



Michigan Department of Community Health Newborn Screening News

Update-Winter 2011

The Michigan Department of Community Health (MDCH) Newborn Screening Follow-up Program works together with the State Laboratory to find and treat infants who need early medical care.

COMING SOON TO MICHIGAN!

ADDITION OF A NEW DISORDER TO THE MICHIGAN NBS PANEL

On October 5, 2010 the Michigan Newborn Screening Quality Assurance Advisory Committee approved the addition of Severe Combined Immunodeficiency (SCID) to the Michigan newborn screening panel. This recommendation will become law on October 1, 2011, if approved by the legislature. SCID had previously been recommended for state newborn screening panels by the federal Advisory Committee on Hereditary Disorders in Newborns and Children, a committee that reports to the Secretary of Health and Human Services. The Secretary approved the recommendation on May 21, 2010.

SCID represents a group of more than 13 inherited disorders that lack functional T and B cells responsible for cellular and humoral immunity, respectively. Newborns with SCID are unable to mount an immune response to infection by viruses, bacteria and fungi. They become severely ill during the first year of life and rarely survive beyond the second year. However, if detected early by newborn screening, newborns with SCID can be successfully treated by bone marrow transplantation. Transplant therapy is most effective if performed early, ideally during the first month of life. It is especially important to transplant prior to the first infection. Because these newborns do not have T cells they are candidates for a haploidentical bone marrow transplant from either the mother or father. This is an important option because there may not be an appropriate HLA identical sibling donor and a search for a matched unrelated donor is sometimes a lengthy process that might not be completed before first infections occur.

Currently, Wisconsin, Massachusetts, Texas, and California are screening for SCID. Preliminary data from these states are encouraging in that newborns with SCID are being detected early and successfully transplanted prior to infection. In addition, the incidence of the disorder appears to be about 1/40,000 as compared to the assumed incidence of 1/100,000 prior to screening.

NBS Courier Service Transition

Attention all lower peninsula birthing hospitals currently using UPS services for NBS specimens!

A goal of the NBS program has been to improve transit times for NBS specimens and to provide NBS coordinators with an effective courier service. We recognize that Quest offers excellent service and addresses the importance of timely specimen transit. Please watch for NBS follow-up emails regarding this transition.

You should have been contacted by a Quest supervisor in November or December regarding initiation of the Quest Courier Service for the transit of your NBS specimens. Service will be provided Monday—Saturday for prompt transit. Quest will place a NBS specimen pick-up basket in an area that is most convenient for you and your staff. If your hospital laboratory is responsible for the collection of specimens, then the basket will be placed in the hospital laboratory. However all staff should be made aware of the pick up location and pick up times.

You must use the MDCH NBS Laboratory white envelopes for the transport of specimens. The necessary envelopes can be readily ordered by calling Val Klasko at (517) 241-5583. The NBS envelopes have a printed UPC bar on them which allows for tracking by the courier and the state NBS laboratory.

We encourage you to have a sign-in log (next to the pick-up basket) for the courier. This will allow you to monitor the time of pick-up and the name of the courier. This log will allow you to inform staff of the daily time schedule for NBS specimen pick-ups.

If you encounter any transit issues we encourage you to first call Quest at (866) MYQUEST (866-697-8378) and they will address your concerns. If necessary you may then call the NBS Follow-up Program at (517) 335-4181 to address your concerns.



NBS NICU Protocol



Clarification:

Hopefully, all hospital units have received the laminated outline of the new newborn screening NICU Protocol that was initiated on July 1, 2010. (If you have not received a copy of the protocol please contact us at newbornscreening@michigan.gov). The following clarifications are in response to questions that were raised since the protocol was implemented:

General:

- It is not necessary to obtain a discharge specimen if a newborn is discharged from the NICU before the 8th day of life.
- It is not necessary to repeat the NICU protocol if a baby is discharged from the NICU and is later re-admitted.
- It is not necessary to wait until discharge to obtain a second specimen. If a NBS disorder is suspected, a NBS specimen can be ordered by the physician, obtained and forwarded to the MDCH, NBS laboratory at any time prior to discharge. Follow-up immediately on requests for an additional specimen if you are notified that a previous specimen was positive, early or unsatisfactory.

