

# Newborn Screening Update

Michigan Newborn Screening Program



Spring 2007

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## Announcement -

As most of you know by now Tammy Ashley has left her position as Newborn Screening Coordinator within the Newborn Screening Program and has accepted a position as Lactation Consultant with the WIC program. We're sorry to see Tammy leave and wish her all the best in her new position.

For now please email the Newborn Screening Program at: [mdch-newbornscreening@michigan.gov](mailto:mdch-newbornscreening@michigan.gov) with any issues you would have contacted Tammy about or call our main line at 517-335-9205 and you will be directed to the person who can help you out. Thank you in advance for your cooperation as we work towards getting this position filled.

## Update on Newborn Screening Card Order -

The repeat blood collection kits (pink cards; DCH-1154) have recently run out of stock. The laboratory has an interim card that is distributed in packages of ten instead of the normal packages of 25 cards. Because of validations from the manufacturer, the expiration date on the current pinks has been extended from 03/07 to 03/08. The interim and older cards in circulation will be replaced as soon as the newly printed cards are received.

We are sorry for any inconvenience caused when using the temporary pink cards and expect a quick resolution to this problem.

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# NEWBORN SCREENING ON-LINE EDUCATIONAL MODULE Free CEUs!\*

The Region 4 Genetics Collaborative, through HRSA Grant Funding\*, is proud to announce the availability of *Newborn Screening: What Prenatal Caregivers Need to Know*. This **self-paced, on-line** educational module is accessible **free** of charge to all health care professionals and providers involved in the care of new and expectant mothers.

The purpose of this course is to increase provider ability to educate expectant and new parents about newborn screening. As a healthcare provider, YOU have an essential role in helping parents to understand the importance of their baby's newborn screening. YOU have the opportunity to educate parents and save lives!

This module features information about:

- The benefits of newborn screening and the components of a successful newborn screening experience
- Where to find state specific newborn screening information
- Detailed information on the critical aspects of specimen collection
- Newborn screening results and follow-up procedures
- Newborn screening laws and regulations
- Where to find disorder specific information and resources

The online course — *Newborn Screening: What Prenatal Caregivers Need to Know* course can be accessed at <http://region4genetics.org/>.

\*The Michigan Public Health Institute Systems Reform Program is acting as the lead agency for the project, which is funded by the Federal Maternal and Child Health Bureau and the Health Resources Services Administration.

<http://region4genetics.org>



\*Continuing Education Units (CEUs) will be granted to nurses successfully completing the course.

Cincinnati Children's Hospital Medical Center (OH-046) is an approved provider of continuing education by the Ohio Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation (OBN-001-91). Provider status valid through 9/1/09.

## Update on the new NICU guidelines -

The new NICU guidelines, for infants weighing less than 1800 went into effect on March 1, 2007. Based on calls for clarification we have received, some revisions have been made in regard to when Transfusions and/or TPN are involved. The revised NICU Guidelines are enclosed with this newsletter as well as a revised NICU algorithm. In addition pages 3 and 9 of the Provider manual have been updated and are also enclosed. All of these revisions are also available on the website: [www.mi.gov/newbornscreening](http://www.mi.gov/newbornscreening).

## NICU Invitation -

The NICU coordinators have been emailed an invitation from Newborn Screening Follow-up for a one day visit in August to share past and current Newborn Screening activities and to plan for the future. If you did not receive the email could you please contact us at [mdch-newbornscreening@michigan.gov](mailto:mdch-newbornscreening@michigan.gov) so that we can update our contact information for you.

Please don't forget to respond to the email with your availability by the end of May.

## More Updates ...

### Mailing Address Change for Hearing Cards:

The Early Hearing Detection and Intervention (EHDI) program is now able to scan hearing screen cards at the office. Please send all newborn **hearing** screen cards to the address below. All blood spot specimen cards still need to be sent to the Martin Luther King address.

