



# Newborn Screening Update

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## Announcements . . .

### NBS HOSPITAL COORDINATOR TRAININGS

MDCH Newborn Screening staff has offered five Regional Trainings in the state this year. The regional trainings were held at a tertiary center, with surrounding hospitals invited to participate in the trainings. The past three offered nurse participants six contact hours for the day long presentations. A total of 40 hospitals and about 100 individuals have participated. The response and active participation has been great. We would like to invite any staff who assists in birthing education, delivery, electronic birth records or the NICU to come and learn more about Newborn Screening in Michigan.

We are planning three more trainings this year. Please consider attending any one of the following:

- Covenant Hospital September 16, 2009 in Saginaw
- Bronson Hospital September 30, 2009 in Kalamazoo
- Marquette General Hospital October 13, 2009 in Marquette

Please contact Vicki Jenks at 517-335-1966

Or Carol Flevaris at 517-335-8959 for a registration form.

### \$\$ NEWBORN SCREENING CARD FEE DECREASING \$\$

The Michigan Department of Community Health's Newborn Screening Program has announced a decrease in the cost of newborn screening blue (initial) cards. The fee is adjusted annually to reflect the cumulative annual percentage change in the Detroit Consumer Price Index. The index declined 1.5% for the past fiscal year. Starting October 2009 you should expect to see a decrease of \$1.32, lowering the cost of each NBS card to \$86.86.

## Michigan BioTrust for Health Stores Leftover NBS Samples

MDCH has recently announced plans for a new initiative called the Michigan BioTrust for Health. The BioTrust will improve storage conditions for dried blood spot samples (DBS) left over after newborn screening is done, and let researchers know dried blood spots can be used for medical and public health research after all identifying information is removed. All research studies must first be approved by the MDCH scientific review panel and IRB (Institutional Review Board).

As technology advances, interest in using stored human tissue samples, such as newborn screening DBS, for biomedical research continues to increase. Over the past few years, MDCH has worked with the state's major research universities and Van Andel Institute as partners to develop a model state-based (DBS) repository. Based on advice from the state Attorney General's office in the 1980's, over three million DBS dating back to 1984 were retained in storage after completion of screening tests. In 2000, the Michigan Legislature amended the public health code to allow use of these residual DBS samples for medical research, as long as confidentiality is maintained. Once screening is completed at the state laboratory, samples are stripped of all identifying information and will be stored indefinitely in a temperature-controlled facility at the Michigan Neonatal Biobank, a non-profit charitable organization located in Wayne State University's Biobanking Center of Excellence.

A population-based biobanking effort such as the Michigan BioTrust raises ethical and legal concerns that are being addressed through consultation with experts as well as a variety of community engagement activities. Presentations, surveys and focus group discussions held over the past year indicate that a substantial majority of the public supports the use of DBS for research to study health concerns including childhood conditions, adult disorders and environmental hazards. However, Michigan citizens say they want to be informed that de-identified newborn screening samples are stored, and may be used for future research.

MDCH Newborn Screening staff are currently working on new informational brochures and a parental consent process for storing a baby's leftover DBS for possible research. Information about the BioTrust is now included in the regional Hospital NBS Coordinator Trainings and we will continue to keep you informed as new developments occur. Many hospital coordinators and mother/baby nurses have already provided extremely valuable and important feedback on ways to obtain parental consent in a variety of hospital settings. Thank you for your suggestions!

We encourage you to learn more about the BioTrust. Anyone who has not already filled out the survey during a training is also invited to participate in our on-line survey. Please visit [www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening) and click on the Michigan BioTrust for Health link. The survey takes only a few minutes to complete, and is intended for any Michigan resident (18 years or older) who wants to provide feedback. For more information, please contact Carrie Langbo, BioTrust Community Outreach Coordinator at [langboc@michigan.gov](mailto:langboc@michigan.gov).



