

Newborn Screening Update

Michigan Newborn Screening Program



October 2006

Volume 5

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Introducing

Derek K. Bair, MD, FAAP, is the Corporate Director, Neonatology, at Oakwood Hospital and Medical Center in Dearborn. His responsibilities include: corporate budgetary and quality assurance responsibilities for the Oakwood NICU and Department of Neonatology; program development within the Oakwood Healthcare System regarding newborns and care delivery system; and, all contractual arrangements between Oakwood Healthcare System and the department physicians, and other healthcare institutions.

Dr. Bair received his undergraduate degree in Biology at the University of Toledo and attended Medical School at Wright State University in Dayton. Dr. Bair completed his residency in Pediatrics at the Medical College of Ohio, Toledo, OH and a Fellowship in Neonatal-Perinatal Medicine at Baylor College of Medicine, Houston, TX.

Dr. Bair has served as the volunteer Chairperson for the MDCH Newborn Screening Advisory Committee since January, 2003. His work in a "front-line" clinical advisory role aids MDCH in its decision processes to advance/improve the newborn screening process offered to the citizens of Michigan. Dr Bair is the Co-Chairperson for the 2006 March of Dimes Prematurity Campaign for the State of Michigan. He is also a volunteer for the Wayne County Fetal Infant Mortality Review Project (FIMR).

Dr. Bair and his wife, Christina, have two children, Emily and Nicholas. He enjoys swimming, attending his daughter's swim meets, dining out, cooking, baking, drawing, and sketching.

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What if a mistake is made on the blue initial NBS specimen card?

If a mistake is made while completing the documentation on the blue initial NBS specimen card please do the following:

1. **Complete the NBS card replacement form** (available on the NBS webpage)
2. Note the reason on the card and tear off the top blue page
3. Place the blue page and the replacement form in an envelope
4. Mail to: **MI Dept of Community Health
Attn: Newborn Screening
4th Floor Lewis Cass Bldg
320 South Walnut
Lansing, MI 48913**

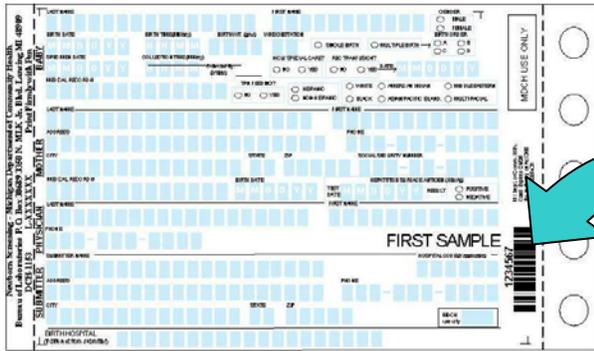
NOTE: Make sure that the same NBS specimen card is utilized for both the hearing screen documentation and the NBS blood specimen.

Electronic birth certificate changes are coming:

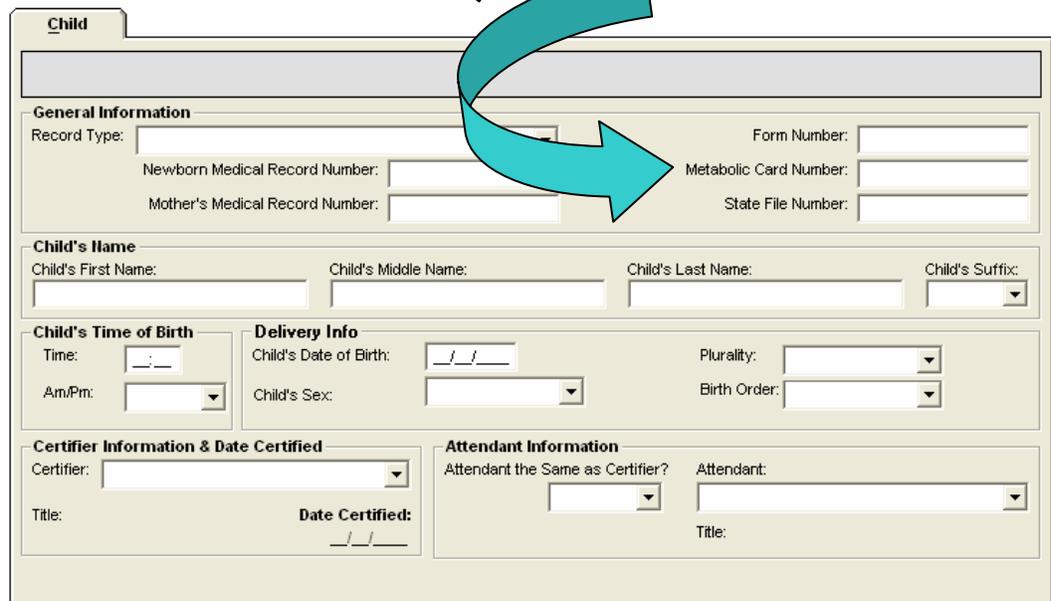
Work is progressing rapidly to develop and implement a revised software package for use in reporting the birth certificate for a newborn. This new system promises to make live birth reporting easier and faster. The new system is scheduled for piloting this fall in 6 counties and for statewide use in January of 2007. Training sessions for hospital personnel reporting births is being planned for November and December to be sure that all are trained and ready by January 1.

