvement in external groups, CCHD screening practices and methods, screening results, and quality assurance information. CCHD Annual Reports can be viewed at [Michigan.gov/CCHD](http://Michigan.gov/CCHD).



Some key points from the 2021 report include:

- 95.5% of infants in well-baby nurseries had pulse oximetry screen results reported to the NBS Program.
- A total of 46 infants failed the screen and three CCHD cases were identified through a pulse oximetry screening.
- An additional nine secondary conditions were detected after the infants received a pulse oximetry screen.
- 74.4% of screens were reported on-time, defined as within 10 days of screening.
- 90% of infants received timely screens, defined as taking place between 20 and 28 hours after birth.



## MDHHS Birth Defects Educational Materials

Every 4 ½ minutes a baby is born with a birth defect. We know that not all birth defects can be prevented. But we also know that women can increase their chances of having a healthy baby by managing health conditions and by adopting healthy behaviors before and during pregnancy.



### BIRTH DEFECTS EDUCATION & OUTREACH

MICHIGAN DEPARTMENT OF HEALTH AND HUMAN SERVICES

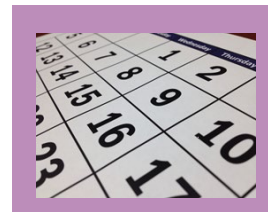
The MDHHS Birth Defects and Education program would like to extend an opportunity for free educational outreach materials available to order. Resources on folic acid, preconception tips, and resources for families of infants and toddlers with special needs are available. The materials are available in English, Spanish and Arabic. [Please visit the ordering page to submit your order: https://migrc.org/order-materials/.](https://migrc.org/order-materials/)

Progress in research brings hope for new treatments and cures each day. Babies with birth defects are living longer and healthier lives. This is thanks to education, newborn screening, early diagnosis, special care and new medical treatments. If you have any questions, [please contact click here to email Courtney Miller \(miller47@michigan.gov\)](mailto:miller47@michigan.gov) or call 517-241-4125.

## Upcoming Holiday Courier Schedule

### Lower and Upper Peninsula Hospitals:

Monday, February 20, 2023 – Holiday/Sunday schedule



## Technical Assistance

- ☐ Angela Aldrich, NBS nurse consultant, is available to work with staff in any hospital that requests help with specimen collection. [Click here to reach her by email](mailto:AldrichA1@Michigan.gov) (AldrichA1@Michigan.gov).
- ☐ Kristen Thompson, NBS Coordinator, is available to work with hospitals on CCHD pulse oximetry screening and reporting. [Click here to reach Kristen by email](mailto:ThompsonK23@Michigan.gov) (ThompsonK23@Michigan.gov).
- ☐ Shelby Atkinson, Genomics and NBS Research Coordinator, is available to assist with questions related to BioTrust for Health. [Click here to reach Shelby by email](mailto:atkinsons2@michigan.gov) (atkinsons2@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](https://www.michigan.gov/NewbornScreening).