

Newborn Screening Update

Michigan Newborn Screening Program

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Updated Brochures are Here!



The importance of educating parents about the newborn screening process cannot be overstated. Ideally, the prenatal care provider initiates newborn screening education. However, the birth hospital should ensure that families have some basic knowledge about the newborn screening process and importance of testing every baby. In addition, parents should also be instructed to check with their primary care physician about their child's newborn screening results.

To assist hospitals in their effort to educate families, the Newborn Screening Program has **new informational brochures** available. The brochure entitled "Your Baby and Newborn Screening" reviews the disorders identified by newborn screening, what happens if the test is positive, storage of the blood specimen, and importance of screening every infant. The new brochures include information on the latest disorder added to the screening panel, Medium-Chain Acyl CoA Dehydrogenase (MCAD) Deficiency so that the insert will no longer be required.

The brochures can be obtained free of charge by calling Valerie Klasko at (517) 241-5583

Supplemental Newborn Screening

Supplemental newborn screening is currently available from several commercial laboratories. Supplemental screening panels test for additional disorders that are not currently included in the Michigan newborn screening panel. However, it must be noted that expanded screening panels may not include all of the disorders that are currently mandated and screened for in Michigan such as sickle cell disease, hypothyroidism, congenital adrenal hyperplasia, galactosemia and biotinidase deficiency.

Supplemental newborn screening should never be used to replace the state mandated newborn screening panel. Parents should be informed that supplemental screening can be completed in addition to but not in lieu of the state mandated screen.

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Quick Updates...

Newborn screening cards with the preprinted biohazard logo are now in stock!

All orders for both first sample “blue” and repeat sample “pink” cards will be filled using these cards thereby eliminating the need to attach the biohazard sticker. **Please note, the biohazard sticker will need to be used until your supply of cards without the preprinted biohazard logo is exhausted.** We appreciate your compliance and patience during this transition.



Unsatisfactory specimens are on the rise!

The number of unsatisfactory specimens has risen across the state. There were 522 unsatisfactory specimens statewide in the first quarter of 2004. This is a significant increase from 398 in the previous quarter. Please review your blood collection procedures to ensure that all specimens are satisfactory. This will prevent both unnecessary retesting of unaffected infants and prompt identification of infants needing medical intervention.



Automatic Fax Reporting Update

Automatic fax reporting of newborn screening results should be initiated in the next few months. To convert your hospital to automatic fax reporting, documentation of a “secure fax” is needed. Many hospitals have done this already. Contact Harry Hawkins at (517) 335-8095, with questions about automatic fax reporting. Information will also be posted on the newborn screening website at www.mi.gov/newbornscreening.



Newborn Screening Results

The Newborn Screening Laboratory sends two copies of screening results. One for the submitter to keep, and one to forward to the physician listed on the screening card. **It is the submitter’s responsibility to forward screening results to the physician listed on the card.**

Unsealed Envelopes Continue

The Newborn Screening Laboratory continues to receive unsealed envelopes. The seal on the envelope must be wetted to activate the glue. For protection of the specimens you are sending, **moisten the glue THOROUGHLY before mailing.** If the seal is questionable, use scotch tape to secure flap. In addition, it is advisable to keep a log of which specimens are placed in each envelope. This information is critical should an envelope arrive unsealed.



NICU Quality Assurance Reports

NICU’s are now able to have their quarterly quality assurance data reported separately from the regular hospital statistics. If this option is desired, the NICU must use a specially assigned Hospital ID that is different from the regular nursery ID. It is also possible to have test results mailed directly to a different NICU address if requested. If your NICU would like to receive separate QA reports or screening results, please contact Denise Archambeault at (517) 335-8959 to set this up.



