

Newborn Screening Update

Michigan Newborn
Screening Program



Announcements....

Important NBS Electronic Birth Certificate Information

The NBS Follow-up Program utilizes the metabolic card number recorded on the Electronic Birth Certificate information to identify and link newborns with metabolic testing information. It is important that all birthing hospitals include the NBS card metabolic number on each birth certificate for NBS follow-up quality assurance purposes.

The metabolic number is copied from the infants NBS card and entered on the infants (blue) EBC health history form by hospital staff. The metabolic number is then copied from the blue health history form and entered into the EBC by medical records staff. This protocol allows NBS Follow-up to link all infants to our NBS records.

Each NBS card has a pre-printed identification **kit number** which is printed above the UPC code. This **kit number** is also called the **metabolic number** on the (blue) health history form and EBC. Each NBS card has a submitters copy which is retained by the birthing or NICU unit. On the NBS card's (yellow) submitter copy the metabolic number/kit number appears in large red print. This metabolic number is to be recorded on the health history form and EBC (page 1). Many hospitals have designated staff that collect completed EBC information that has been entered on the health history form. Instruct unit staff to provide the EBC staff with the metabolic card number for inclusion on the EBC. This can also be achieved by attaching the NBS card submitters copy onto a medical chart sheet along with the patient ID. Instruct hospital staff to include the "red" metabolic number on the EBC. Either procedure will provide EBC staff with easy access to the NBS metabolic number for EBC entry. The inclusion of the NBS metabolic number on the EBC will provide ongoing quality assurance. See page 2

Contact Carole Flevaris, NBS Follow-up Coordinator for further information or assistance at (517) 335-8959.

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Contacts

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| NBS Follow-up Manager William Young (517) 335-8938 |
| NBS Follow-up Coordinator Carole Flevaris (517) 335-8959 |
| NBS Laboratory Manager Harry Hawkins (517) 335-8095 |
| NBS Accountant Valerie Klasko (517) 241-5583 |

Michigan Newborn Screening Card

Kit Number/Metabolic Number

The diagram illustrates the data flow between a physical Michigan Newborn Screening Card and an online Electronic Birth Certificate form. A teal arrow originates from the 'FIRST SAMPLE' section of the card and points to the 'Metabolic Card Number' field in the online form. Another teal arrow points from the 'Metabolic Card Number' field back to the card, indicating a bidirectional relationship or data exchange.

Michigan Newborn Screening Card Fields:

- Kit Number
- Metabolic Card Number
- State File Number
- Form Number
- Child's Name (First, Middle, Last, Suffix)
- Child's Time of Birth (Time, AM/PM)
- Delivery Info (Date of Birth, Sex, Plurality, Birth Order)
- Certifier Information & Date Certified (Certifier, Title, Date Certified)
- Attendant Information (Attendant, Title)

Electronic Birth Certificate (On-line) Fields:

- General Information: Record Type, Newborn Medical Record Number, Mother's Medical Record Number, Form Number, Metabolic Card Number, State File Number
- Child's Name: Child's First Name, Child's Middle Name, Child's Last Name, Child's Suffix
- Child's Time of Birth: Time, AM/PM
- Delivery Info: Child's Date of Birth, Child's Sex, Plurality, Birth Order
- Certifier Information & Date Certified: Certifier, Title, Date Certified
- Attendant Information: Attendant the Same as Certifier?, Attendant, Title

Electronic Birth Certificate (On-line)

Metabolic Number

• **Announcements continued**

NBS Epidemiologist Appointment

The MDCH NBS Follow-up Program is pleased to announce the appointment of another outstanding person to the NBS team. Mary Kleyn, MS is the newly appointed epidemiologist to the MDCH Newborn Screening Program. Mary has an undergraduate degree in chemistry from Hope College and a master's degree in epidemiology from Michigan State University. Mary is particularly interested in disparities in maternal and child health outcomes due to neighborhood context. Prior to joining the NBS program, Mary was previously employed as the epidemiologist for the Birth Defects and Early Hearing Detection and Intervention (EHDI) Programs at MDCH.

NBS Nurse Consultant Appointment

The MDCH NBS Follow-up Program is pleased to announce the appointment of a registered nurse to the NBS team. Vicki Jenks, RN, BSN, MPA is the NBS Nurse Consultant. Vicki has held several positions within MDCH. She was a regional consultant with the MDCH Children's Special Health Care Services Program, a contract manager for the Medicaid Ventilator and Traumatic Brain Injury Program, and a health care surveyor for the MDCH Licensing and Certification of Nursing Homes Program. Vicki has an undergraduate degree from the University of Michigan and a graduate degree in public administration with a focus on health care from Western Michigan University. Currently both of her children are enrolled at the University of Michigan.

