

Winter 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 third quarter of 2021, eight 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
- McLaren Port Huron - SCN
- Henry Ford Allegiance Health
- Mid-Michigan Medical Center - Alpena
- St. Joseph Mercy Ann Arbor
- Three Rivers Health
- War Memorial Hospital
- Metro Health Hospital

#### **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: Spring NBS Conference and Virtual Baby Fair
- ✓ CCHD Awareness Week
- ✓ Avoiding Unsatisfactory Specimens
- ✓ Replacement NBS Cards
- ✓ Reducing NBS Demographic Errors
- ✓ BioTrust Verbal Consent
- ✓ 2020 NBS & CCHD Annual Reports
- ✓ Sickle Cell Disease Initiatives
- ✓ Daylight Savings Reminder
- ✓ Hospital Contact Changes Form

During the third quarter of 2021, 23 hospitals met all three of the critical congenital heart disease (CCHD) screening performance goals. Four hospitals with the highest percent of CCHD results reported to the Newborn Screening Program within ten days are listed below. Congratulations to the following hospitals on their impressive efforts:

- Mid-Michigan Medical Center - Alpena
- ProMedica Monroe Regional Hospital
- McLaren Lapeer Region
- Mid-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 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: highlight of two endocrine disorders, tips for collecting a satisfactory blood spot specimen, NBS card accuracy review, Michigan BioTrust for Health, critical congenital heart disease, and more!

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

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

Topics include:

- Endocrine Disorders Highlight
- Improving Newborn Screening Specimen Quality
- Newborn Screening Card – Accuracy is Critical
- Program updates:
  - Newborn Screening
  - BioTrust for Health
  - Critical Congenital Heart Disease
  - Early Hearing Detection & Intervention

Nursing contact hours are available!



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: Virtual Baby Fair

The Newborn Screening Program is excited to share an opportunity at MDHHS for new and expecting parents across the state of Michigan! We are sharing this in hopes that you will pass this message and save the date along to expecting or new parents.

MDHHS is hosting a free virtual baby fair. 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 will have an opportunity to ask experts questions.



#### Summer 2022 Dates:

Tuesday, June 14 6:30-8:30 pm  
Wednesday, June 15 9-11 am  
Wednesday, June 22 9-11 am

The following MDHHS programs are participating in this event: Newborn Screening, Michigan BioTrust for Health, Infant Safe Sleep, Women, Infants, & Children (WIC), Childhood Lead Poisoning Prevention Program, Vital Records, Unintentional Injury Prevention, Immunizations, Early Hearing Detection and Intervention, Maternal Infant Health Program, Michigan Home Visiting Initiative, Children's Special Healthcare Services, Eat Safe Fish, Birth Defects Education and Outreach, and State Breastfeeding Promotion.

MDHHS is so excited to offer a safe way for parents to get all the important information they need! We appreciate your help in promoting this event and encourage you to share as you see fit.



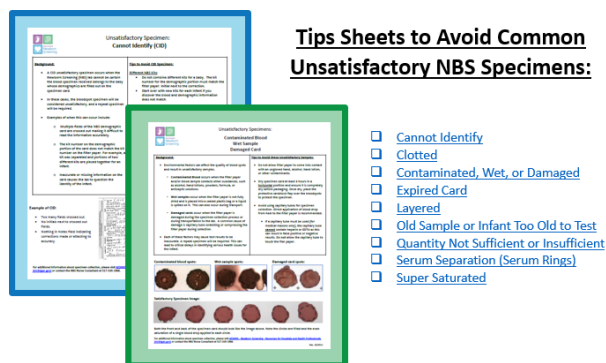
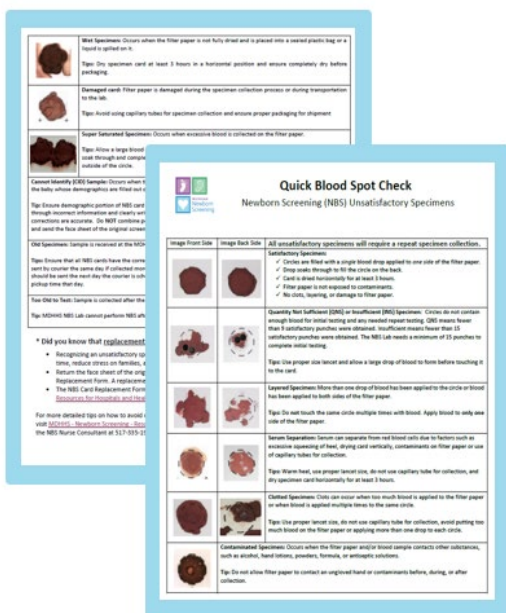
### February 7-14 is Congenital Heart Disease Awareness Week!

In 2020, a total of 91,739 babies were screened for CCHD in Michigan. Of those screened, five were diagnosed with a CCHD and eight were diagnosed with another previously unrecognized hypoxic condition.

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!

