

YOUR BABY'S NEWBORN SCREENING

*Information parents need
to know*



Public Health Laboratory Division

WHAT CAN BE DETECTED BY THE NEWBORN SCREEN?

PKU (phenylketonuria): Problems digesting protein are treated with special diet to prevent mental retardation.

Congenital Hypothyroidism: Reduced thyroid hormone levels are treated with medicine to prevent short stature and mental retardation.

Hemoglobinopathies: Diseases of red blood cells treated with medicine and special care to prevent pain episodes and organ damage.

Congenital Adrenal Hyperplasia (CAH): Adrenal gland defect that is treated with medicine to prevent hormone problems and death.

Galactosemia: Problems digesting milk sugar (galactose) are treated with a special diet to prevent liver disease, mental retardation and death.

Amino Acid Disorders: Problems digesting proteins are treated with special diets and medicine to prevent neurological damage and death.

Fatty Acid Oxidation Disorders: Problems digesting fats are treated with special diets and medicines to prevent low blood sugars and death.

Organic Acid Disorders: Toxic chemical imbalances are treated with special diets and medicines to prevent organ and neurological damage.

PARENTS:

Between 24-48 hours after birth, your baby will be screened for more than thirty-five rare diseases. This screening is important. If any of these diseases is found and treated early, serious problems may be prevented.

WHY YOUR BABY IS SCREENED

One in a thousand (1/1000) babies in Minnesota who seem healthy at birth have a hidden rare disease that can be treated. Minnesota state law (144.125) requires screening ALL newborns for these diseases unless parents sign a waiver, opting out of the program.

HOW YOUR BABY IS SCREENED

- A few drops of blood from your baby's heel will be sent to the Minnesota Department of Health to test for over thirty-five rare diseases.
- The blood sample and results are stored securely by the Minnesota Newborn Screening Program for future reference. Unless requested by parents, no additional testing is performed on samples that can be traced to an individual after completion of newborn screening.
- Test results go to the doctor who will be caring for your baby. Ask about your child's newborn screening results at the two-week well-child visit.

QUESTIONS & ANSWERS

YOU SHOULD ALSO KNOW:

- Screening tests are not perfect. They sometimes are abnormal for a baby who does not have a disease (false positive).
- Newborn screening may miss a baby who has one of the diseases being screened.
- Risks of not screening a child are serious. If affected, a child may have permanent damage, including mental retardation, growth failure and even death before showing symptoms of these diseases.
- Parents can choose not to have their baby screened by completing the "Parental Refusal of Newborn Screening" form available from the nursery staff or physician.
- Parents can have the results of testing and the sample destroyed by submitting the "Parental request to dispose of newborn specimen and/or newborn screening results" form available from MDH.
- Many hospitals provide newborn hearing screening. Ask your nursery staff or doctor about this screening.

How do I find out about my baby's newborn screening results?

Results are available from your child's primary care provider. The provider will contact you if the screening results are abnormal. Ask about your child's results at the two-week check-up.

I don't have a family history of any of these disorders; does my child still need newborn screening?

Yes. Most infants with the disorders detected by newborn screening DO NOT have a family history of genetic or chemical disorders and often seem perfectly healthy at birth.

Why is a repeat screen sometimes necessary?

There are many reasons why a repeat screening test may be needed. Often, this is caused by a sample problem or by the timing of the blood draw (prior to 24 hours of age). Repeating the screening is important to make sure every baby has complete screening.

If my baby has an abnormal screen, does that mean he/she has the disease?

Not necessarily. Because this is a "screen", it identifies babies at increased risk for a disease. However, additional testing and evaluation by a specialist is required to determine if the disease is present. The testing and evaluation are critical because early identification and treatment can prevent many problems.

Where can I find more information on newborn screening?

Information on newborn screening programs can be found at: www.health.state.mn.us/divs/fh/mcshn/nbs.htm or by calling: (800) 728-5420.

NOTE ON EARLY DISCHARGE

If babies go home from the hospital before they are 24 hours old, the newborn screen must be done again. The hospital should tell you if your baby needs to have it repeated.

If this happens, you will need to bring your baby to the hospital or doctor's office for repeat screening before he/she is two weeks old.

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