UPDATE - NBS Hospital Coordinator Regional Meetings

The second NBS Follow-up Program Hospital Coordinator Western Michigan Regional Meeting took place on January 29, 2009 at Spectrum Health/DeVos Children's Hospital. NBS coordinators from sixteen birthing hospitals from Region 6 were invited to the meeting hosted by the MDCH NBS Follow-up Program. The follow-up education and coordination activities provided valuable information and tools for NBS Coordinators. Guest speaker, Robert Grier, Ph.D., FACMG, Technical Director of the Detroit Medical Center University Laboratories and Harper Hospital Pathology Department, presented a very informative lecture titled "Update on Michigan Newborn Screening: 30+ Rare Genetic Disorders." Janice Bach, MDCH Director of the Genomics and Genetic Disorders Section presented an overview of the MI BioTrust Initiative. Following the meeting the NBS coordinators received valuable tools which included the Clinical Laboratory and Standards Training Manual and Video along with the NBS Manual and MI Birth Defects Tool Kit. A tour of the Spectrum Health/DeVos Children's Hospital NICU was provided by Irene Mussin, R.N., NICU Discharge Manager.

The next NBS Follow-up Program Coordinators Regional Meeting scheduled will be announced in the near future. Registration materials will be forwarded to NBS Coordinators. Conducting NBS Regional Coordinator Meetings across the State of Michigan will provide for enhanced information sharing between NBS coordinators and MDCH NBS staff.

- **Newborn Screening Card Pricing**

Official notification will be going out to hospital administrators in September 2009 regarding price increase. As soon as this occurs the notification will be updated on our website under: **NBS card fee adjustment effective October 1st**. The Public Act 14, of 1987 statute requires that the fee charged (\$88.18) to support the NBS program be adjusted annually to reflect the cumulative annual percentage change in the Detroit Consumer Price (DCP) Index. October 1, 2008, The Michigan Department of Community Health applied the 3% increase in the Detroit Consumer Price Index to the cost of each newborn screening card purchased. Again on October 1, 2009 the fee for each newborn screening card will be determined according to DCP Index and a letter will be sent to hospital administrators and posted on the NBS website.

- **Newborn Screening Card and Brochure Ordering Reminder**

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

- **Entering Correct Race and Ethnicity Information**

It is important to fill in either the Hispanic or Non-Hispanic box and in addition fill in one of the six boxes on the newborn screening card for race. An infant may have more than one race or ethnicity checked IE Black/Hispanic, Arab Descent /White and Black/ American Indian, etc. Likewise an individual can be checked as multi-racial if the racial indicators available on the NBS Card do not apply. For example one parent is Black and the other is White and neither parent is identified as Hispanic, the card should be marked as Non-Hispanic and multi-racial.

Informing NBS of Deceased Infants

Please call or fax the names of all deceased newborn infants to the NBS Follow-up Program. This prevents needlessly contacting grieving parents regarding NBS issues. Please call or fax the NBS Follow-up Program at 517-335-4181, (fax) 517-335-9419 or (fax) 517- 335-9739.



- **IMPORTANT Reminders**



- **Saturday Testing**

It has been noted that the mail rooms or shipping departments of the majority of hospitals are closed on Saturdays. This lends to hospital staff being responsible for the mailing of NBS specimens to the MDCH laboratory on Saturdays. Often NBS specimens drawn during the afternoon and evening on Friday are not picked up or mailed until Monday morning. In an effort to address this issue, the NBS Follow-up Program has contracted with both Quest Diagnostics and UPS Courier Services for Saturday pick-up of NBS specimens. If you do not have courier service we recommend that you contact the Newborn Screening Follow-Up, Coordinator, Carole Flevaris at 517-335-8959. At that time you will be directed to the most appropriate courier service according to logistics. For UPS you will be provided with pre-printed UPS labels and instructions for contacting UPS for prompt Saturday pick-up at your site. Using a courier service will require that you

develop a protocol within your department for the additional utilization of courier services on Friday and early Saturday morning NBS specimens.

- **EDUCATION- Congenital Adrenal Hyperplasia**

There are 49 metabolic disorders currently tested in MI at the MDCH NBS Laboratory. Congenital Adrenal Hyperplasia, is an inherited endocrine disorder that affects the production of cortisol in the adrenal cortex. It is defined as a group of autosomal recessive disorders resulting from the deficiency of one of five enzymes responsible for the synthesis of cortisol. Steroid 21 hydroxylase deficiency, the most common form of CAH is due to the loss of enzyme function, affected individuals cannot synthesize cortisol efficiently and over produce cortisol precursors. Thus the adrenal cortex is stimulated by corticotrophin and overproduces cortisol precursors. Aldosterone deficiency, a cortisol precursor, may cause salt wasting CAH which contributes to hypovolemia, shock and failure to thrive. The cortisol precursors may also effect the biosynthesis of sex hormones. The cortisol precursors may also effect the biosynthesis of sex hormones. There is a classical and non classical form of CAH. Michigan had 2 diagnosed cases in 2007.

NBS Quality Assurance Information

- **Importance of Filling Out Newborn Screening Cards Correctly**

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, not using military time and entering data in the wrong fields on the specimen card are costly errors. Double check Birth Date/Time, Specimen Date/Collection Time, PHYSICIAN contact information and all required information to avoid time consuming errors that could delay reporting out a positive result. See information on pages 7.

