



Michigan Department of Community Health

Newborn Screening News

Fall 2013

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.

MICHIGAN HIGHLIGHTS

50th Anniversary of Newborn Screening

The Association of Public Health Laboratories (APHL) and the Centers for Disease Control and Prevention (CDC) is sponsoring a national traveling exhibit through 2013 celebrating the nation's 50 years of saving babies' lives through newborn screening. In honor of Newborn Screening Awareness Month and to celebrate Michigan's accomplishments, the exhibit visited Michigan in September. It stopped at three Children's hospitals in Detroit, Grand Rapids and Ann Arbor and finished the tour at the Capitol in Lansing.

Events began at C.S. Mott Children's Hospital in Ann Arbor. The Family Center was home to the exhibit for two days and had some special visitors. Riley and Teagan Barth, highlighted on the Michigan poster created by APHL, are two sisters who were diagnosed with cystic fibrosis through the Michigan Newborn Screening program. To read more about their story visit the [APHL blog](#).



Children's Hospital of Michigan in Detroit was the second stop. The exhibit resided outside the cafeteria for two days. The high traffic area exposed the program to many Children's Hospital employees and visitors. A lunch lecture on the Michigan Newborn Screening program was presented for nurses, including information on the history of NBS, follow-up program and various medical management centers.

Next, the exhibit was displayed at Helen DeVos Children's Hospital in Grand Rapids. Physicians from the Neonatal Intensive Care Unit (NICU), hospital staff, and NBS parents joined the NBS program in celebrating this great accomplishment. Dr. Lana Gagin, event organizer, announced that 7,000 babies are born each year at Helen DeVos Children's Hospital and that NBS provides "peace of mind" for new parents. A lovely cake was provided by the hospital for a special "meet and greet" and cookies were served in the hospital lobby following grand rounds.



Continue reading on the next page for details on the Capitol event.

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50 years of Newborn Screening

The final stop for the Michigan celebration was at the Capitol in Lansing. For three days, the exhibit was accessible on the first floor of the Capitol building. All Michigan legislators received a packet of information and were encouraged to visit the exhibit. The [Lansing press event](#) on the morning of Wednesday, September 18 aligned with the national event in Washington D.C. that afternoon.

During the press conference, four speakers voiced the benefits of Michigan's Newborn Screening program and the BioTrust for Health. The Michigan Department of Community Health's Chief Medical Executive, Dr. Matthew Davis, highlighted the Michigan program while Dr. Beth Tarini, Assistant Professor of Pediatrics at C.S. Mott Children's Hospital, spoke on the history of NBS and her own research. Both provided their firsthand experiences with infants who had positive screens. Dr. Nigel Paneth, Professor of Epidemiology and Biostatistics and Pediatrics at Michigan State University, expressed his



Picture of speakers (from left to right): Dr. Matthew Davis, Alex MacVicar, Dr. Nigel Paneth, Dr. Beth Tarini.

support and described the usefulness of the blood spots preserved through the BioTrust for Health. The final speakers were Neil and Alex MacVicar. Alex was diagnosed with galactosemia through Michigan's Newborn Screening program. After Neil introduced his son, Alex talked about how fortunate he was to be born at the time he was. He noted that if he had been born in an earlier time, before screening was implemented, he may not be here today. Alex gave a face to newborn screening and showed why newborn screening is vital and how it has become such a great national public health achievement.

NBS laboratory staff at the Capitol.



Michigan's Newborn Screening program has screened more than 6.6 million babies since 1965. Michigan hospitals, health care providers and public health professionals are to thank for ensuring more than 99% of newborns benefit from screening, rapid diagnosis and specialty medical treatments to prevent disability or death. Thank you for your great work!

For additional information on the event, visit www.michigan.gov/newbornscreening.

NBS follow-up staff at the Capitol.



NEW! CCHD screening



Congenital heart defects are the most common group of birth defects, affecting 9 in 1000 newborns. Critical congenital heart defects (CCHD) are those requiring surgery or catheter intervention in the first year of life. CCHDs remain one of the most significant causes of infant death in the United States. **Pulse oximetry** has been shown to detect some forms of congenital heart defects in the newborn. This screening targets twelve specific anomalies that have been classified as CCHD. Failure to detect such heart defects while in the hospital puts the baby at risk for serious complications within the first few days or weeks of life, often requiring emergency room care.

