

Newborn Screening Update

Michigan Newborn Screening Program

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Introducing ...



My name is Pat Fineis and I have worked for the Michigan Department of Community Health for 15 years. I am the Perinatal Hepatitis B Prevention Program Coordinator. I have a Bachelors degree in Family Life Education which I have used to develop training programs and to work with families enrolled in the Perinatal Hepatitis B Program. Primarily, I work with women who have tested positive for hepatitis B surface antigen (HBsAg) prenatally or at delivery. I help them understand what it means to be infected, how they can take care of themselves as well as their infants, household, and sexual contacts.

I coordinate program activities and have been working on ways to identify HBsAg-positive women so that we can treat their infants and family members appropriately. The Centers for Disease Control and Prevention (CDC) estimate there are 396-597 women in Michigan who are pregnant and are hepatitis B infected. In Michigan we are only identifying approximately 300 of these women. Current review of the newborn screening (NBS) cards has shown that over 24,000 cards come in without mom's HBsAg status or test date indicated on the card. We have worked for the past year with staff from all of Michigan's delivering hospitals to reduce the number of cards missing this information to ensure that we are not missing any women who could potentially infect their infant.

You all have been very cooperative and I appreciate the time and effort you have put into this project to ensure that all pregnant women are being tested for HBsAg for every pregnancy. With the new recommendations from CDC we have been encouraging all hospitals to review their policies and procedures to ensure that all babies receive the birth dose of hepatitis B vaccine, that all women have a documented HBsAg test result for every pregnancy, and if no record of their status to test them STAT.

I have had the pleasure of meeting many of you, and look forward to meeting and working with all of you. If you have questions about our program, the birth dose of hepatitis B vaccine, or if I can help in any way, please call me at 517-335-9443 or contact me by e-mail at fineisp@michigan.gov.

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What is the effective date for the new NICU guidelines?

The new NICU guidelines, for infants weighing less than 1800 grams is scheduled to go into effect on March 1, 2007. The NICU Guidelines are enclosed with this newsletter. Specific calling times will be available for questions. They are noted in this newsletter as well. Contact Tammy if you have questions.

Friendly Reminders ...

NBS card documentation:

Please remember to use the two digit number when documenting gestational age on the NBS specimen card, i.e., 38, 40, etc.

Please remember to document the infant's birth weight in grams **NOT** pounds and ounces. A copy of the Weight Conversion Chart can be viewed, downloaded, and printed from the NBS webpage.

Please remember to document the birth time using Military Time. A copy of the Military Time Chart can be viewed, downloaded, and printed from the NBS webpage.

Physician name:

Please make every effort to verify with the parent the name of the health care provider who will follow the infant after discharge. If this information changes after the NBS specimen card has been mailed to the state lab, please call the NBS program with the correct information. This information is especially critical if the infant has a positive newborn screen or requires a repeat specimen.

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.

Hospital Survey:

Please respond to the request to identify whether or not your hospital has a NICU or SCN. If you did not receive Tammy's e-mail regarding this, please let her know.

NICU and SCN Numbers:

Effective March 1st, 2007 the hospitals with NICU and/or SCN will be issued separate numbers to be documented on the NBS specimen card for the hospital number. Therefore, the number for the mother-baby unit, NICU, and SCN will be different. This will enable us to quickly identify the infant's level of care while in the hospital.

Tammy's Tidbits ...

MCAD is one of those disorders where children are often hospitalized when they have a normal childhood illness because of the need for IV therapy to keep them alive. If your hospital has a child in your neighborhood, who has been diagnosed with MCAD, I have been contacting the ER managers to give them a "heads up" and to provide them with information on the disorder. I know, as a Nurse Practitioner, I would rather know about ways to handle a new type of emergency prior to taking care of the patient during the emergency situation. I want hospitals to be aware of the service I am providing and how thankful parents have been with the great response of hospitals when the need arose. The hospitals I have contacted have gone above and beyond when moms contact them, providing tours and meeting them prior to a crisis situation. I can not tell you what a positive influence those little acts of kindness have made in reducing the anxiety on the parents with these special children. I wanted to let you all know what a difference you have made to these children and tell you "Thanks" on behalf of those families.

Jenna and Jesse's Story ...

