



Michigan Department of Community Health Newborn Screening News

Update-Summer 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.

New Nurse Consultant

We are delighted to introduce our new NBS Follow-up Nurse Consultant, Lois Turbett, RN.

The Newborn Screening Follow-up Unit welcomes **Lois Turbett**, who joins the program after spending three years as a nurse consultant in Children's Special Health Care Services (CSHCS). Lois is proud of her maize and blue background, having received both her Bachelor of Science in Nursing and her Master of Science in Parent-Child Nursing from the University of Michigan. Prior to working for the Michigan Department of Community Health, Lois spent 18 years working in local public health. Her background includes general public health nursing, jail and prison nursing, immunizations, well child clinics, maternal-child health, and CSHCS.

Contact information:

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NATIONAL HIGHLIGHT

DO YOU KNOW

The U.S. Department of Health and Human Services, Health Resources and Services Administration and Newborn Screening Connection?

The U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA) chartered the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) in 2003.

The SACHDNC advises the HHS Secretary by providing:

- ◆ Recommendations for grants and projects authorized under the Heritable Disorders Program
- ◆ Technical information to develop policies & priorities that will enhance the ability of State and local health agencies to provide for newborn and child screening, counseling and health care services for children at risk for heritable disorders
- ◆ Recommendations, advice or information that may be necessary to enhance, expand or improve the ability of the Secretary to reduce the mortality or morbidity in newborns and children from heritable disorders

Recently SACHDNC recommended point of care pulse oximetry screening for detection of congenital cyanotic heart disease. However, Secretary Sibelius has deferred a final national recommendation on the issue, pending further review of the evidence gaps. Hyperbilirubinemia screening is currently under consideration for universal screening.

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 Hemoglobinopathy

The Michigan Hemoglobinopathy Quality Improvement Committee

(MiHemQIC) was created in April 2009 by the Michigan NBS Follow-up Program. This committee consists of pediatric and adult hematologists, NBS laboratory and follow-up staff, and other Michigan residents interested in sickle cell anemia and other hemoglobinopathies. Meetings are held three times a year to review screening, diagnosis and treatment services for newborns and children with hemoglobinopathies.

Currently, MiHemQIC is reviewing expanded screening for alpha and beta thalassemia. Of particular interest is maximizing the detection rate of Hemoglobin H Disease by quantification of Bart's hemoglobin from dried blood spots. In addition, since October 2010, as part of Michigan's CDC funded Hemoglobinopathy Surveillance Project, the committee has overseen development of the hemoglobinopathy long-term follow-up database now available through the Michigan Care Improvement Registry (MCIR).

In 2010, the newborn screening program detected 61 newborns with sickle cell anemia or a related condition. Screening for sickle cell anemia was initiated in 1987, and since that time a total of 1565 newborns have been detected with these conditions.

June 19 has been designated World Sickle Cell Day. On Saturday, June 11 the MDCH Newborn Screening Program in conjunction with the Sickle Cell Disease Association of America-Michigan Chapter, in recognition of World Sickle Cell Day, provided a picnic and day-long outing at the Detroit Zoo for children with sickle cell anemia and their families. There were more than 100 in attendance.

REMEMBER - NEWBORN SCREENING SAVES LIVES

Michigan law requires the screening of all newborn infants for rare but serious disorders which can be treated if identified early.

NEWBORN SCREENING FAMILY RECOGNITION DAY—FALL 2011

Plans are underway for the Newborn Screening Family Recognition Day in Grand Rapids, Michigan on September 24, 2011. This special event will take place at the Frederik Meijer Gardens and Sculpture Park (<http://www.meijergardens.org/>).

Invited guests:

- ✓ Children diagnosed by newborn screening and their families
- ✓ Hospital Newborn Screening Coordinators and NBS medical clinic staff are invited.

The fun filled day, 10 AM—2:00 PM will include lunch, children's activities, tram rides and docent tours, exhibits from other MDCH programs and other organizations such as Save the Babies, PKU Perspectives, Fatty Acid Oxidation Disorders, and the March of Dimes.

Please contact the NBS Follow up Program for additional information at (517) 335-4181, or register online by September 1, 2011 at www.michigan.gov/newbornscreening. Early registration is encouraged.



