



Michigan Department of Community Health Newborn Screening News

Update-Spring 2012

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.

REGISTER NOW!!

2012 NEWBORN SCREENING TRAININGS

It's time to update hospital NBS coordinators and nursery personnel on recent changes in Michigan's newborn screening program! During 2012, training will be provided by the MDCH Newborn Screening Program at six regional sites and include updates, best practices, and presentations on some of the NBS disorders. The full day training will include lunch, with nursing contact hours available. Advance registration is required— see below.

Training dates and sites:

March 29, 2012—FULL

Children's Hospital of Michigan, Detroit

May 4, 2012

C.S. Mott Children's Hospital, Ann Arbor

August 7, 2012

Marquette General Hospital, Marquette
(video teleconference available in U.P.— see registration website for details)

September 11, 2012

Covenant Hospital, Saginaw

September 18, 2012

Helen DeVos Children's Hospital, Grand Rapids

October 11, 2012

Beaumont Hospital, Royal Oak

All newborn screening coordinators, supervisors, nurse educators and other select nursery personnel are encouraged to attend the full day training. Neonatologists and pediatricians are invited to join us for the noon presentation on "Severe Combined Immunodeficiency Disorder (SCID)". (Registration required to receive lunch)

PLEASE REGISTER ONLINE AT:

www.michigan.gov/newbornscreening

Registration confirmation and directions will follow two weeks prior to the event. Questions? Contact Carole Flevaris at 517-335-8959 or Valerie Ewald at 866-852-1247

NATIONAL HIGHLIGHT

DO YOU KNOW

About 1 in 33 babies is born with some type of significant birth defect, a medical condition present at birth that requires treatment and may have lifelong effects on health and development. Congenital heart defects (CHD) are the most common, affecting about 1 in 100 babies. Newer technology allows earlier detection of the most severe types, called "critical congenital heart defects" (CCHD). CCHDs affect about 1 in every 1,000 babies. Some CCHDs will be obvious at birth because of health problems,



New Recommendations for Congenital Heart Disease Screening

or may even be found before birth, by prenatal ultrasound. Some babies with CCHDs will be born healthy and will go home from the hospital with the heart condition unrecognized. These infants are at high risk to become very ill, and may even have a life-threatening event before treatment. For this reason, the US Secretary of Health and Human Services, as well as the American Academy of Pediatrics, recently recommended that CCHD screening by pulse oximetry be added to the newborn screening panel. MDCH, together with certain Michigan birthing hospitals and pediatric cardiology referral centers, is exploring the implementation of CCHD newborn screening in a pilot project beginning this year. Stay tuned for more CCHD-NBS news coming soon or contact Bill Young at (517) 335-8938 or youngw@michigan.gov for more information.



REMINDER! Please hand out the NBS and BioTrust brochures to all parents. Is your supply running low?

Contact Val Klasko at 517-241-5583 or email: klasko@michigan.gov
Visit: www.michigan.gov/newbornscreening for additional NBS information.

Spotlight on Metabolic Disorders

The Children's Hospital of Michigan Metabolic Clinic (CHMMC) provides confirmatory testing and specialized clinical care for infants and children diagnosed through NBS with over 30 inborn errors of metabolism that include:

- ◆ Amino acid disorders such as PKU
- ◆ Biotinidase deficiency
- ◆ Fatty acid oxidation disorders such as MCAD
- ◆ Galactosemia
- ◆ Organic acid disorders such as propionic acidemia

The goal of screening is to identify infants with these disorders and provide medical intervention before a metabolic crisis occurs, which could lead to mental impairment or even death. About 80 infants with these disorders are detected by NBS each year. Following a positive newborn metabolic screen, infants are referred to CHMMC in Detroit where clinic staff work with the primary care provider to confirm the diagnosis. The multi-disciplinary clinic team includes biochemical geneticists, dietitians, nurse practitioners, and genetic counselors; and the treatment plan may include further laboratory analysis, pharmacological evaluation, dietary intervention, psycho-social evaluation and genetic counseling. CHMMC collaborates with the University of Michigan to coordinate a network for metabolic follow-up services provided in Ann Arbor, and at satellite clinics in Southfield and Grand Rapids. To reach the metabolic clinic, call (313) 745-4513.