Often the best gift is the one that you least expect. Yet someone knew you so well that they knew what you needed – possibly before YOU even knew what you needed. For our family, Michigan's Newborn Screening program is the best gift we could have been given. And until we needed it – we didn't KNOW we needed it! It has definitely saved the lives of our 2 youngest children.

We are the Carl & Sandy, the parents of four children ages 13 to 21. Our youngest 2 children, Jenna (15) and Jesse (13) have a rare metabolic disorder called "Maple Syrup Urine Disorder" (MSUD). This is a genetic disorder. What it means in easy terms is that their bodies cannot metabolize 3 amino acids contained in protein, and these become toxic to their brain. MSUD must be diagnosed in the newborn period, or the child becomes brain damaged or dies. We are fortunate to live in Michigan, where Newborn Screening for MSUD has saved my children's lives and protected their brains. The screening for MSUD began in 1987. Jenna was born in 1991, and was the first baby diagnosed with MSUD from Newborn Screening.



I still clearly remember the day. I had just gotten home from the hospital on Thursday night. I was sure I could conquer life with three children. The first thing Friday morning, we received a call from our pediatrician. He said that the newborn screening had come back positive on Jenna, and that she may have a rare disorder called "Maple Syrup Urine Disease". My mind was numb...the name was odd...I couldn't believe my healthy little baby could have any thing wrong with her. Sure she seemed colicky, but everyone got at least one colicky baby, right? We immediately called the clinic and learned all that we could about MSUD. We were provided with formula and made an appointment to see the specialists on Monday. Doctors were glad to see the screening for MSUD was necessary and worked! We didn't actually feel so relieved – we were overwhelmed! It was not until later that we could look back and realize that Newborn screening was a lifesaver.

Over the weekend, she cried violently, never slept, but I still thought she was OK. Monday, our visit with the metabolic team determined that she was doing well, just continued to need more MSUD formula. We went back home. By Tuesday, her sucking reflex was gone, and she had a seizure. We headed immediately to the hospital. Jenna was in the hospital for one week on MSUD TPN. She underwent an MRI and CAT scan. Over the next few days, the change in her was unbelievable. She was comatose and not sucking when we brought her in. She began drinking, and was more alert as days went by. We felt that we had our baby back. Once her leucine levels stabilized, we had a happy, healthy girl again.

Two years later, when I became pregnant with Jesse, doctors recommended that we have an amniocentesis done to check for MSUD. The tests came back positive and we prepared ourselves for another MSUD child in our family. That meant bringing the formula and blender to the hospital at birth. The nurses were sure we were prepared to make daiquiris for everyone! Jesse has benefited from this early detection and treatment. Again, this reinforced how necessary good Newborn Screening is. The earlier treatment is begun, the healthier the brain.

Jenna and Jesse are now healthy, smart kids in 10th and 8th grades. Living with MSUD requires drinking 20 ounces daily of a special formula, and adhering to a very strict low protein diet of no meat, milk, eggs, soy, etc. Jenna may eat only 4 grams of protein due to her growth period being done. Jesse is growing like crazy, and currently eats 16 grams of protein. Just to put this in perspective, 1 slice of white bread is over 2 grams of protein. They eat a lot of fruits, vegetables, and potatoes- mainly because they are filling and lower in protein. There are many excellent low protein products available, but they are quite costly. We buy these sparingly. This is one reason our family is working hard to get legislation passed in Michigan to cover the low-protein foods and formula. We hope Michigan will soon be able to join 26 other states in offering life-saving treatment for life!

Common illnesses are dangerous with MSUD because it throws off their delicate metabolic balance. So an ear infection, cold, or sore throat can cause "high levels" – dangerously high levels of the 3 amino acids. Jenna and Jesse are dizzy, disoriented, and lethargic when high levels occur. It is very important to protect their brain and lower these levels as soon as possible with extra formula, lots of calories, and protein-free foods. This is when we look around the cupboards and realize most foods are "poison" to their brain due to the high protein content.

