GALACTOSEMIA (GALT)

FAMILY FACT SHEET

What is a positive newborn screen?

Newborn screening is done on tiny samples of blood taken from your baby's heel 24 to 36 hours after birth. The blood is tested for rare, hidden disorders that may affect your baby's health and development. The newborn screen suggests your baby might have a disorder called galactosemia.

A positive newborn screen does not mean your baby has galactosemia, but it does mean your baby needs more testing to know for sure.

You will be notified by your primary care provider or the newborn screening program to arrange for additional testing.

What is galactosemia?

Galactosemia affects an enzyme needed to break down a sugar that is part of all milk products, including breast milk and most formulas. Galactosemia is a more serious problem than lactose intolerance.

A person with galactosemia doesn't have enough enzyme to break down the sugar known as galactose. If galactose is not broken down, it builds up in the body and can cause problems.

Galactosemia is a genetic disorder that is passed on (inherited) from parents to a child. The mother and father of an affected child carry a gene change that can cause galactosemia. Parents usually do not have signs or symptoms, or even know they carry the gene change.

What problems can galactosemia cause?

Galactosemia is different for each child. Some children have mild galactosemia with few health problems, while other children may have serious complications.

If galactosemia is not treated, a child might develop:

- Liver failure
- Brain damage
- Poor growth
- Cataracts (cloudiness) in the eyes

It is very important to follow the doctor's instructions for testing and treatment.

What is the treatment for galactosemia?

Galactosemia can be treated. Treatment is life-long and includes:

- Restriction of milk or foods that have galactose in them – a dietitian will help you set up the best diet for your child.

Children with galactosemia should see their regular doctor, a doctor who specializes in galactosemia, and a dietitian.

Prompt and careful treatment helps children with galactosemia live the healthiest lives possible.

Michigan Resources and Support

Michigan Newborn Screening
Nurse Consultant
Toll-free: 1-866-673-9939
newbornscreening@michigan.gov

Michigan Metabolic Coordinating Center
C.S. Mott Children's Hospital, Michigan Medicine:
1-734-764-0579

Children's Special Health Care Services
Toll-free: 1-800-359-3722

MDHHS Michigan Department of Health & Human Services | Michigan Newborn Screening

Phone 1-866-673-9939
www.michigan.gov/newbornscreening

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