FREDERIK MEIJER Gardens & Sculpture Park





BioTrust Parental Consent Process

We would like to thank all hospitals for their work to implement the BioTrust Parental Consent. During the first quarter of 2011 many of the consent forms were completed correctly, but a significant number were filled out incorrectly. Please note the following clarifications on how to fill out the BioTrust Consent Form:

- ☑ Be sure to use the current version of the BioTrust Consent Form that contains the “Administrative Uses Box”. If this box is not present on the BioTrust Consent Form, please contact the NBS Accountant at 517-241-5583 or KLASKO@michigan.gov to obtain replacement cards.
- ☑ Return the BioTrust Consent Form to the State Public Health Laboratory in the envelope along with NBS specimens. BioTrust Consent Forms should not be sent to the EHDI Program, or to accounting.
- ☑ Obtain a signature on the BioTrust Consent Form from the parent or legal representative ONLY if they wish to grant consent. If a parent declines, please do not collect a signature. CHECK “Information Provided to Parent” and “Parent Declined” in the Administrative Uses Box.

PARENT DECLINES:

- Check the “Information Provided to Parent” box
- Check “Parent Declined” box
- Parent **does not** sign

PARENT GRANTS CONSENT:

- Check the “Information Provided to Parent” box
- Parent signs and dates

The image shows a sample of the BioTrust Parental Consent Form with several annotations:

- Red arrows:** Point to the "Information Provided to Parent" and "Parent Declined" checkboxes in the "Admin. Use Only" box.
- Green arrow:** Points to the "Parent Signature" line.
- Green oval:** Encircles the "Parent Signature" and "Date" fields.
- Green box:** A callout box on the right side of the form contains the text: "Remove. Discuss with parent. If granted, collect parent signature and submit original signed copy to MDCH Laboratory. Give the parent this copy." This box is positioned over the barcode and the "Parent Signature" area.
- Yellow box:** A callout box on the right side of the form contains instructions: "DO NOT REMOVE OVERLAY See attached instructions for specimen collection and sending. Allow blood to dry for 3-6 hours using the overlay for support. Close the overlay when dry. Send within 24 hours of collection. Do not send specimens in plastic bags." This box is positioned over the right edge of the form.



If you have questions please contact the NBS Follow-up Program at 517-335-4181 or newbornscreening@michigan.gov

Question: Where are NBS laboratory reports sent?



Answer:

Two copies of the NBS laboratory report are sent to the submitting hospital. The submitter is asked to keep one copy and forward the second copy to the newborn's physician. Labels at the bottom of the report indicate the "Submitter Copy" and the "Physician Forward Copy".

NEWBORN SCREENING FOLLOW-UP PROGRAM

The newborn screening follow-up program is responsible for assuring that all Michigan newborns are appropriately screened and that parents, primary care physicians and pediatric sub-specialists are notified promptly when a newborn screen is positive. The program contracts with the University of Michigan, the Children's Hospital of Michigan and the Sickle Cell Association of America—Michigan Chapter to provide diagnostic and clinical services for all newborns with disorders detected through newborn screening.

Follow-up Program staff :

William Young, PhD, Program Manager
Carole Flevaris, PhD, Program Coordinator
Lois Turbett, RN, Nurse Consultant
Mary Kleyn, MS, Program Epidemiologist
Karen Andruszewski, BS, Program Specialist
Rosalind Lewis-McPhaul, Departmental Technician
Carolyn Smith, Departmental Technician
Valerie Ewald, Administrative Assistant
Kristy Tomasko, BS, Data Analyst
Carrie Langbo, MS, BioTrust Coordinator

Program Contact Information—517-335-9205

Medical Management Clinics:

Children's Hospital of Michigan
Metabolic Clinic—313-745-4513
Primary Immunodeficiency Clinic—313-745-4450
University of Michigan
Pediatric Endocrine Follow-up—734-647-8938
Cystic Fibrosis Follow-up—734-647-8938
Sickle Cell Center—313-864-4406

NEWBORN SCREENING NICU PROTOCOL REMINDER!