Jenna and Jesse have big plans for their future. Jenna is currently in 10th grade. Friends and fun are most important right now, and she enjoys youth group, reading and listening to music. She also sings in a traveling group called "Gratitude". Jenna is interested in interior design or teaching in her future. Jesse is in 8th Grade. He is active in the school play, plays percussion in band, is in the Honors Choir, plays piano, keyboard, and is taking drum set lessons. Jesse has started a basement band this past year with 2 friends – JRM (germ). (Yes, it's in OUR basement – quite loud every Friday afternoon!) Jesse wants to go to Michigan Tech, like his older brother, and become an engineer, or be a professional drummer.

So it's easy to understand that for our family, Newborn Screening is a gift from God! We know that every day of health is a gift, and we were given the wonderful gift of Newborn Screening – the perfect gift we did not even know we needed! We owe a debt of gratitude to Bill Young and the many people who continue to work hard every day and demand that Michigan offer the best possible Newborn Screening program. There are many children whose lives are spared...whose quality of life is improved...who need the gift!

Thanks to Carl and Sandy for sharing their story.

NICU <1800 Grams Protocol Start Date 3/01/07

Neonatal Intensive Care Unit Coordinators, Physicians, & Staff Teleconference Call Dates

Informational calls have been scheduled to provide you with the opportunity to discuss the NICU protocol for infants weighing <1800 grams prior to start date. Copies of NICU fact sheet, Algorithm, and NICU Manual will be e-mailed to coordinators for distribution to appropriate staff. The NBS coordinator and a neonatologist from each hospital are requested to participate in one of the sessions.

Toll Free Call: 1-888-252-9637 Pass Code 9128604

Day	Date	Times	
		Session 1	Session 2
Monday	2/12/2007	12:00 -12:30	16:00 -16:30
Tuesday	2/13/2007	12:00 -12:30	14:00 -14:30
Wednesday	2/14/2007	12:00 -12:30	16:00 -16:30
Thursday	2/15/2007	8:00 - 8:30	14:00 - 4:30
Friday	2/16/2007	13:00 -13:30	15:00 -15:30

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

Thanks!

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 combine to 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 2nd specimen, then that is the last specimen.

Why obtain specimen before transfusion?

If the infant requires transfusion before 24 hours of age, collect the initial specimen pre-transfusion and the next specimen at 14 and 30 days of age or upon discharge. A pre-transfusion specimen is essential for detection of galactosemia, sickle cell disease, and biotinidase deficiency. If the infant receives a blood transfusion before the screen is collected, the newborn screen must be repeated 90 days post-transfusion. Results from a post transfused specimen are not valid and may represent a false negative.

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 days of age. Positive results on repeat screens will be treated the same way as positive results in other babies.
- If the amino acid pattern is consistent with 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 measure plasma amino acids when the child is receiving full enteral feedings.

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.

TJA 1/26/2007

I would like to share the following story with you. I was told this story by Herman Gray, MD, when I began work as a Specialized Care Manager with Children's Special Health Care Services many years ago. It has influenced many of my decisions and actions over the past 16 years. – Midge —

The Starfish Story



Once upon a time, there was a wise man who used to go to the ocean to do his writing. He had a habit of walking on the beach before he began his work.

One day, as he was walking along the shore, he looked down the beach and saw a human figure moving like a dancer. He smiled to himself at the thought of someone who would dance to the day, and so, he walked faster to catch up.

As he got closer, he noticed that the figure was that of a young man, and that what he was doing was not dancing at all. The young man was reaching down to the shore, picking up small objects, and throwing them into the ocean.

He came closer still and called out "Good morning! May I ask what it is that you are doing?" The young man paused, looked up, and replied "Throwing starfish into the ocean." "I must ask, then, why are you throwing starfish into the ocean?" asked the somewhat startled wise man. To this, the young man replied, "The sun is up and the tide is going out. If I don't throw them in, they'll die."

Upon hearing this, the wise man commented, "But, young man, do you not realize that there are miles and miles of beach and there are starfish all along every mile? You can't possibly make a difference!"

At this, the young man bent down, picked up yet another starfish, and threw it into the ocean. As it met the water, he said,

"It made a difference for that one."

Adapted from The Star Thrower by Loren Eiseley (1907 – 1977)

Points to Ponder ...

"Success isn't measured by the position you reach in life; It's measured by the obstacles you overcome." Booker T. Washington

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: mccaustlandm@michigan.gov

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