Newborn Screening Update

Important Changes to NBS Quarterly Reports

The Newborn Screening (NBS) Follow-up Program has been working to improve the entire NBS system. Beginning in the first quarter of 2010, your quarterly reports will contain information on two more measures: batching (i.e., specimens being batched together and not sent to the NBS laboratory within 24 hours of collection) and recording the NBS metabolic card number on the electronic birth certificate. Additionally, we have set performance goals for each measure and will use the information from the quarterly reports to determine which hospitals may benefit from a phone call or a site visit from a member of the NBS Follow-up staff.

The following table indicates which measures we are focusing on and the performance goal that we have set for each measure.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Performance Goal for 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Late Screens</td>
<td>Less than 2% of screens collected greater than 36 hours of life</td>
</tr>
<tr>
<td>Courier Time</td>
<td>More than 90% of screens arrive in the state laboratory by the 4th day of life</td>
</tr>
<tr>
<td>Unsatisfactory Screens</td>
<td>Less than 1% of screens are unsatisfactory</td>
</tr>
<tr>
<td>Batching</td>
<td>Less than 2% of envelopes are batched</td>
</tr>
<tr>
<td>NBS Card Number</td>
<td>More than 95% of electronic birth certificates have the NBS card number recorded</td>
</tr>
</tbody>
</table>

During the fourth quarter of 2009, three hospitals met all five performance goals. We would like to congratulate these hospitals for their impressive efforts! These hospitals include:
- Genesys Regional Medical Center—Health Park
- William Beaumont—Troy
- Zeeland Community Hospital

We hope that you will be able to use the information in the quarterly reports to find ways that you can improve your part of the NBS system. If you have any questions, please call the NBS Follow-up Program at 1-866-673-9939.
Newborn Screening Educational Online Tutorial

The Newborn Screening training video has been updated and is now available on the web. This tutorial is especially for nurses and hospital staff who obtain the newborn screening specimen. 1.2 nursing contact hours are available. Please go to the Michigan Newborn Screening website, [www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening) and scroll down the page to “Important information for Professionals” then to [Newborn Screening Educational Online Tutorial](http://www.michigan.gov/newbornscreening) or go directly to [http://training.mihealth.org/](http://training.mihealth.org/). Once on the MiHealth web page, click on Newborn Screening. If you have never been on this training website you will need to click on “First time user” and register. There is no cost and they do not use your information. If you have any difficulty using the training, please call Vicki Jenks at 517-335-1966 or email [jenksv@michigan.gov](mailto:jenksv@michigan.gov).

How to access the MCIR.....

Newborn screening (NBS) results are now available on the Michigan Care Improvement Registry (MCIR). Our goal is to have newborn screens available on the MCIR approximately four weeks after birth.

To obtain access to the MCIR, you will need to contact your regional office to register. Go to [http://www.michigan.gov/documents/mdch/MCIR_Brochure_196978_7.pdf](http://www.michigan.gov/documents/mdch/MCIR_Brochure_196978_7.pdf) to learn more about the MCIR and locate the phone number for your regional office. Due to increased activity at the regional offices, you may have to wait several weeks in order to receive approval for MCIR access.

Once you are able to log-on to the MCIR, the NBS results will be available under the “NBS Mailers” tab. If you click on “Mailer” under the “NBS Mailers” tab, you can retrieve a copy of the child’s NBS results.

If a child does not have a “NBS Mailers” tab or the child does not have a “Mailer” option under the “NBS Mailers” tab, please call 1-866-673-9939 to obtain a copy of the child’s NBS results.

Capillary Tubes

MDCH is asking that you do not use capillary tubes that have either EPHI or heparin in them. There appears to be some interference with laboratory testing. If you are using them, please stop and perform the heel stick by collecting a drop of blood directly on the card. We really appreciate your assistance trying to resolve this problem.