**Please Note:
Upcoming State Holidays 2012**

May 28—Memorial Day
July 4—Independence Day
September 3—Labor Day
November 23, 24—Thanksgiving
December 24, 25—Christmas Holiday Observed
December 31—New Year's Eve Observed

Update on SCID Screening

Newborn Screening for Severe Combined Immunodeficiency and related disorders began October 1, 2011. Although numerous positive screens have been detected in the laboratory, so far none of those babies was confirmed to have SCID or other primary immune disorders. It should be noted that the screening technology also identifies infants with secondary immune deficiencies associated with certain birth defects and cardiac surgery. Several such cases have already been detected. MDCH laboratory and follow-up staff continue to work closely with our Primary Immune Deficiency Quality Improvement Committee to improve screening, diagnostic and treatment protocols. Representatives include Children's Special Health Care Services, a parent, and the state's three SCID treatment centers: Children's Hospital of Michigan (serves as the state coordinating center), C.S. Mott Children's Hospital and Helen DeVos Children's Hospital. To learn more about SCID, be sure to attend this year's NBS training!

Thank you, Advisory Committee Members!

The MDCH Newborn Screening Advisory Committee meets twice a year to provide guidance on program operations and review activities of the five quality improvement sub-committees that address cystic fibrosis, hemoglobinopathies, endocrine, metabolic, and primary immune deficiency disorders. These committees provide expertise that is vital for ensuring a state-of-the-art NBS program in Michigan. Advisory and sub-committee membership includes endocrinologists, geneticists, hematologists, infectious disease specialists, neonatologists, nurses, parents, pediatricians, pulmonologists, and transplant experts along with representatives from the MDCH Children's Special Health Care Services Program, Medicaid, NBS Laboratory and Follow-up Program. We wish to acknowledge and thank all our advisory committee members for their dedicated service to newborn screening and Michigan's children!

NEWS & NOTES... Newborn Screening Family Recognition Day was held September 24, 2011, at Frederik Meijer Gardens & Sculpture Park in Grand Rapids. Families were greeted by NBS staff; then visited resource tables, participated in children's games and enjoyed the beautiful gardens. Thanks to all attendees and exhibitors for making the day a success!



We would like to thank all of Michigan's hospitals and healthcare providers for your work to implement the BioTrust parental consent process this year. We are currently receiving just over 90% of consent forms and over 80% of the forms are filled out properly. We are looking forward to working in 2012 to ensure all hospitals reach the benchmarks for returning over 95% of forms with over 90% filled out properly. We are also excited to announce we will be evaluating the BioTrust consent process in 2012 from both a parent and health care provider perspective. Please look for more information to come!



Unsatisfactory Samples Demand Attention



Unsatisfactory specimens are a problem for any newborn screening program. They make additional work for hospital and newborn screening staff and place an unnecessary burden on parents who have to bring their baby back for a repeat screen. The resulting delay in getting a valid test result could negatively impact the health of a baby with a rare metabolic disorder. The unsatisfactory specimen rate in Michigan has risen in recent years to about 1.8%, the sixth highest in the country. More recently the rate has climbed to over 3%!

The laboratory makes four 3.2 millimeter punches on two different blood spots for the initial screen. The punch arrangement within the spots are preset and cannot be adjusted to accommodate a smaller blood spot. Additional punches are often made on the remaining spots to confirm a result or for use in reflex tests such as the mutation assay for cystic fibrosis. The severe combined immunodeficiency (SCID) screening, which started last October, can require several more punches.

