



Newborn Metabolic Screening Program

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Frequently Asked Questions (FAQ)

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Why is my baby tested?

To help assure that your baby will be as healthy as possible. A simple blood test provides important information about your baby's health that you or even your doctor might not otherwise know. The Newborn Screening Program identifies the infants who may have one of the uncommon birth defects for which this program screens.

Early diagnoses and medical treatment can usually prevent complications such as mental retardation or even death from these serious conditions.

How is my baby tested?



All of the tests are performed on one tiny sample of blood obtained by pricking the new baby's heel. The blood is allowed to dry on a special absorbent paper, which is sent to the laboratory for testing.

All babies are required to be sampled prior to discharge from the hospital or birthing facility. The first specimen should be collected between

24 and 48 hours after birth; a follow-

up specimen is required to be collected between 10 and 30 days of age.

Important: A sample collected before or after the recommended time period is better than no test at all. If you are not able to arrange testing or have questions, call (907) 269-4762 or 907-269-3430.

Remember: The conditions for which testing is done are treatable. The serious effects of these disorders can usually be completely prevented if treatment is started early enough.



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But we've never had any birth defects in our family. . .

Parents who have already had healthy children don't expect any problems with birth defects. They are almost **always** right. The disorders for which screening is done are not very common and chances are excellent that your child will NOT have one of these conditions. The few children who are born with these problems, however, are generally from healthy families. By testing every baby soon after birth, we can be sure that each infant who has a metabolic disorder will be identified and started on early treatment.

But my Baby seems very healthy. Are the tests still necessary?

Yes. Most infants with birth defects screened by this program show no obvious signs of disease immediately after birth. In each of these disorders there is an "invisible" problem in one of the many chemicals produced naturally in the baby's body. The Newborn Screening Program uses special laboratory tests to identify the infant who may have one of the disorders so that the baby's doctor can be alerted to the need for special care for the infant. Hopefully, this can be done before the condition has had time to cause damage.

If my baby has one of these disorders, can it be cured?

No, not really. It cannot be "cured," just as eye color and height cannot be permanently changed. The serious effects of the disorder can be lessened, however, and often completely prevented, if a special diet or other medical treatment is started early.

Will I be told the test results?

Your doctor or clinic will be informed when the tests are completed. Parents are notified only if there is a problem. You should, however, ask about the results when you take your baby to the doctor for a regular checkup. It is important to remember that these tests provide information only about some uncommon chemical disorders. An infant free of these disorders may have other medical problems for which these methods do not test. It is very important for your baby to have regular checkups and good general medical care.

If a retest is necessary, does that mean that my baby has one of these birth defects?

Not necessarily. Retesting may be required for a number of reasons. The most frequent reason is that the first sample did not contain enough blood to allow for completion of all tests. This does NOT mean there is anything wrong with your baby.

On the rare occasions when the first tests indicate a possible problem, the results are not considered final; a new blood sample is requested, and the tests are repeated. As a general rule, only when a child's test is unusual for a second time will the doctor discuss the need for further evaluation.

If you are asked to have your child retested, act quickly in order that repeat tests can be completed and final results obtained while the baby is still very young. It is very important that treatment, if needed, be started as quickly as possible.

How can I help the doctor to help my baby?

If the doctor asks you to bring in your baby for retesting, **DO IT AS SOON AS POSSIBLE!** If your child does have a disorder, prompt action is very important.

If you do not have a telephone, be sure to leave with your doctor the phone number of a friend, relative or neighbor who can contact you. Also be sure to notify your doctor immediately if you move after your baby is born. If your child should need to be retested, your doctor needs to know where to reach you. **Remember, time is of great importance.**

For those babies not born in hospitals or maternity care facilities.

It is essential that a blood sample for screening be taken before the child is 5 days old. This can be done by a doctor or at

a Health Department clinic.

The ideal time for a sample collection is when the baby is 24-48 hours old for the 1st screen and 2-3 weeks of age for the 2nd screen. A sample collected before or after that is better than no test at all.

If my child is found to have a disorder, will my future children have it also?

It is possible in some cases that future children also may be affected. Families with affected children may obtain information about their future risks from trained professionals with the Alaska Genetic Services Program. For additional information about counseling services available in your area, call (907) 269-3430.

As a parent, you can help to assure the health of your children by your cooperation with the Newborn Screening Program.



The footer of the website features the Alaska Department of Health & Social Services logo on the left, which includes the text "Alaska Department of Health & Social Services" and a graphic of seven stars. Below the logo are links for "Contacts", "Accessibility", "Public Notices", and "Staff", along with social media icons for Facebook, Twitter, YouTube, and a mail icon, and a "Webmaster" link. To the right of the logo is a grid of departmental links: "Alaska Pioneer Homes", "Behavioral Health", "Boards & Councils", "Office of Children's Services", "Office of the Commissioner", "Finance & Management Services", "Health Care Services", "Juvenile Justice", "Public Assistance", "Public Health", and "Seniors & Disabilities Services". At the bottom of the footer is a dark blue bar containing navigation links: "State of Alaska", "myAlaska", "My Government", "Resident", "Business in Alaska", "Visiting Alaska", "State Employees", and "State of Alaska | © 2012 | Webmaster". A decorative graphic of a map of Alaska surrounded by seven stars is centered at the bottom of the footer.