1. Fill out all NBS cards completely
2. It is not necessary to wait until discharge to obtain a second NBS specimen if a NBS disorder is suspected.
3. If you need a copy of the NBS NICU Protocol laminated outline for staff that was initiated on July 1, 2010 please contact us at newbornscreening@michigan.gov

Follow-up of Strong Positive NBS Results

When MDCH NBS identifies a strong positive result, the physician/health care provider is immediately notified by fax. The fax contains the following information:

1. Newborn Screening test results
2. Action required
3. Sub-specialist contact information

Simultaneously, MDCH NBS notifies the appropriate sub-specialist. The health care provider is contacted by the consulting sub-specialist to develop a plan of action for necessary diagnostic testing and evaluation.

This process requires accurate physician contact information. Please encourage staff to fill out all NBS information correctly.



For more NBS educational information visit our website: www.michigan.gov/newbornscreening

Important Changes to NBS Quarterly Reports

From the fourth quarter of 2010 on, your NBS quarterly reports will contain information on two additional measures related to the BioTrust for Health consent forms: returned consent forms and non-blank consent forms (i.e., signed, declined, or information provided).

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

Measure	Performance Goal
Late Screens	Less than 2% of screens collected greater than 36 hours after birth
Courier Time	Greater than 90% of screens arrive in state laboratory less than or equal to 4 days after collection
Unsatisfactory Screens	Less than 1% of screens are unsatisfactory
Batching	Less than 2% of envelopes are batched
NBS Card Number	Greater than 95% of electronic birth certificates have the NBS card number recorded
Returned BioTrust for Health Consent Forms	At least 95% of specimens have a returned BioTrust for Health consent form
Completed BioTrust for Health Consent Forms	At least 90% of returned BioTrust for Health consent forms are completed appropriately based on parent decision to consent or decline. (see page 3)



NBS Quarterly Reports and Stellar Performance

During the first quarter of 2011, 15 hospitals met all five original performance goals. Three hospitals, designated by an asterisk (*), met all seven performance goals, including the two new goals related to the BioTrust for Health consent forms. We would like to congratulate these hospitals for their impressive efforts!

Bay Regional Medical Center
 * **William Beaumont Hospital-Troy**
 * **Botsford General Hospital**
Huron Medical Center
 * **Huron Valley-Sinai Hospital**
Ingham Regional Medical Center
Lakeland Community Hospital-Niles

Hackley Lakeshore Community Hospital
Mercy Memorial Hospital-Monroe
Metro Health Hospital
Port Huron Hospital
Providence Park Hospital
St. Francis Hospital
St. Mary Mercy Livonia
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.

FOR YOUR INFORMATION: Infants Diagnosed by NBS in 2010

There were 280 Michigan newborns diagnosed in 2010 with at least one of the 49 disorders on the current newborn screening panel. Hospitals with the greatest number of newborns diagnosed include: The Spectrum Health System - 29 cases; William Beaumont Hospitals -28; Hutzel Hospital -25 and Henry Ford affiliated hospitals -16. Hospitals with at least one newborn with a diagnosed disorder are listed below.