The most common reason for an unsatisfactory specimen is an insufficient amount of blood applied to each of the five circles. A single large drop of blood should be applied to one side of the card and allowed to soak through to the other side. Multiple applications of blood to a circle on the filter paper can cause layering and clotting. Collection technique is very important. The Clinical and Laboratory Standards Institute has published a guideline for collecting heel stick specimens. A copy of this guide was distributed to each birthing hospital in 2010. A simplified version of the instructions is on the back of each filter paper collection kit.

The lab is now taking pictures of the unsatisfactory bloodspots. If there is a question about a particular sample, please contact Lois Turbett at TurbettL@michigan.gov

The Newborn Screening Follow up Program strives to help hospitals reduce their unsatisfactory specimen rate. Every newborn screening coordinator receives a report entitled

Filling the five circles completely with blood would have the most impact on reducing the rate of unsatisfactory specimens.

"Newborn Screening Quality Assurance Notification" at the end of each quarter. Nine performance measures are listed, one of which is the number of unsatisfactory specimens for the individual hospital. Lois Turbett is available to work with staff in any hospital that requests help with specimen collection. She can be reached Toll-free at (866)-673-9939 or TurbettL@michigan.gov to answer your questions. 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.



NBS Quarterly Reports and Stellar Performance

During the fourth quarter of 2011, three hospitals met all seven NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

**Ingham Regional Medical Center
Pennock Hospital
Port Huron Hospital**

Performance Goals for NBS Quarterly Reports

1. <2% of screens are collected >36 hours after birth
2. >90% of screens arrive in the state laboratory ≤4 days after collection
3. <1% of screens are unsatisfactory
4. <2% of envelopes are batched (i.e., contain screens with collection dates >2 days)
5. >95% of electronic birth certificates have the NBS card number recorded
6. >95% of specimens have a returned BioTrust for Health consent form
7. >90% of returned BioTrust for Health consent forms are completed appropriately

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 1-866-673-9939.

Lab News: The Michigan Department of Community Health encourages hospitals to receive Newborn Screening laboratory reports via an **AUTOMATIC FAX TRANSMISSION**. Fax reporting provides significant improvement in screening result turn around time to your facility. See the form included with this newsletter.



Question: How can birthing hospitals save time and assure quality?

Answer: USE PRE-PRINTED ADDRESS LABELS!

MDCH is now encouraging all hospitals to use pre-printed hospital address labels on all NBS Specimen Cards! Using pre-printed labels will save staff time and eliminate incorrect information from appearing in the submitter area of the NBS card. The correct hospital code on the pre-printed label will prevent staff error.

Sample Address Label

Franklin Medical Center 32663 Riverside Avenue Franklin, Michigan 48205 517-335-8989	108000
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Important!! Hospital Code (points to 108000)

Nursery Phone Number (points to 517-335-8989)

CORRECT CONTACT INFORMATION NEEDED!
Please update your **provider contact list** so that current information is written on the card. Sometimes the physician information we receive is very outdated. Incorrect contact information can delay medical intervention for a baby with a positive test result. Remember that time is critical in the diagnosis and treatment of NBS disorders!

Instructions for Printing Address Labels:

Go to Microsoft Word Tools on your computer. See Letters & Mailings, Envelopes & Labels. Select label. Use Avery Template Label #5960. Use Avery Labels 5960.

Label Placement on the Filter Paper Matters:

The hospital address label is to be placed **only** on the **submitter** section of the newborn screening card.

Please Note:

Some hospitals place other labels and bar codes on other parts of the newborn screening card for internal use. We ask that any label added to the filter paper part of the card not be placed beyond the perforation at the distal end. After laboratory testing is completed, the cards are ripped apart at the perforation and sent to the Michigan Neonatal Biobank for storage. Any identifying information on the stored cards must be removed or defaced. Placing labels on the side of the perforation opposite the blood spots will prevent any HIPAA issues from being encountered when the spots are prepared for storage.

PLACE LABEL HERE (points to the submitter section)

MICHIGAN USE ONLY (points to the right side of the card)

NOTE card changes coming soon—additional data will aid interpretation of screening results