MDCH/EHDI Washington Square Building Attn: Erin Estrada 109 Michigan Ave, 3rd floor Lansing, MI 48913
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### Discontinue:

Please discontinue use of the **Newborn Screening Program Hospital Discharge Sheet** that had been sent to hospital coordinators back in February. Based on user comments and usage we are re-evaluating if it met original intentions.

### Returning the blue initial NBS specimen card for credit:

Please include the completed NBS Card Replacement form with the top copy of the blue initial NBS specimen card when requesting credit. Please send both to the address noted on the form.

Michigan Department of Community Health

## Newborn Screening for NICU Infants < 1800 Grams

### Provider Fact Sheet

#### **Newborn screening and premature infants**

Newborn Screening is an important part of infant health maintenance. However, like so many other programs designed primarily for the healthy term baby, newborn screening of the premature, low birth weight, and ill infants is not a simple or straightforward process. The neonates' immaturity and the necessary therapeutic interventions interfere with both the collection of samples and the interpretation of newborn screening results.

#### **Why should premature infants be screened differently?**

Premature infants should be screened differently to minimize both the false positive and false negative results in these small babies. Collecting three specimens from each infant, and viewing the results together, will give a clearer picture of the neonate's risk for the disorders included in Michigan's screening panel.

#### **How should the specimens be collected?**

Specimens should be collected on the blue screening cards at 24-36 hours after birth, unless the infant receives blood. In this case, obtain the specimen prior to blood administration including ECHMO (Extracorporeal Membrane Oxygenation). Repeat specimens are obtained on pink cards at 14 and 30 days of age or upon discharge if discharge is prior to 14 or 30 days of age. Ordering all three screens upon the infant's admission to the NICU will be most efficient. If the baby goes home after the 2<sup>nd</sup> specimen, then that is the last specimen.

#### **Why obtain specimen before transfusion or TPN?**

If the infant requires transfusion or TPN before 24 hours of age, collect the initial specimen pre-transfusion/TPN and specimens at 14 and 30 days of age or upon discharge.

If the infant receives a transfusion or TPN before the initial screen is collected still proceed to collect an initial 24-hour specimen and specimens at 14 and 30 days of age. In addition, 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. 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 at that time. This specimen would be in place of the 14 or 30-day specimen whichever is closer. The 90-day post transfusion specimen would still be required.

#### **Are these screens done differently than regular newborn screens?**

No. The laboratory testing is the same. Clinicians will still be notified of all abnormal results.

#### **Are the reports different?**

The report format is the same for all newborns except as noted below. Please follow instructions on the reports in obtaining repeats when requested.

The following situations are reported differently for infants in the NICU:

- If the initial screen for congenital adrenal hyperplasia (CAH) is positive, the report will suggest clinical evaluation of the infant and a repeat screen at 14 and 30 days of age. Positive results on repeat screens will be treated the same way as positive results on other babies.
- If the amino acid pattern is consistent with transfusions and/or total parenteral nutrition (TPN) on the initial or 14-day sample, no special action will be recommended; the next screening sample will simply be requested. Only if the result is consistent with TPN on the 30 day specimen is the request made to repeat the newborn screen >72 hours after TPN and/or transfusions discontinued.

Any questions about requests for repeats or infant status in relationship to testing can be answered by medical management centers.