ALLEGIANCE HEALTH _____	8	MID-MICHIGAN REGIONAL HEALTH CENTER _____	5
ALPENA REGIONAL MEDICAL CENTER _____	1	MT CLEMENS REGIONAL MEDICAL CENTER _____	1
ANNAPOLIS HOSPITAL _____	1	MUNSON MEDICAL CENTER _____	3
BATTLE CREEK HEALTH SYSTEM _____	2	MUNSON MEDICAL CENTER NICU _____	1
BAY REGIONAL MEDICAL CENTER _____	2	NORTHERN MICHIGAN HOSPITAL _____	3
BEAUMONT OF GROSSE POINTE HOSPITAL _____	1	OAKLAWN HOSPITAL _____	1
BORGESS MEDICAL CENTER _____	5	OAKWOOD HOSPITAL _____	6
BOTSFORD GENERAL HOSPITAL _____	6	OAKWOOD HOSPITAL - NICU _____	1
BRONSON METHODIST HOSPITAL - NICU _____	2	OAKWOOD SOUTH SHORE MEDICAL CENTER _____	2
CARSON CITY HOSPITAL _____	2	PENNOCK HOSPITAL _____	1
CENTRAL MICH. COMMUNITY HOSPITAL _____	2	PORT HURON HOSPITAL _____	2
CHARLEVOIX HOSPITAL _____	1	PORTAGE HEALTH SYSTEM LAB _____	1
CHILDREN'S HOSPITAL OF MICH NICU _____	1	PROVIDENCE HOSPITAL _____	1
COMMUNITY HEALTH CENTER OF BRANCH COUNTY _____	3	PROVIDENCE PARK HOSPITAL _____	4
COVENANT HOSPITAL _____	6	SINAI-GRACE HOSPITAL _____	9
COVENANT HOSPITAL NICU _____	2	SPECTRUM HEALTH BUTTERWORTH CAMPUS _____	20
CRITTENTON HOSPITAL _____	3	SPECTRUM HEALTH CARE- NICU _____	7
EW SPARROW HOSPITAL _____	2	SPECTRUM HEALTH GERBER MEMORIAL _____	1
EW SPARROW HOSPITAL - NICU _____	2	SPECTRUM HEALTH UNITED MEMORIAL _____	1
GARDEN CITY OSTEOPATHIC HOSPITAL _____	1	ST FRANCIS HOSPITAL _____	1
GENESYS REGIONAL MED CTR - HEALTH PARK _____	4	ST JOHN DETROIT NICU _____	2
GRATIOT MEDICAL CENTER _____	2	ST JOHN HOSPITAL _____	7
HENRY FORD WYANDOTTE SCN _____	1	ST JOHN MACOMB HOSPITAL _____	1
HENRY FORD HOSPITAL _____	10	ST JOSEPH MERCY HOSPITAL _____	6
HENRY FORD MACOMB HOSPITAL _____	2	ST JOSEPH MERCY HOSPITAL PONTIAC _____	6
HENRY FORD W BLOOMFIELD HOSPITAL _____	2	ST JOSEPH MERCY LIVINGSTON _____	1
HENRY FORD WYANDOTTE _____	2	ST MARY HOSPITAL - LIVONIA _____	2
HOLLAND HOSPITAL _____	4	ST MARY'S HEALTH CARE - GRAND RAPIDS _____	3
HOME BIRTH _____	2	THREE RIVERS AREA HOSPITAL _____	1
HURLEY MEDICAL CENTER _____	8	OHIO HOSPITALS _____	2
HURON VALLEY-SINAI HOSPITAL _____	4	U OF M HOSPITAL _____	10
HUTZEL WOMEN'S HOSPITAL _____	23	WAR MEMORIAL HOSPITAL _____	1
HUTZEL WOMEN'S HOSPITAL SCN _____	1	WEST BRANCH REGIONAL MEDICAL CENTER _____	1
HUTZEL WOMEN'S HOSPITAL NICU _____	1	WILLIAM BEAUMONT HOSPITAL - RO _____	13
INGHAM REGIONAL MEDICAL CENTER _____	4	WILLIAM BEAUMONT HOSPITAL - RO - NICU _____	6
LAKELAND MEDICAL CENTER - ST JOSEPH _____	1	WILLIAM BEAUMONT HOSPITAL - TROY _____	7
MECOSTA COUNTY MEDICAL CENTER _____	2	WILLIAM BEAUMONT HOSPITAL - TROY - NICU _____	2
MEMORIAL HEALTH CARE _____	1	ZEELAND COMMUNITY HOSPITAL _____	2
MERCY GENERAL HEALTH PARTNERS - MUSKEGON _____	1	Total _____	280
MERCY HEALTH PARTNERS HACKLEY CAMPUS _____	4		
MERCY HEALTH SERVICES NORTH-CADILLAC _____	1		
METRO HEALTH HOSPITAL _____	3		



Disorder	Confirmed to date for 2010 births
Amino Acids	14
Fatty Acid Oxidation	25
Organic Acids	16
Biotinidase Deficiency	13
Galactosemia	11
Congenital Hypothyroidism	101
Congenital Adrenal Hyperplasia	5
Cystic Fibrosis	34
Sickle Cell Conditions	61

280

Update on SCID testing in Michigan

The Michigan Newborn Screening Quality Assurance Advisory Committee approved the addition of Severe Combined Immunodeficiency Disorder (SCID) to the Michigan newborn screening panel. The Michigan NBS Laboratory testing for SCID will begin October 1, 2011.

SCID represents a group of more than 13 inherited disorders that lack functional T and B cells responsible for cellular and humoral immunity, respectively. In addition, the incidence of the disorder appears to be about 1/40,000 as compared to the earlier assumed incidence of 1/100,000 prior to screening.

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, infants with SCID can be successfully treated by bone marrow transplantation.