In September of 2011 the United States Secretary of Health and Human Services (HHS), Kathleen Sebelius, approved adding CCHD screening to the recommended uniform newborn screening panel, and this recommendation was later endorsed by the American Academy of Pediatrics.

Currently sixty-five (77%) hospitals in Michigan are screening for CCHD using pulse oximetry, and another fourteen are implementing a screening program in their birthing center. Statewide screening for CCHD has been recommended by the Michigan Newborn Screening Quality Assurance Advisory Committee and the Michigan Department of Community Health, was approved by the legislature and will become part of the mandated screening panel in April 2014. Michigan joins thirty-one other states that have already mandated pulse oximetry screening for CCHD in their newborns.

For more information please visit our website www.michigan.gov/cchd

Critical Congenital Heart Defects detected by pulse oximetry	
<i>Most likely to be detected:</i>	<i>Less likely to be detected:</i>
Hypoplastic left heart syndrome	Coarctation of the aorta
Pulmonary atresia (with intact septum)	Double-outlet right ventricle
Tetralogy of Fallot	Ebstein anomaly
Total anomalous pulmonary venous return	Interrupted aortic arch
D-Transposition of the great arteries	Single ventricle
Tricuspid atresia	
Truncus arteriosus	



NBS Quarterly Reports and Stellar Performance

During the second quarter of 2013, six hospitals met all six NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

**Crittenton Hospital
Huron Medical Center
Huron Valley-Sinai Hospital
Sturgis Hospital
William Beaumont Hospital-Troy
Beaumont of Grosse Pointe Hospital**

Performance Goals for NBS Quarterly Reports

- <2% of screens are collected >36 hours after birth
 - >90% of screens arrive in the state laboratory ≤4 days after collection
 - <1% of screens are unsatisfactory
 - <2% of envelopes are batched (i.e., contain screens with collection dates >2 days)
 - >95% of electronic birth certificates have the NBS card number recorded
 - >90% of specimens have a returned BioTrust for Health consent form that is completed appropriately
- *The Performance Goals were modified. Measures 6 and 7 have been combined.

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.



Important Reminders!

2012 NBS Annual Report

Each year, the Michigan NBS program releases a report that provides an overview of the program, screening performance metrics, and quality assurance information. Of the 111,509 infants screened in 2012, 275 (0.2%) were diagnosed with a disease. Overall, one infant out of 405 screened was diagnosed with one of the disorders included in the NBS panel. Through 2012, over 6.6 million infants have been screened in Michigan and over 5,100 diagnosed with diseases included in the blood spot NBS panel.

For more information, including a list of disorders included in the NBS panel, number of infants confirmed with each disorder in 2012 and cumulatively, and quality assurance information by nursery type, click on the "Documents, Forms, and Reports" link on the NBS website (www.michigan.gov/newbornscreening) and navigate to the 2012 NBS Annual Report.

- * As we approach the end of 2013, remember to check the year recorded under birth and collection date. Issues with incorrect year being recorded can cause delays in reporting.
- * Beginning December 1, 2013, cards that expire 2013-11, including some blue (initial) and pink (repeat) cards, will be designated unsatisfactory – expired card. Be sure to check the expiration date in the lower right hand corner of the card.
- * We have observed an increase in the number of specimens with the wrong hospital submitter code recorded. This error results in NBS mailers with patient identifiers being sent to the wrong hospital. To prevent this, MDCH is encouraging hospitals to use pre-printed labels with the hospital address and submitter code on all NBS specimen cards. Pre-printed labels will save staff time and eliminate incorrect information from appearing in the submitter area of the NBS card.



Be on the lookout for revised BioTrust Consent brochures!

These brochures will replace the BioTrust consent booklets for use with all new parents and will be sent to your hospital now with any new orders. We hope your staff and new parents find the brochure easier to read. Please have staff read the brochure prior to use with new parents and contact us if you have any questions!



Please Note: Upcoming State Holidays

November 11 — Veterans Day
November 28 and 29—Thanksgiving
December 24 and 25—Christmas
December 31 and January 1—New Year's

Mother's HBsAg Test Date and Result Article Correction.

In the last newsletter, the percentage of NBS cards that had mom's HBsAg date of testing and test results were reported incorrectly. Below is the correction. We apologize for the mistake.

For the first quarter of 2013, there were 26,257 NBS cards received by MDCH Vital Records. Out of these cards, 5,777 (22%) *did NOT include* mom's HBsAg date of testing and 3,973 (15%) *did NOT include* mom's HBsAg test result.

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