Physician Responsible for Care of the Newborn

Please do not use the names of resident physicians on the newborn screening card. **The attending or supervising physician should always be listed as the “physician responsible”.**

Newborn Screening Panel to Expand



The Michigan Department of Community Health is pleased to announce the expansion of the newborn screening panel to include four additional disorders; Homocystinuria, Tyrosinemia, Citrullinemia, and Argininosuccinic Acidemia (ASA). Statewide screening is expected to begin late summer. There is no newborn screening card fee increase planned with the addition of these four disorders.

Detection of these four aminoacidopathies can be accomplished by measuring the levels of the appropriate amino acids in dried blood spot specimens. The technology used is tandem mass spectrometry which can measure multiple analytes from a single dried blood spot. This technology was introduced on April 1, 2003, when screening for MCAD deficiency was initiated. **The addition of these four disorders will not require collection of any additional blood.**

A brief description of each new disorders is listed below. More information will be provided as the implementation date approaches. Be sure to check the MDCH Newborn Screening website for updates at www.mi.gov/newbornscreening.

1) Homocystinuria

Babies with homocystinuria are unable to metabolize the amino acid methionine. If not treated, homocystinuria can lead to seizures, developmental delay, displacement of eye lens, mental retardation and possible blood clot formation leading to life-threatening complications. Treatment includes the diet restriction of methionine through special formula and protein restriction, as well as large doses of vitamin B6.

2) Tyrosinemia

Babies born with tyrosinemia are unable to metabolize the amino acid tyrosine. In the acute form of the disorder babies show poor weight gain, an enlarged liver and spleen, a distended abdomen, swelling of legs, and an increased tendency to bleed in the first few weeks of life. The symptoms in the chronic form are similar although the onset is more gradual and usually less severe. Tyrosinemia is managed by a special diet and medication (NTCB). Many infants and children will require a liver transplant.

3) Citrullinemia and 4) Argininosuccinic Aciduria (ASA)

Citrullinemia and Argininosuccinic Aciduria are two types of Urea Cycle Disorders. Urea Cycle Disorders are rare inherited disorders that result when a baby can not remove certain waste products from the blood. There are several different types of urea cycle disorders. Symptoms may occur in infancy or later childhood and include abnormal behavior followed by vomiting, lethargy (lack of energy), seizures, brain damage, coma that could result in death. The treatment for urea cycle disorders will depend on the type of disorder but often includes a special diet and supplements as well as medications to remove waste products from the blood. Dialysis may be necessary in some individuals. **It should be noted that the newborn screening test can not differentiate Citrullinemia from Argininosuccinic Acidemia ASA. Further diagnostic testing is needed.**

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"Late" Specimen Reminder



The new change in criteria for a late specimen has gone into effect. Beginning with the first quarter of 2004 (January 1, 2004), **all specimens received in the newborn screening laboratory greater than 6 days from the date of birth will be considered "late"**. The newborn screening panel continues to expand with the addition of serious disorders that require prompt medical intervention to ensure the best possible outcome. Therefore, it is now more important than ever to ensure that newborn screening specimens arrive at the Newborn Screening Lab for testing in a timely manner.

Studies have shown that once mail is in the postal system, it will arrive to its destination within 1-2 days from anywhere in the state. If a specimen is drawn between 24-36 hours and dried for 3-4 hours, the specimen should be ready for mailing when the infant is 2 days old. If the specimen spends 2 days in the postal system, the infant is now 4 days old. That gives an additional 2 days leeway for weekend, holiday and mailroom issues making the 6 day criteria very realistic.

The hospital mailroom is not considered part of the US postal system. Often specimens are delayed entry into the postal system because they must work their way through the hospital mailroom. Inadequate postage can also cause delays. Waiting until you have several specimens to send all at once instead of sending them as they are ready to go is called batching and will result in higher numbers of "late" specimens.

The overall "late" rate for the state has increased to 11% using the new criteria. Some hospitals may notice a large increase in their number of "late" specimens, while some may not have any increase at all. It is imperative that procedures for collecting and sending newborn screening specimens be reviewed to ensure all affected infants are quickly identified and treated.