



Newborn Screening Highlights for Primary Care Providers

Obtaining Newborn Screening (NBS) Results:

- The NBS Program does not provide NBS results over the telephone.
- Most NBS results are available on the Michigan Care Improvement Registry (MCIR) website once the NBS record is successfully linked to the newborn's birth certificate and immunization records.
 - If you are not listed as the infant's PCP in MCIR, please update.
 - If the patient address and phone number are not in MCIR, please update.
- Medical providers can utilize the [NBS Report Request Form](#) to request results not found in MCIR. The form is located at michigan.gov/newbornscreening in the "Resources for Hospitals and Health Professionals" section.
 - This form can also be used to request an abbreviated report for patients requiring sickle cell trait results for college sports.

Normal NBS Results:

- Share NBS results with the family at the first visit, if available.
- Remember that a normal screening result does not completely rule out the possibility of disease or carrier status.
- Always use clinical judgment. Diagnostic evaluation by a specialist is recommended if there is a clinical concern or family history of a disorder.

Abnormal NBS Results:

- The physician listed on the NBS card is the primary contact notification for abnormal results.
- Your office will receive a fax notification for abnormal results if you are listed on the card. **Read the "action required"** on the report. You may need to:
 - Write an order for a repeat screen.
 - Order labs.
 - Consult with a specialist from the follow-up coordinating center listed on the fax to arrange for confirmatory testing.
- Repeat screens may be requested due to unsatisfactory (poor quality) blood spot specimens, specimens collected early (before 24 hours of life), borderline results, or apparent transfusions.
- If you receive a fax notification for an infant not seen in your practice, fax the NBS notification back to the NBS Program with a note indicating this is not your patient. Note the correct provider, if known.
- If the NBS results retrieved from MCIR indicate an abnormal result for your patient and you have not been notified, please contact the NBS Program immediately for more information.



Communicating Abnormal NBS Results to Parents

- Give the results as soon as possible, preferably in person.
- Remind parents that abnormal screening results does not mean their infant has the disorder. Emphasize the need for timely diagnostic testing, if indicated. Review relevant symptoms to monitor while waiting for results.
- If repeat screening is needed, encourage parents to take the infant back to the hospital or midwife as soon as possible. Depending on hospital preference, collection may take place in an outpatient lab or on the hospital unit, and a primary care provider order may be required. If you are unsure of the process for the birthing hospital, please contact the hospital directly.
- Provide written information, such as disorder fact sheets, and encourage the use of reputable sources for internet searches, like the Michigan Newborn Screening website (listed below).
- Additional resources are available for families, including:
 - Transportation assistance to access follow-up care is available through Medicaid health plans for those enrolled.
 - Uninsured or underinsured families should be referred to Children’s Special Health Care Services (CSHCS) for a diagnostic evaluation and transportation assistance if confirmatory testing of a disorder is indicated. If diagnosed with a NBS disorder, all families should be referred to CSHCS for additional assistance. Families should call 800-359-3722 or their local health department for enrollment information.

Discussing NBS with Parents Who Would Not Permit Collection:

- Approximately 500 Michigan newborns each year do not receive a screen due to parents not permitting collection. With a detection rate of 1 out of every 340 screened infants, there is potential every year for an infant to have a delayed diagnosis of a NBS-identifiable disorder.
- Explain the purpose of NBS and provide written information, along with links to reputable sites for more information.
- Remind parents that many affected newborns do not have any family history, so all babies should be screened. NBS gives affected newborns the opportunity for the healthiest life.
- Share the list of disorders on the Michigan NBS panel found on the NBS website.
- Discuss the Michigan BioTrust for Health and the parents’ option to store or destroy the residual blood spots once testing has been completed.
- The MDHHS NBS Lab will provide screening until age one, but earlier detection leads to better treatment outcomes for many disorders.

Michigan Newborn Screening Resources

For additional information about newborn screening, providers and families are encouraged to contact our program at:
517-335-4181 or
newbornscreening@Michigan.gov

Websites:

Michigan.gov/NewbornScreening

Michigan.gov/BioTrust

Michigan.gov/CCHD

Newborn screening brochures and infographics are available to order at no cost at
Michigan.gov/NBSorders.