If you have any questions please feel free to call Vicki Jenks RN, MPA at 517-335-1966 or email [jenksv@michigan.gov](mailto:jenksv@michigan.gov).
An Update on the Michigan BioTrust for Health

The Michigan Department of Community Health (MDCH) has continued its work to implement the Michigan BioTrust for Health (BioTrust), a resource of residual newborn screening (NBS) dried blood spots (DBS) available for medical and public health research. To date the BioTrust has improved storage conditions for over 575,000 residual de-identified DBS by transferring them to the Michigan Neonatal Biobank (MNBB), a 501c3 non-profit organization and designated storage facility for the BioTrust. The BioTrust Community Values Advisory Board (CVAB) continues to meet almost monthly to investigate and recommend policies for implementing parental consent, educating the public and protecting privacy. The BioTrust Scientific Advisory Board is now operational making a pool of experts available to review study proposals requesting the use of DBS.

This spring marks an important phase for the BioTrust with the early implementation of the proposed parental consent process in some hospitals across the state. The hospitals have initiated the consent process to determine if any unforeseen complications present with the intended protocol. Feedback from these hospitals will ensure a smoother transition when the remaining Michigan birthing hospitals are asked to implement the BioTrust consent process this fall. To date, feedback has been positive. The parental consent process, developed using input from Michigan’s NBS nurse coordinators, MDCH and the CVAB, will make use of a redesigned NBS kit that contains a BioTrust Consent form for parents to sign if they wish to allow possible research using their child’s de-identified residual DBS after NBS is complete. An informational booklet will accompany this BioTrust Consent form. Please look for additional information on this parental consent process coming soon!

Educating the community remains a primary goal of the BioTrust initiative. An updated NBS brochure is currently being disseminated which includes information on the BioTrust. An educational DVD will be available in the coming weeks with information on NBS and the BioTrust. Additional educational outreach will continue as progress moves forward with the Michigan BioTrust for Health. Everyone is invited to learn more. Please visit www.michigan.gov/biotrust for information and updates or contact Carrie Langbo, BioTrust Community Outreach Coordinator at langboc@michigan.gov or 517-335-6497.

NBS Briefs

The Michigan Newborn Screening (NBS) Follow-up Program is now creating NBS Follow-up Briefs. These briefs describe how existing data sources can be used to monitor the prevalence, morbidity, and mortality across the life span for specific disorders included in the NBS panel. The first brief, focusing on sickle cell disease, came out in November 2009. The next brief will be on phenylketonuria. The briefs are available at the NBS website (www.michigan.gov/newbornscreening).

Langboc@michigan.gov.
Michigan Healthy Mothers, Healthy Babies Coalition
Educational Conference (and Pre Conference)
June 2, 3 & 4, 2010
Mount Pleasant Comfort Inn and Suites

The conference attracts nurses, social workers, health agency administrators, health planners, dietitians, health educators, social activists, physicians, educators and other professionals who are interested in the health and well being of women and children across Michigan. The theme of this year’s conference is *Growing Strong Families, Building Healthier Communities* and features keynote speakers and workshops addressing a wide variety of maternal and child health topics. Additionally, the Michigan Chapter of the March of Dimes is sponsoring a preconference grant writer’s workshop.

For more information, including sponsorships and exhibits, contact Diane Drago, Conference Coordinator, Diversified Management Services at 517-663-5147 or DMSdiane@concentric.net.

The Early Hearing Detection and Intervention (EHDI) program works in collaboration with birth hospitals, clinics, parents, and audiologists to implement a statewide universal system for timely screening and identification of newborns with hearing loss. The EHDI goals are as follows:

**Goal 1.** All newborns will be screened for hearing loss no later than 1 month of age, preferably before hospital discharge.

**Goal 2.** All infants who screen positive for hearing loss will have a diagnostic audiologic evaluation no later than 3 months of age.

**Goal 3.** All infants identified with hearing loss will receive appropriate early intervention services no later than 6 months of age.