## Newborn Screening Laboratory Implements an Improved Screen for CAH

One goal of newborn screening is to reduce the number of false positive results without missing any true cases. For congenital adrenal hyperplasia (CAH), the laboratory measures 17  $\alpha$ -hydroxyprogesterone (17-OHP) which can accumulate from a defect in 21-hydroxylation cortisol production. Low birth weight babies in the Neonatal Intensive Care Units often have stress related 17-OHP elevations. The high 17-OHP can also be due to cross reactivity of other steroids with the antibody used in the laboratory test. The MDCH laboratory has been working since May to validate a new kit with improved specificity from a different formulation of antisera and thus, less cross reactivity with other steroids. In August, the laboratory switched to this kit and early indications are that the number of false positives will be more than cut in half.



STATE OF MICHIGAN  
DEPARTMENT OF COMMUNITY HEALTH  
LANSING

JENNIFER M. GRANHOLM  
GOVERNOR

STATE OF MICHIGAN  
DEPARTMENT OF COMMUNITY HEALTH  
LANSING

JANET OLSZEWSKI  
DIRECTOR

July 30, 2009  
Dear Doctor:

**Re: Important change in reference ranges for Neonatal 17-alpha- OH-progesterone.**

Please note that on or about Monday, August 3, the reference ranges for neonatal 17-alpha-OH-progesterone (17-OHP, PerkinElmer Life & Analytical Sciences, Turku, Finland) used for screening newborns for congenital adrenal hyperplasia (CAH) will change at the MDCH Newborn Screening Laboratory. These changes are summarized below and based on data from about 3000 newborns tested from June 8 to July 15, 2009. All units for 17-OHP listed are **ng/ml**.

**For newborns, >= 2500 gms, >12 hrs old**

<u>Current cutoff</u>	<u>New cutoff</u>	<u>Result</u>
<90	<65	Normal
90-109	65-89	Borderline positive
>109	>89	Strong positive

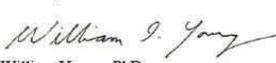
**For newborns, <2500 gms and/or <= 12 hrs old**

<u>Current Cutoff</u>	<u>New Cutoff</u>	<u>Result</u>
<150	<100	Normal
150-209	100-149	Borderline positive
>209	>149	Strong positive

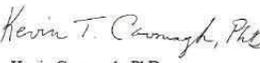
These reference range changes are necessary because of a reagent formulation change for the 17-OHP assay. Dried spot values for 17-OHP are approximately 50% lower with the new formulation because of improved antibody specificity. These new reagents have less cross reactivity with other steroid hormones than was observed with the current lot of reagents.

For questions or comments on this important change, please contact the Newborn Screening program (517-335-4181).

Sincerely,



William Young, PhD  
Director, Newborn Screening Program  
Bureau of Epidemiology



Kevin Cavanagh, PhD  
Division Administrator  
Bureau of Laboratories

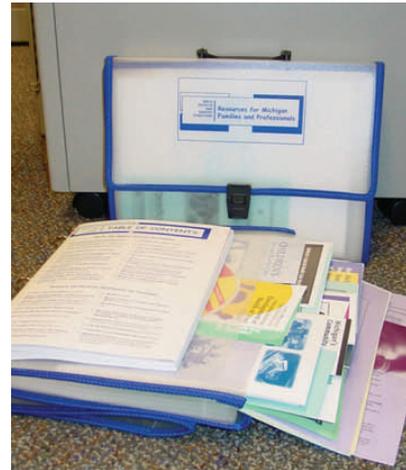
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Birth  
Defects  
and  
Genetic  
Conditions

## Resources for Michigan Families and Professionals

### **Resource Highlight: Birth Defects Toolkit**

The MDCH Birth Defects Program is located in the Genomics and Genetic Disorders Section of the Division of Genomics, Perinatal Health and Chronic Disease Epidemiology. A key program objective is to help link children with birth defects to available services and support systems. The Birth Defects Toolkit is designed to give health care and service providers information about state resources they can share with the families of children with special needs. Each kit contains more than 100 pamphlets, brochures, fact sheets and order forms from Michigan programs that support babies and young children. Materials from the Children's Special Health Care Services (CSHCS), Newborn Screening (NBS), Early Hearing Detection and Intervention (EHDI) and *Early On*® Michigan are just a few of those represented. Plus, there are resources designed especially for families and providers with input from community reviewers. *Special Care for Special Kids: A Guide for Michigan Families* follows the Medical Home theme to support the need for accessible, family centered, coordinated, compassionate, and culturally effective care. The guide includes a section to help families keep track of information by providing sample forms to keep everything in one place. The *Hospital Referral Guide*, for healthcare providers, summarizes Best Practices in referral to community resources when preparing for discharge of an infant with special care needs. The Newborn Screening and Genetic Disorders series of fact sheets provide condition-specific information and resources to families and providers for more than two dozen rare conditions.