As this new system will enable each newborn to be reported so much faster, usually within a couple days of delivery, the birth report can now serve as a very effective tool for rapidly identifying newborns for whom the Department did not receive a metabolic screening card. This will enable prompt follow up to be sure each child is screened.

To facilitate this idea, the hospital staff reporting the birth can also supply the metabolic card number used for the child. This will make cross-matching with the newborn screening data very efficient. If you could review this new ability with the staff in your hospital that handle birth reporting to be sure they have ready access to the card number for each child, it would be very helpful to this effort.

A scan of a Michigan birth certificate form. The form is filled with text and has a barcode on the right side. A label on the right side of the form reads "MICR USE ONLY". The form includes fields for parent names, child's name, date of birth, and other identifying information.

Did you know that metabolic card (kit) numbers will be important to get the newborn screening results from MICR? This is the way we will be able to link the baby's name to our records.

A screenshot of a software interface for reporting a child's birth. The interface is titled "Child" and contains several sections: "General Information" with fields for Record Type, Newborn Medical Record Number, Mother's Medical Record Number, Form Number, Metabolic Card Number, and State File Number; "Child's Name" with fields for First Name, Middle Name, Last Name, and Suffix; "Child's Time of Birth" and "Delivery Info" with fields for Time, Am/Pm, Date of Birth, Sex, Plurality, and Birth Order; "Certifier Information & Date Certified" with fields for Certifier, Title, and Date Certified; and "Attendant Information" with fields for Attendant, Title, and a dropdown for "Attendant the Same as Certifier?". Two large teal arrows point from the MICR form to the "Metabolic Card Number" field in the software interface.

For more information on this new system, contact Kay Bertrau at 517 335-8384 (Bertrauk@michigan.gov) or Kathy Humphrys at 517 335-8714 (HumphrysK@Michigan.gov)

Laine's Story

Our daughter Laine was born on August 5, 2005. It was a great delivery and we thought we had a perfectly normal baby. We brought Laine home from the hospital 2 days after being born. She was the typical newborn although a little less hungry and a little more sleepy than our first baby. We went to our Pediatrician appointment when she was 5 days old and things looked normal. On day 6 we got a phone call from our Doctor who wanted us to bring Laine in to her office. She said she would explain everything when we got there, but said Laine had an abnormal newborn screening. When we got there she did explain the disorder Very Long Chain Acyl CoA Dehydrogenase Deficiency VLCAD (I had been a nurse for 7 years prior to that and never heard of it or Metabolic disorders). It is a rare Fatty Acid Oxidation disorder that lacks an enzyme for normal metabolism of the breakdown of fats into energy. If left untreated it can cause severe hypoglycemia, seizures, coma, or even death.