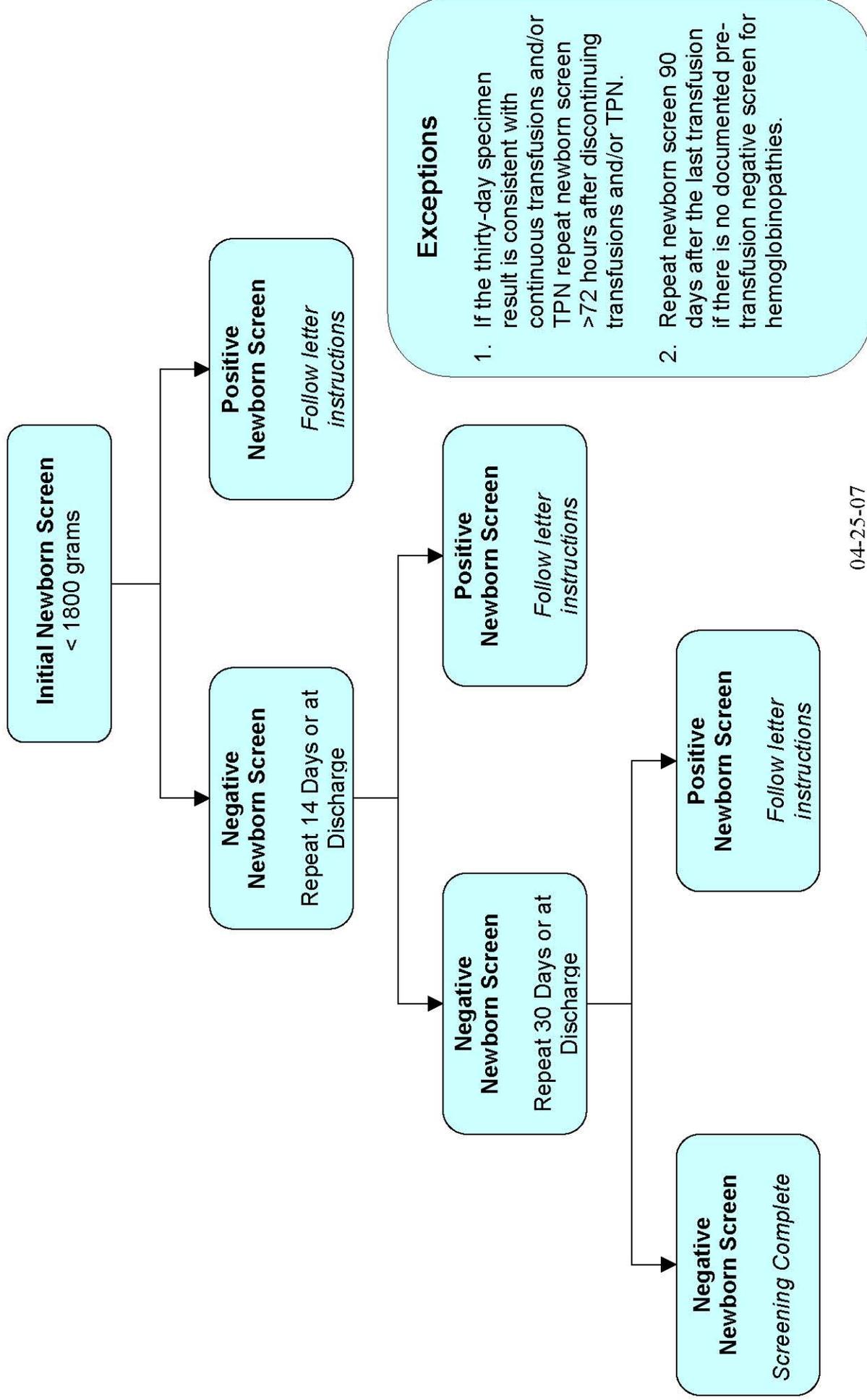
#### **Where can I get additional information?**

- Newborn Screening NICU Provider Manual for Michigan is available on-line at: <http://www.michigan.gov/newbornscreening> Hard copy versions of the manual are provided to Michigan's NICU coordinators.
- The staff of the Newborn Screening Program at the Michigan Department of Community Health is available to answer your questions at 1-866-673-9939.

Michigan would like to acknowledge and thank Minnesota Department of Health staff Abbie Abboud and Beth-Ann Bloom, for their creation of this document and willingness to share it for the benefit of Michigan's children.