Hospital Transfers:

- If a newborn is transferred a NBS specimen should be obtained prior to transfer even if obtained prior to the recommended 24-36 hour for the first specimen. Some results are valid on early specimens (Hemoglobin, Galactosemia) and obtaining this specimen will avoid the request for a 90 day specimen if there is a transfusion before a second specimen is obtained. The birthing hospital specimen also provides a link to the electronic birth record allowing all NBS results to be available later on MCIR.
- The receiving hospital NICU should still follow the protocol and obtain a 24-36 hour specimen. If the initial specimen was not obtained prior to transfer, the receiving hospital NICU should record the birthing hospital on the NBS card and develop a procedure to provide the birthing hospital EBR staff with the NBS card number to include on the EBR submitted to the MDCH Vital Records.

Transfusions:

Ideally a first specimen should be obtained prior to transfusion even if the specimen is drawn early (<24 hrs). Please check transfused if the newborn was transfused prior to the NBS specimen being obtained.

Also please write on the card the date of the transfusion and the start time of the transfusion (ex: 10/13/10 23:20). The next printing of kits will have boxes for entering the start time.

- Specimens obtained after transfusion should be at least 24 hours after the transfusion has ended (the MDCH Laboratory will assume that the specimen was obtained 24 hours after the transfusion ended if the specimen was obtained at least 28 hours after the transfusion start time). NBS will contact NICU staff for any newborn where a transfusion is suspected and the date and start time that the transfusion was started are not on the card.

Antibiotics:

Please check "Antibiotics" if the newborn is currently receiving antibiotics or if you are taking the 24-36 hour specimen and the mother was receiving ongoing antibiotics at the time of birth. You do not need to check antibiotics if the mother received one dose prior to a c section or if you are taking a 30-day specimen and the newborn received antibiotics in the past and is not currently receiving them.

If you have any further questions please feel free to email newbornscreening@michigan.gov or call Bill Young at 517-335-4181.

REMINDER:

Fill out cards COMPLETELY!

Missing information results in a call to the hospital.

Farewell and Good Luck, Vicki!

MDCH Newborn Screening Follow-up said good-bye to Vicki Jenks at the end of December when she retired after many years in state government. Vicki served as the NBS Nurse Consultant over the past two years, and will be greatly missed.

Do You Know?

Genetic Alliance, <http://www.geneticalliance.org/dis>, has an online database of advocacy organizations and resources for genetic conditions. The site, which also provides a search engine tool, contains up-to-date information and quality links on: support groups, insurance issues, treatments, clinical descriptions and research updates.

The Distinguished Michigan NBS Quality Assurance Advisory Committee

Since 2006 the MDCH Newborn Screening Quality Assurance Advisory Committee (QAAC) has met annually to evaluate the need for additional NBS disorders and to address budgetary concerns. The committee is made up of appointed members who are community leaders representing organizations with significant knowledge regarding NBS. The committee includes a Michigan neonatologist, representative of a non profit health care corporation, the state medical director, a representative of the MI Health and Hospital Association, a representative of MDCH Administration, members of the community, representative of the MI Osteopathic Association and a representative of a health maintenance organization. The members review NBS program recommendations, vote and then forward their recommendation to MDCH who in turn sends the recommendations to the Michigan legislature according to the MI Public Health Code.

Share with Parents

From time to time MDCH wants to contact families of children diagnosed by newborn screening. The reasons might include:

- Notifying them about special events
- Providing them with updates
- Offering an opportunity to participate in research studies
- Asking them to complete a survey to help improve the program or clinic services
- Finding parents willing to advocate on behalf of Newborn Screening

We are currently compiling an email list to make communication with parents faster and easier. If a parent would like to be included, please have them send their name, email address, county, child's age and diagnosis to newbornscreening@michigan.gov. This email list will ONLY be used by MDCH newborn screening staff.

Update on Parental Consent Process



The MDCH Newborn Screening Program is pleased to announce that as of October 1st, nearly all birthing hospitals were able to initiate the parental consent process for the Michigan BioTrust for Health (BioTrust). We greatly appreciate the commitment and cooperation shown by hospital newborn screening coordinators, managers and staff in helping to implement the new consent procedures. Since June, over 500 Michigan nurses have received continuing education certificates by participating in on-line training and in-service presentations about newborn screening and the BioTrust. **Thank you, one and all! We could not have achieved this remarkable milestone without you!**

All birthing hospitals have now received the re-designed NBS kit that contains the BioTrust consent form for parents to sign if they wish to allow possible research using their child's de-identified residual dried blood spots after newborn screening is complete. The NBS Follow-up Program will be monitoring receipt of these consent forms (signed and un-signed forms are to be returned to the state laboratory for tracking) to help facilitate resolution of any barriers that may arise. The percentage of forms returned will soon become one of the indicators included on your hospital's quarterly quality improvement report, so be sure to check and see how your hospital is doing.