## New Resources: Avoiding Unsatisfactory Specimens

A goal of the Newborn Screening (NBS) Program is *less than 1% of first and repeat sample specimens are unsatisfactory for testing*. Between January and September 2021, there were 832 (1.1%) unsatisfactory specimens submitted to the NBS Laboratory. Each of these require a repeat NBS collection. Unfortunately, sometimes a repeat specimen is never collected, and the cases are never fully resolved.



## Tools for Success!


*A Simple Blood Spot Check* can help staff recognize unsatisfactory specimens immediately. This easy-to-use reference tool helps staff identify poor quality spots and gives quick tips improve collection. In addition, tip sheets have been created for the most common unsatisfactory specimens. These guidance documents provide in-depth information about each type of unsatisfactory specimen and recommendations for avoiding them.

These resources can be found at [MDHHS/NewbornScreening](#) under the “Resources for Hospitals and Health Professionals” section. Feel free to print for quick access.

## Did you know that replacement NBS cards are free?

- Mistakes happen! Recognizing unsatisfactory blood spots and immediately recollecting saves time and money.
- It is simple and easy to request a replacement NBS card for a specimen you suspect will be deemed unsatisfactory. Return the face sheet of the original NBS card and the NBS Card Replacement Form to the address on the form.
- A replacement card will be sent upon receipt.
- The NBS Card Replacement Form and instructions are located at [MDHHS/NewbornScreening](#) under the “Resources for Hospitals and Health Professionals” section in the “Forms” section.
- Please follow directions carefully, as requests should not be submitted to the NBS Laboratory or sent in courier envelopes.

**NEWBORN SCREENING CARD REPLACEMENT FORM**

 Michigan Department of Health & Human Services  
www.michigan.gov/dhhs

Date: \_\_\_\_\_

FACILITY NAME: \_\_\_\_\_

ATTN: (DEPT) \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY, STATE, ZIP: \_\_\_\_\_

CONTACT NAME: \_\_\_\_\_ TELEPHONE # \_\_\_\_\_

NUMBER OF CARDS RETURNED FOR REPLACEMENT: \_\_\_\_\_

I.D. NUMBERS ON THE CARDS RETURNED: \_\_\_\_\_


- This form should be filled out completely.
- Attach **WHITE FACE SHEET(S) ONLY**.
- If there is blood on the white face sheet, place it in a biohazard bag.
- **DO NOT** send card replacement requests to the NBS Laboratory.
- **DO NOT USE COURIER ENVELOPES** for card replacement requests.

SEND FACE SHEET(S) OF CARD(S) TO BE REPLACED AND THIS FORM TO:

**Michigan Department of Health and Human Services**  
**Attn: Newborn Screening**  
 333 S. Grand Ave., 2<sup>nd</sup> floor  
 PO Box 30195  
 Lansing, Michigan 48909

## New Resource: Reducing Newborn Screening Card Demographic Errors

Did you know that incorrect demographic data on newborn screening cards leads to a significant increase in follow-up work for both hospital and NBS staff?

Missing or incorrect data must be resolved by phone or fax and often requires that hospital staff review medical records to obtain correct information. Accuracy is critical for test interpretation of age or birth weight-dependent analyte cutoff values. The NBS goal is *less than 1% of specimens have errors in the demographic data (i.e. dates, times, birth weights, etc.) on the NBS card*. Between January and September 2021, 2.3% of NBS cards received had demographic errors. That is a total of 1,770 cards with errors!

The *Completing the Newborn Screening Card* infographic is a simple tool to help hospital staff to correctly complete the demographic section of the card. Additional details can be found in the *Michigan Newborn Screening Guide for Hospitals*. Both resources are located at [MDHHS/NewbornScreening](https://mdhhs.michigan.gov/NewbornScreening) under the “Resources for Hospitals and Health Professionals” section.

## Important Reminders for the BioTrust Consent Process: Verbal Consent

Recently, MDHHS has identified an increase in the number of BioTrust consent forms that indicate verbal consent has been obtained from parents. Per departmental policy, these forms are not valid or considered complete since the BioTrust requires written consent from families.

**Only a parent or legal guardian of the child can sign the BioTrust consent form. There is never a situation where it is appropriate for a staff member to collect a verbal decision or to sign on behalf of the family. When this occurs, the BioTrust for Health is unable to honor a family's decision to allow blood spots to be used for de-identified health research.**

Consent forms do not have to be returned at the same time as the blood spots. If a family needs additional time to make their consent decision, **do not delay** sending the blood spots back for newborn screening. The white copy of the consent form can be picked up by the courier on a different day.

We understand that the COVID-19 pandemic has changed the workflow for providers in many ways. Below are resources to help staff members who may have questions on how to collect the BioTrust consent decision from families:

- [Staff instruction sheet](#)
- [30-minute BioTrust Training Module](#)

For any questions related to the BioTrust consent process, please contact Shelby Atkinson at 517-335-6497 or at [BioTrust@Michigan.gov](mailto:BioTrust@Michigan.gov).



