

FREQUENTLY ASKED QUESTIONS

What is the purpose of the Iowa Metabolic Screening Program?

The purpose of the Iowa Neonatal Metabolic Screening Program is to screen all newborns in Iowa for genetic and metabolic disorders that can lead to serious health consequences. By early identification of these disorders, a newborn can be treated before symptoms appear, preventing mental retardation, serious illness, and death.

What is the chance that a baby will actually have one of the disorders detectable by screening?

The chance that a baby will have one of these disorders is very small. In the rare cases when a disorder is found, early diagnosis and treatment can usually prevent the problems associated with these disorders. All abnormal screen results should be taken seriously and recommended follow-up should be done as soon as possible.

Who decides which disorders are included on the Iowa's newborn metabolic screening panel?

The Center for Congenital and Inherited Disorders of the Iowa Department of Public Health is responsible for deciding the list of disorders. A Congenital and Inherited Disorders Advisory Committee, made up of doctors, nurses, legislators, parents and consumers, advises the Center regarding which disorders to include, based on nationally accepted criteria. The Iowa State Board of Health provides final approval for the addition of new disorders to the screening panel.

Is there a charge for repeat screening?

Although there is a charge for the initial screen, the Iowa Neonatal Metabolic Screening Program does not charge for repeat screens. However, facilities collecting the repeat screen may have specimen collection charges.

Why is it necessary to retest some babies?

Premature babies may have immature enzyme systems or thyroid functioning. It may be necessary to monitor their progress to be certain they reach normal levels. Unnecessary repeat testing can be avoided by collecting blood specimens 24 hours after birth, before a transfusion, and using correct specimen collection procedures.

Why do the collection forms require birth date and time and collection date and time information?

Recording the date and time for both infant birth and specimen collection is necessary to assure that the specimen has been collected at least 24 hours after birth. Blood specimens should be collected from newborns between 24 hours and 5 days of age. If the specimen collection time is not recorded on the form, the Iowa Neonatal Metabolic Screening Program must assume for the benefit of the infant, that the specimen was collected early and a recollection is required.

Why is it necessary to wait 24 hours before collecting a newborn screen specimen?

A screening specimen collected before 24 hours of age could give false positive or false negative test results. Blood specimens should be collected from newborns between 24 hours and 5 days of age.

Exceptions to the 24-hour rule: A newborn screen should always be collected prior to transfusion or discharge. Facilities responsible for transferring an infant are encouraged to collect a newborn screen prior to the transfer.

Why is the infant's weight at time of specimen collection required?

Transient elevations of 17-OHP, the analyte for the congenital adrenal hyperplasia (CAH) screen may occur in pre-term and low birth weight babies. Because of this, four weight related 17-OHP ranges are in place to minimize the number of false positive results.

Without a weight indicated on the collection form, CAH results cannot be reported. If the weight is inadvertently omitted you can fax the weight at time of collection to the lab and we will reissue the report based on the new information. The fax number is 515/243-3071.

I am having trouble collecting blood. Should I try to get some blood inside each circle?

No. It is better to have 3 or 4 fully filled circles than many partially filled ones. Please review the [specimen collection instructions](#) for additional information.

Why was the screening specimen reported as poor quality when I know there was plenty of blood in the circles?

All tests performed by INMSP are calibrated to an expected blood volume contained in a 1/8-inch punch of filter paper. There must be an even penetration of blood for the test to be accurate. This means soaking through the filter paper with ONE application and filling the entire circle. Refer to section [reasons for which specimens are rejected](#).

Submitting a poor quality specimen results in the inconvenience of recollecting another specimen and delays the screening of the newborn. This places the newborn at risk for delayed diagnosis of a metabolic condition. It is important that another sample is collected from the newborn as soon as possible.

Why do some newborn screens have "false positive" results?

False positive results may be due to immature endocrine or enzyme function in the newborn, the stress of birth on an infant, or the specimen being collected prior to 24 hours after birth. INMSP establishes screen cutoff values which keep the number of false positives at a minimum, yet minimizes the likelihood of an affected newborn being missed.

What do I do if the parents refuse the screen?

The parents or legal guardians and the licensed health care provider should sign the Iowa Neonatal Metabolic Screening Program Waiver for Newborn Screening Refusal. The

original should be placed in the child's medical record with a copy provided to the parents or guardians. A copy should also be sent to the Iowa Neonatal Metabolic Screening Program. The waiver serves as documentation that the parents were informed about the possible adverse outcomes of not performing newborn metabolic screening and that they accept legal responsibility for the consequences of their decision.

If newborn metabolic screening is not done for some reason in the first week of life, is it worthwhile to still screen the baby later?

Yes. While some disorders may begin to be expressed and some damage may have already occurred, treatment begun at any time will always be beneficial to the infant. Additionally, the family should be made aware of the infant's metabolic disorder, its genetic implications, and given appropriate counseling. Ideally, all babies should be screened in the first week of life, but screening a baby later is better than never screening at all.

Is there an age limit for newborn metabolic screening?

Infants can be screened for all disorders up to one year of age. CH and CAH ranges apply to the newborn period, and interpretation of results from specimens collected after the newborn period should be performed in consultation with the appropriate specialist. A specimen received on a child greater than one year of age will not have CH and CAH reported.

Will breast-feeding alter the results of the newborn screen?

Breast milk is an adequate source of protein challenge and should not adversely affect results of the newborn screen.

What do I do if a baby has moved here from out of state?

Collect another specimen if you don't have documentation that the infant had a newborn metabolic screen prior to the move.

Do I need to repeat the screen if the infant is receiving antibiotics?

No. Antibiotics do not interfere with current screening methodologies.

Whose responsibility is it to advise the parents about the screen?

The licensed attending health care provider has the ultimate responsibility for ensuring that an infant under their care has newborn metabolic screening. A parent or guardian should be informed of the type of specimen collected, how it is obtained, the nature of the disorders being screened, and the consequences of treatment and non-treatment. The responsibility includes following up on any abnormal screening results.

Can newborn metabolic screening be done if a baby is born at home?

Yes. Parents should arrange with a doctor, hospital, or midwife to have a newborn metabolic screening specimen collected. The Bureau of Vital Records at the Iowa Department of Public Health distributes newborn metabolic screening collection forms and parent brochures with their home birth registration packets. The specimens should be collected between 24 hours and 5 days of age.

What are the usual turn-around times for newborn metabolic screening test results?

Test results are routinely mailed to submitting facilities within two to three days after the receipt of the specimen. Presumptive positive (clinically significant) test results are phoned to the health care provider listed on the collection form within 24 hours of obtaining the result.

What if I need to talk with someone at the lab or one of the consultants?

Refer to the [Important Contacts](#) section for a list of telephone numbers.