Remember that multiple educational tools are available to help ensure parents' understanding of newborn screening, the BioTrust and consent process. English versions of the NBS brochure entitled *Michigan Newborn Screening Saves Babies*, and the BioTrust Consent Booklet, entitled *After Newborn Screening*, will now routinely be included with your hospital's NBS kit order. Please make sure these materials find their way to the person or unit that is responsible for distributing them to parents! All additional products can be ordered by downloading a product order form at www.michigan.gov/newbornscreening or by calling 517-335-8887. Community outreach and education will continue to be a primary focus of the BioTrust initiative. Please visit www.michigan.gov/biotrust to learn about these efforts as well as any upcoming events. We invite you to learn more and encourage you to contact Carrie Langbo, BioTrust Outreach Coordinator, at 517-335-6497 or langboc@michigan.gov for information or to plan an educational event or presentation.

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NBS Quarterly Reports

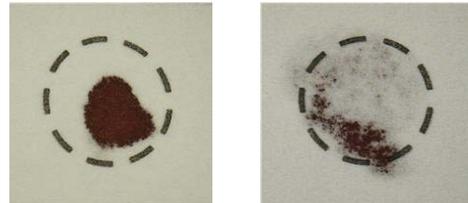
During the second quarter of 2010, the number of unsatisfactory screens was not reported on hospital quarterly reports. This was because many of the unsatisfactory specimens were caused by card defects due to a specific printing of the NBS cards and not related to blood collection practices. We are happy to report that has been resolved and the number of unsatisfactory screens will be reported on the quarterly report for the third quarter of 2010.

During the third quarter of 2010, eight hospitals met all performance goals. We would like to congratulate the following hospitals on their impressive efforts!

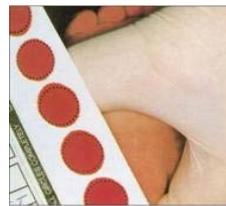
- Borgess Medical Center**
- Crittenton Hospital**
- Genesys Regional Medical Center—Health Park**
- Henry Ford Hospital Macomb**
- Metro Health Hospital**
- Port Huron Hospital**
- St. Mary Hospital, Livonia**
- Zeeland Community Hospital**

NBS Specimen Update Insufficient Samples

There has been an increase in the number of NBS cards with “insufficient” blood. When a specimen is received without enough blood, a repeat specimen is requested. If the infant has left the hospital, the family will have to go to a hospital outpatient laboratory and have the heel poked again for the repeat specimen. Here are some pictures of cards received at the MDCH Newborn Screening Laboratory. Please talk to your staff about good techniques to get large drops of blood to put in each circle. If you have not seen the Clinical and Laboratory Standards Institute (CLSI) DVD titled “**Making a Difference Through Newborn Screening: Blood Collection on Filter Paper**”, please ask your NBS coordinator for the DVD in the blue binder and review it. Thank you for your willingness to improve the NBS process and save families that extra trip back to the lab!



Actual specimens received by the MDCH Laboratory
Back side of card with insufficient blood to soak through. The NBS laboratory is unable to get the required four punches from the circle in order to complete the screening tests.



Correct specimen: Circles should be completely and evenly filled. Note blood is applied from the front side only but in sufficient quantity to soak through to the back.

Update

2010 Early Hearing Detection Intervention (EHDI)

Michigan Monitor Newsletter

Valuable information regarding hearing loss and birth defects can be found at www.michigan.gov/mchept.
Click on: Maternal and Child Health Epidemiology Products

2011 State Holidays

- January 17 – Martin Luther King, Jr. Day
- February 21 – Presidents’ Day
- May 30 – Memorial Day
- July 4 – Independence Day
- September 5 – Labor Day
- November 11 – Veterans’ Day
- November 24 and 25 Thanksgiving Holiday
- December 23 and 26 – Christmas Holiday Observed

For more information:
MDCH Newborn Screening Follow-up Program
website: www.michigan.gov/newbornscreening