

PARENT INFORMATION about POSITIVE Newborn screening results for **GALACTOSEMIA**

When your baby was born a small blood sample was taken from your baby's heel to test for certain diseases. These diseases usually cannot be found by just looking at your baby. That is why the blood test is very important.

The results of your baby's screening test were positive for a disorder called Galactosemia (Guh-LAK-toe-SEE-me-ah). It is important to remember this is only a screening test. A new blood sample will be collected from your baby for a new test. This will be done to help find out if your baby has galactosemia or not.

What does a positive screen mean?

A positive test means that your baby needs to have a new blood test to check for galactosemia. A small number out of all the babies screened will be identified as positive. Some are later found not to have galactosemia. This is just a screening test and further testing needs to be done to find out if your child has this disorder or not.

What is the next step?

Be sure to follow your baby's doctor's instructions for getting a new blood sample for further testing. Because newborns with Galactosemia can become sick very quickly from too much galactose, they should be switched to a powder-based soy formula as soon as the new blood sample is drawn. Galactosemia is a rare disease, so your baby's doctor might talk with or have your baby seen by a specialist.

What exactly is Galactosemia?

Galactosemia is a disease which causes galactose not be broken down by the body. Galactose is a simple sugar found in breast milk, many formulas and milk products.

Children with galactosemia cannot break down the galactose, so it remains at high levels in their bodies. High levels of galactose can harm a child's eyes, liver, and brain. Finding out early if your baby has galactosemia, allows steps to be taken to prevent most of these effects.

About 1 in 4 infants with untreated galactosemia develop serious infections in the first or second week of life. Placing the child on a powder based soy formula within the first few days of life can minimize these problems.

What should I do?

Three things to do immediately:

- 1) **Take your baby to have the new blood sample collected and tested.**
- 2) **Begin feeding your baby a powder-based soy formula after the blood is drawn.**
- 3) **Report to your baby's doctor immediately, if your baby shows any signs of illness such as fever, vomiting, or diarrhea.**

If your baby has galactosemia, there is good treatment available. The metabolic specialists and nutritionists will help you manage this by changing your baby's diet and checking the galactose levels.

You have probably already done this, but now is also a good time to be sure your newborn is covered by your health insurance. Most health insurance covers all or part of the tests needed for treating galactosemia.

For more information, talk with your baby's doctor. You can contact the Nebraska Newborn Screening Program at (402) 471-0374 for information on Metabolic Specialists in Nebraska.

Department of Health & Human Services



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