Laine's doctor sent us to the lab for additional testing and had also been in touch with Children's Hospital of Michigan Metabolic Clinic (CHMMC). The results we were told would take about a week. In the meantime we began treating Laine as if she did have VLCAD and were in contact with the staff from CHMMC with any concerns. We were told to feed Laine frequently at least every 2-3 hours and signs and symptoms of what to watch for. It was determined that Laine needed some additional testing with a skin biopsy and an appointment was made for her at CHMMC. Over the last year we have learned about her disorder and the different forms. It does look like she has the "Mild Variant" form of VLCAD. It still means having an Emergency Room protocol when she is sick and a low fat diet among other things but she is a happy, healthy baby. With treatment the outlook for Laine looks great. She is developing normal in all areas. She is walking now and so curious about the world. She loves her big sister Paige who is 5 and like to tease her too. She is a joy to us and her family and we are so thankful for being able to know about and treat her condition.

I am so thankful for Michigan expanding the Newborn Screening. Had Laine been born 4 months prior to when she was, we may have not know about the condition. We are also lucky to live in a state that has a comprehensive Metabolic Clinic. They have a professional and caring staff that has been so supportive during this last year. We trust her doctors to help us deal with Laine's condition.

Thank you again

Jennifer, Jeffrey, Paige and Laine

Let us remember ...

We have received inquiries asking how Kaitlin was doing. You may remember that she is the child whose story appeared in the July issue of the NBS Update..

The following message was received from Kaitlin's father:

"I just wanted to let you know that our daughter Kaitlin lost her battle with Krabbe on August 18. Kaitlin is a great inspiration and I will continue to see to it that people have a chance to fight this disease. Best Regards, Chris"

I am sure that our thoughts and prayers are with Kaitlin's family during this difficult time.

Points to Ponder ...

"Courage is the human virtue that counts most — courage to act on limited knowledge and insufficient evidence. That's all any of us have." – **Robert Frost**

Information Sharing ...

Thanks to Hollie Pippin, a nurse on the OB unit at Mercy Hospital, Grayling, who shared the following information on how their unit utilizes the NBS card as a tool and log sheet. The yellow copies of the NBS card are kept in the department in a small ring binder. When the binder is too full, they place the older copies in the manager's office and still have access. They made a stamp for the hearing screen where staff circle the hearing screen results. This makes keeping a record of both the NBS specimen and hearing screen results simple and complete.

HEARING-SCREEN

R	PASS	FAIL
L	PASS	FAIL

FIRST SAMPLE

HOSPITAL CODE (if applicable) 00

Here are samples of the NBS card with the hearing stamp and of the hearing stamp itself:

HEARING SCREEN

R	PASS	FAIL
L	PASS	FAIL

Tammy's Tidbits ...

Newborn Screening program updates are getting so exciting as we welcome our new hospital helping hands.... Newborn Screening Coordinators

I am so excited to get a point of contact in each hospital that will facilitate communication to hospitals and in turn hospitals will know who to call directly at the State Of Michigan. It makes both the hospitals and our staff's lives easier not to make multiple calls to find out a simple question or informing hospitals of upcoming changes before they happen. This team approach will advance our education and improve the quality of the program for the benefit of Michigan's Newborns.

NOTICE:

If a baby is going to be released to adoptive or foster parents **do not** write the birth mother's name and contact information on the newborn screening card. In the section labeled MOTHER write in the space above the mother's name, if she is an adoptive or foster parent. Complete the rest of the section with the adoptive/foster mother's contact information. Do not place sticky notes or use red ink because the information will not be recorded when the card is scanned into our system. Accurate adoptive/foster mother contact information can be critically important when needed to contact parents of a baby with one of the newborn screening disorders.

Contact Tammy if you have questions at ashleyt1@michigan.gov or 517-335-8959.

Welcome To Holland

by

Emily Perl Kingsley

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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this ...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned.

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

* * *

Friendly Reminders ...

Please take a few moments to review your hospital's NBS practice and procedures. It is important to ensure the integrity of both the NBS card and the NBS specimen. Therefore remember: to check the expiration date on the card prior to obtaining the sample; to complete the documentation on the NBS card; to obtain the sample from the newborn's heel between 24 and 36 hours after birth; to lay the specimen card flat to dry; to keep the specimen card and sample away from direct sunlight and heat; and, to send the NBS specimen to the state NBS lab on a daily basis, within 24 hours of obtaining the specimen. It is important not to hold or batch specimens but rather to send them to the state NBS lab, even if there is only one specimen card in the envelope. Pre-addressed envelopes can be obtained by contacting Val Klasko at 517-241-5583 or KLASKO@michigan.gov.

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