- **Parental Refusal Form**

If a parent should refuse the newborn screening, please fax a copy of the signed Parental Refusal Form your institution uses to the NBS Program at 517-335-9419 or 517-335-9739. Missed NBS cases are found if there is a Newborn Hearing Screen and a birth certificate but there is no matching NBS blood specimen in the database. If the NBS Program had the parental refusal form on file we would know not to contact your institution about getting a family to return for a missed newborn screening blood test.

EARLY Specimens and Corrections

Just a reminder on Early specimens, drawn at < 24 hours. At the bottom of the Early Letter Notice there is an area to CORRECT Birth Date, Time and Collection Date and Time information. If information was filled out incorrectly on the specimen card submitted, please correct the information (please see page 5 for example). The majority of the time corrections save the baby from being poked again unnecessarily. Please do not send detailed pages from the medical record with this information. See page 7.

- **NBS Website**

Please refer to our website www.michigan.gov/newbornscreening for these helpful tools your staff can review:

[Instructions for completing the Newborn Screening card](#)

[Newborn Screening Specimen Collection Presentation](#)

[Newborn Screening Program Presentation.](#)

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.



Newborn Screening Program
 201 Townsend CV4
 PO Box 30195
 Lansing, MI 48909

Phone: (517) 335-9205 Fax: (517) 335-9419
 Email: mdch-newbornscreening@michigan.gov
 Website: www.mi.gov/newbornscreening

FACSIMILE TRANSMISSION ONLY

July 31, 2008

**EARLY SPECIMEN*
 NEEDS PHYSICIAN REVIEW**

Dear Doctor,

The newborn screening specimen obtained from this infant identified on the newborn screening card as your patient, was collected when the infant was less than 24 hours of age. This causes some of the test results to be inconclusive.

Baby: Accession #: Kit Number:
 Birth Date: Specimen Type: Medical Record:
 Collection Date: Gender: Gestation: wks
 Collection Age: Weight: grams NICU:
 Birth Order: TPN:
 Birth Facility:
 Mother Name: Phone:

Physician: Phone: Fax:
 Submitter: Phone: Fax:

| If the infant is NOT in the NICU / SCN | If the infant IS in the NICU / SCN and birth weight => 1800gms | If the infant IS in the NICU / SCN and birth weight <1800gms |
|---|---|---|
| <p>Call the parents and inform them of the early specimen.</p> <p>A second newborn screen should be obtained on a pink repeat specimen card. The repeat newborn screen can be collected at the delivering hospital or nearest outpatient laboratory and should be forwarded to the Newborn Screening Laboratory ASAP.</p> | <p>If on TPN and/or Transfusions repeat newborn screen >72 hours after TPN and/or Transfusions discontinued.</p> <p>If not on TPN and/or Transfusions repeat newborn screen ASAP</p> | <p>Follow NICU protocol for obtaining repeat specimens at 14 and 30 days of age (or upon discharge).</p> <p>If the infant is positive for any disorder please follow instructions as directed on the positive report.</p> <p>If the infant receives continuous transfusion and/or TPN during the first 30 days, a repeat specimen should be obtained 72 hours after discontinuing transfusion and/or TPN and at 90 days post transfusion.</p> <p>Alternatively, if there is a 72-hour window of opportunity during the first 30 days that the infant is not being transfused or receiving TPN, the post-72 hour repeat specimen should be obtained. This specimen would be in place of the 14 or 30-day specimen whichever is closer. The 14 day post transfusion specimen would still be required.</p> |

***Note: If your records indicate this specimen was collected at => 24 hours please provide the following information and fax back to 517-335-9773 so that we may correct our records on this infant.**

Birth Date: _____ Birth Time: _____ Collection Date: _____ Collection Time: _____
 (Military) (Military)

CONFIDENTIAL

The information contained in this fax/print-out from the Michigan Department of Community Health, Newborn Screening Program is confidential in nature. It is for the sole use of the subscriber named on the report(s). If you are not the intended recipient, you are hereby notified that any disclosure, distribution, copying or the taking of any action in regard to the contents of this report is strictly prohibited. If you have received this report(s) in error, please telephone us immediately at (517) 335-9205 so that corrective action and destruction or return of the document(s) can be arranged.
 DCH-1272 (07/05) (W)

We invite you to share positive experiences, suggestions and other NBS highlights in our newborn screening newsletter.

Please contact Carole Flevaris, Ph.D. at 517-335-8959



201 Townsend Street
Lansing, MI 48913

Phone: 517-335-9205
Fax: 517-335-9419
Email:mdch-newbornscreening@Michigan.gov

Please complete the questionnaire below so that we may update our records to serve you best. Fax to 517-335-9419 or 517-335-9739

Name _____ **Title** _____

Hospital or Institution _____

Address _____

Email _____

Phone _____ **Fax** _____

I prefer to receive a hardcopy of the NBS Newsletter _____

I prefer to receive e-mail copy only _____

NBS Screening & Follow-up topics that I would like to learn more about are:

1 _____

2 _____

3 _____

4 _____