The electronic version of the Birth Defects Toolkit and other program resources can be found online at [www.michigan.gov/genomics](http://www.michigan.gov/genomics) - the MDCH *Michigan Public Health Genomics* webpage. Request a toolkit by contacting the program. E-mail [BDRFollowUp@michigan.gov](mailto:BDRFollowUp@michigan.gov); call Toll Free 1-866-852-1247 or go to the genomics webpage. Every toolkit is numbered - register the toolkit to receive updates by providing your contact information.

*January is Birth Defects Prevention Month.* Risks to mother and baby when mother has diabetes is the focus in January of 2010. Be on the lookout for the Michigan virtual resource folder coming soon...

Joan Ehrhardt, Program Coordinator  
Birth Defects Prevention and Referral Program  
Division of Genomics, Perinatal Health and Chronic Disease Epidemiology  
Michigan Department of Community Health



## Newborn Screening Follow-up Program Family Recognition Day

The Michigan Department of Community Health (MDCH) Newborn Screening (NBS) Follow-up Program will host the second Parent and Family Network Initiative during the spring of 2010 at the Impression 5 Science Center in Lansing, Michigan. The participating children and families represent the NBS Program's early identification of children with 49 rare but treatable disorders. The Parent and Family Network Initiative Event was launched in 2008 to ensure that the families identified have a voice in the policies and programs impacting the services provided by the Newborn Screening Follow-up Program.

The NBS Family Recognition Day for children and parents will include new activities and valuable learning experiences for the whole family. Exploration of the fun-filled Science Center will be open to families. Hands on learning opportunities, parent networking activities, workshops and refreshments will be provided for all participants. Last year, over 150 individuals and 14 exhibitors participated in this special event. Please watch for further details and encourage parents to bring their children and join the NBS Follow-up Program for a memorable day. Further information [and registration] is available by calling Carole Flevaris, NBS Follow-up Coordinator at (517) 335-8959 or the Newborn Screening Follow-up Program Main number at (517) 335-9205.

### MCIR

The Michigan Care Improvement Registry (MCIR) is a database that physicians use to record and view immunization records. NBS results are now available on the MCIR, and the goal is for health care providers to be able to access their patients' results in MCIR by 14 days of age. You can help us achieve this goal by following a few simple steps:

1. Develop an internal hospital procedure, so your Electronic Birth Records (EBR) staff can add the NBS kit number to the EBR. Recording the NBS kit number allows our staff to quickly link the results of the screen to the EBR and add this information to the MCIR.
2. Please encourage your EBR staff to submit their electronic information to the state of Michigan as quickly and often as possible, so we can reach our 14 day goal!

## Reminders....

### Hospital Codes on NBS Card

In an effort to improve the data NBS keeps and sends to each hospital, we are asking that NICU please add an "01" and specialty units add an "02 at the end of your individual hospital number.

### Hospital Visits

Vicki Jenks, NBS Nurse Consultant is available to make individual visits to your hospital unit. If you wish to have her come, please email [jenksv@michigan.gov](mailto:jenksv@michigan.gov) or call 517-335-1966.

### Courier System

If you currently use UPS as the primary courier for newborn screening lab cards, please put an orange sticker on your UPS envelope on Friday to ensure delivery to the NBS lab on Saturday.

### Quality Assurance

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 can delay reporting of results and treatment which are costly if the child has one of the disorders. Always double check birthdate and time, specimen date and collection time, physician contact information and all other necessary information located on the Newborn Screening card.

### NBS Card Ordering Information

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

## Michigan Newborn Screening Program

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Website: [www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening)

State of Michigan  
Newborn Screening Program

If you have co-workers who would like to receive an electronic copy of the Newborn Screening Newsletter please send the name, job title and email address to:

Email: [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov)  
or

Have them email us at the above address

### *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.*