# Newborn Screening Neonatal Intensive Care < 1800 Grams Algorithm

Effective Date March 1, 2007



On March 1, 2007, the MDCH Newborn Screening Program undertook an initiative to improve the screening process for infants with birth weights under 1800 grams. Due to their immaturity, these small infants are more likely to have conditions that are missed by standard screening protocols. Prematurity, together with the therapeutic regimens that very low birth weight infants require, also make false positive and false negative results more likely. When an infant weighing less than 1800 grams is born, **in addition to ordering the initial newborn screen, request that specimens be collected for the MDCH Newborn Screening Program at 14 and 30 days of age.** Reviewing the results of the three screens, as the infant matures, is likely to give a more accurate assessment of risk that the newborn has or does not have one of the newborn screening disorders. This reflexive re-screening protocol is likely to reduce both false positive and false negative results for NICU infants.

Look for highlighted text throughout this manual for more information on the initiative to improve newborn screening for infants weighing less than 1800 grams (see appendix 10).

## HEARING SCREENING

Approximately 250 deaf and hard of hearing infants are identified, annually, by newborn hearing screening in Michigan. Although hearing screening is not currently mandated, all Michigan infants should have hearing screening as a standard of care. NICU infants are at increased risk for hearing loss when compared to the general newborn population. Hearing screening of premature, ill, and infants with birth defects can be problematic due to confounding factors presented by their conditions and the treatment they require. Michigan has instituted a **mandated reporting system** for universal newborn hearing screening. The first goal of the hospital-based program is to screen all infants by one month of age. Infants who exhibit evidence of hearing loss should have an hearing assessment by an audiologist by three months of age and early intervention services by six months of age. Hearing screening should be completed by one month of age through either of the following methods: Otoacoustic Emissions (OAE) or Automated Auditory Brainstem Response (AABR). The NICU should have a protocol to appropriately screen the hearing of infants. When MDCH is informed about an infant who does not pass the hearing screen, additional information is requested from the hospital and recommendations for referral and follow-up are sent to the family doctor. Please contact the MDCH Early Hearing Detection Intervention (EHDI) Program to receive the "Medical Follow-up Protocol: Newborn Hearing Screening". For additional information see appendix 5.

- (5) If a newborn is discharged from the hospital prior to 24 hours of age, a newborn screening specimen should be collected and arrangements should be made to collect a subsequent specimen.

Interpreting screening results for specimens obtained from newborns less than 24 hours of age is difficult, and both false positive and false negative results are more likely to occur. A repeat specimen should be obtained on all newborns screened before 24 hours of age. All positive screening results from early specimens are reported to the submitting physician with appropriate instructions for follow-up. Hemoglobinopathies, galactosemia and biotinidase deficiency, and screening results are valid on early specimens. All other results, positive or negative, cannot be accurately interpreted.

For specimens collected before 24 hours of age from infants weighing less than 1800 grams, MDCH will include a different request for repeat specimens on the infant's report:

The newborn screening specimen obtained from this infant was collected at less than 24 hours of age, this causes some of the test results to be "inconclusive".

Follow NICU protocol for obtaining repeat specimens at 14 days of age (or upon discharge) and 30 days of age (or upon discharge).

### **Special Circumstances: Transfusion**

- (1) An infant who requires a transfusion before 24 hours of age should have a newborn screening specimen collected prior to transfusion.
- (2) If an infant is transfused before the newborn screening specimen is obtained note the time and date of transfusion on the newborn screening card. Screening of the <1800 gram newborn transfused prior to obtaining the newborn screen is no different than screening the  $\geq$  1800 gram transfused baby. In either case obtain a repeat specimen >72 hours after the last transfusion date and an additional repeat specimen for hemoglobins 90-days after the last transfusion date. If the newborn leaves the hospital prior to the 72-hour or three-month intervals, include instructions for collection of the repeat newborn screen in the discharge summary to the primary care provider.

**If you would like to receive the NBS Update, have previously requested to be placed on the mailing list, have additions, corrections or deletions, please *complete the information below* and *return this page* to the address listed below.**

**If preferred, you may also send an e-mail: [mdch-newbornscreening@michigan.gov](mailto:mdch-newbornscreening@michigan.gov)**

**Please indicate if your preference is to receive this newsletter by e-mail or regular mail.**

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