**Please mail ALL hearing cards directly to EHDI:**

MDCH-EHDI  
Attn: Erin Estrada  
PO Box 30195  
Lansing, MI 48909

If you have any questions regarding newborn hearing screening and follow-up please contact Michelle Garcia, EHDI Follow-Up Consultant at 517-335-8878 or garciam@michigan.gov.
Newborn Screening Follow-up Program Family Recognition Day  May 1, 2010

The Michigan Department of Community Health (MDCH) Newborn Screening (NBS) Follow-up Program hosted its second Family Recognition Day on May 1, 2010 at the Impression 5 Science Center in Lansing, Michigan. The participating children and families have been diagnosed by NBS Program’s early identification of children with 49 rare, but treatable, disorders. The family event was launched in 2008 to encourage the voice of families in the policies and programs impacting the services provided by the NBS Follow-up Program.

The NBS Family Recognition Day for children and families included fun filled learning activities and valuable learning experiences for the whole family. Exploration of the fun-filled Science Center and special health program exhibitors, hands-on learning opportunities, parent networking activities, workshops and refreshments were provided for all participants. This year, over 130 individuals and 18 exhibitors participated in this special event. The next Family Recognition Day will be announced in the future.

New NBS Brochures Now Available

'Michigan Newborn Screening Saves Babies' is a free brochure available from the Newborn Screening Program. This brochure contains information on the Newborn Screening Program, frequently asked questions about disorders and contact information. Please discard your old brochures and contact Val Klasko, (517)241-5583 or KLASKO@michigan.gov to order the new brochures.

NOTE: This brochure will also be available soon in both Arabic and Spanish.
Helpful Reminders…..

State Employees’ Holidays (Thru July 2010)

- May 31, 2010
- July 5, 2010
- Sept 6, 2010

Hospital Codes on NBS Card

In an effort to improve the data MDCH keeps and sends to each hospital, we are asking that NICU please add an “01” and specialty units add an “02” at the end of your individual hospital number.

Hospital Visits

Vicki Jenks, NBS Nurse Consultant is available to make individual visits to your hospital unit. If you wish to have her come, please email jenksv@michigan.gov or call 517-335-1966.

Courier System

If you currently use UPS as the primary courier for newborn screening lab cards, please put an orange sticker on your UPS envelope on Friday to ensure delivery to the NBS lab on Saturday.

Quality Assurance

We ask that you please remind staff of the importance of filling out the newborn screening card completely and accurately. Incomplete or incorrect data entry can delay reporting of results and treatment which are costly if the child has one of the disorders. Always double-check birth date and time, specimen date and collection time, physician contact information and all other necessary information located on the newborn screening card.

NBS Card Ordering Information

The contact person for newborn screening card/brochure ordering is NBS Accountant Valerie Klasko at (517) 241-5583.

*******************************************************************

New NBS NICU Screening Protocol

The Michigan Newborn Screening Program in conjunction with our Advisory Committee has developed a new NICU screening Protocol.

There will be a conference call discussion of the New Newborn Screening NICU screening protocol on Wed, June 23 at 9:00 AM. Bill Young and I will be sharing the protocol with you and anyone who wants to listen in. There will be time for questions and comments. Please invite any of your nursing staff, laboratory staff or neonatalogists to participate.

Please call 1-877-336-1829 access code 1916507. In the near future you will be receiving the new 2010 version of the NBS Hospital Guide with the New NICU protocol.

Please try to participate. If you have any question please feel free to call Vicki Jenks 517-335-1966 or email: jenksv@michigan.gov.
**NBS Follow-up Program Goals**

The Newborn Screening Follow-up Program at the Michigan Department of Community Health (MDCH) assures that all newborns are screened for 49 rare but treatable disorders and that all infants with positive tests receive confirmatory diagnosis and treatment. The Newborn Screening Follow-up Program strives to provide education and support to families touched by these disorders.