## 2020 NBS Annual Report Summary

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 ([Michigan.gov/NewbornScreening](https://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 2020, a total of 102,236 infants were screened in Michigan and 287 (0.3%) were diagnosed with a disease on the blood spot panel. Overall, one infant out of 356 screened was diagnosed with one of the disorders. Since the NBS Program began in 1965, more than 7,300 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 121 and 63 infants born in 2020, respectively. The third most commonly diagnosed disorder is cystic fibrosis, with 22 cases diagnosed in 2020. Spinal muscular atrophy (SMA) was added to the Michigan NBS panel in March 2020 and eight cases were detected.

## 2020 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 CCHD Annual report gives a general overview of the 2020 year in review, including 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](https://Michigan.gov/CCHD).

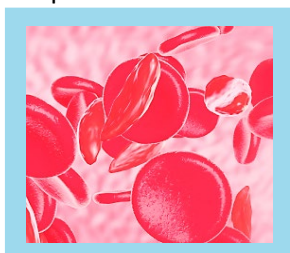


Some key points from the 2020 report include:

- 93.4% of infants in well-baby nurseries had pulse oximetry screen results reported to the NBS Program.
- A total of 69 infants failed the screen and four CCHD cases were identified through pulse oximetry screening.
- An additional eight secondary conditions were detected after the infants received a pulse oximetry screen.
- 74% of screens were reported on-time, defined as within 10 days of screening.
- 87.5% of infants received timely screens, defined as taking place between 20 and 28 hours after birth.

## Michigan Legislature Funds \$6.7 million for Sickle Cell Disease Initiative

The Michigan Department of Health and Human Services is excited to share a newly funded, statewide sickle cell disease (SCD) initiative that enables the expansion of the Children's Special Health Care Services benefit to adults beyond age 21; provides support to enhance clinical capacity which will be available through a Request for Funding proposal process in 2022; and maintains services provided by the Sickle Cell Disease Association of America – Michigan Chapter.

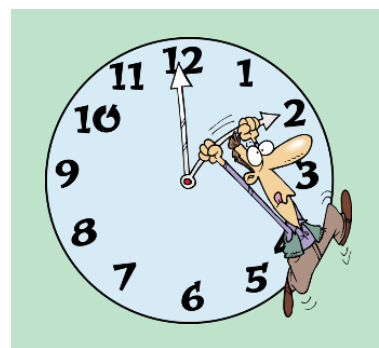


SCD is the most common inherited blood disorder identified through Michigan's NBS Program and is associated with early mortality and substantial morbidity. Approximately 3,500 individuals living with SCD in Michigan are racial and ethnic minorities who face significant gaps in accessing comprehensive, cohesive, highly specialized disease management and treatment services. This endeavor will advance multiple cross-cutting priorities to improve the quality of life for individuals impacted by this condition.

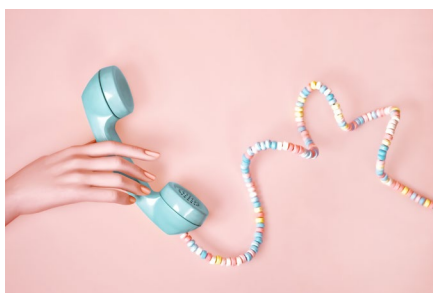
## Spring Forward, Lose an Hour

Remember to adjust the collection time for your newborn screening blood spot specimens with the time change.

Daylight Savings Time Begins Sunday, March 13, 2022. Clocks will adjust from 0200 Eastern Standard Time (EST) to 0300 Eastern Daylight Time (EDT) on March 13, 2022. An infant born on Saturday, March 12, 2022 at **0200 EST** will not be 24 hours old until Sunday, March 13, 2022 at **0300 EDT**.



## Contact Updates



Quick communication is critical for newborn screening. Reporting of abnormal screens, confirming demographic information, following up on missing blood spot or critical congenital heart disease screens, and distributing hospital quarterly metric reports are just a few of the reasons NBS staff may need to reach out to key hospital staff.

Please help keep us informed of any staffing changes or updated phone, fax, and email contact information for these key positions:

- NBS coordinator
- NBS back-up coordinator
- Lab contact
- CCHD contacts (including IT staff)

Email updates to [NewbornScreening@Michigan.gov](mailto:NewbornScreening@Michigan.gov) or complete the hospital contact update form located at [Michigan.gov/NewbornScreening](https://Michigan.gov/NewbornScreening) under the “Resources for Hospitals and Health Professionals” section.

## Upcoming Holiday Schedule

### Lower Peninsula Hospitals:

- Monday, February 21, 2022 – Holiday/Sunday schedule
- Monday, May 30, 2022 – Holiday/Sunday schedule

### Upper Peninsula Hospitals:

- Monday, February 21, 2022– Normal operations
- Monday, May 30, 2022 – 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](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](https://Michigan.gov/NewbornScreening).