



Weill Cornell Medical College

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Patient Education:

Galactosemia, Pediatric

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Galactosemia, Pediatric

Galactosemia is when your child lacks the proteins (*enzymes*) needed to digest galactose, a naturally occurring sugar. Galactose is mainly found in milk and other dairy products. It is also often found in bread, candy, lunch meats, and other processed or prepared foods. When galactose cannot be digested, it builds up in your child's body and may damage his or her liver, brain, eyes, kidneys, and other body systems. Galactosemia is usually diagnosed during infancy or childhood.

CAUSES

Galactosemia is caused by an abnormal gene that is passed down through families.

SIGNS AND SYMPTOMS

Signs and symptoms of galactosemia include:

- Yellowing of the skin and eyes (*jaundice*).
- Vomiting.
- Severe infection of the blood (*septicemia*).
- Poor weight gain.
- Difficulty eating or refusing to eat.
- Tiredness.
- Irritability.
- Shaking.
- Bleeding.
- Seizures.
- Speech and language problems.

DIAGNOSIS

Galactosemia can be diagnosed through a blood test. Galactosemia may also be diagnosed by:

- Urine tests.
- Genetic testing.

TREATMENT

The treatment for galactosemia is to avoid galactose. Children with galactosemia must stay on a galactose-free diet for life. A consultation with a nutritionist or registered dietitian is very important in managing your child's galactosemia.

HOME CARE INSTRUCTIONS

- Make sure your child follows a galactose-free diet as directed by your child's health care provider.
 - Read food, supplement, and medicine labels carefully to make sure they do not contain galactose.
- The following ingredients contain galactose:

- Lactose. Lactose is a sugar in milk that is made up of galactose and glucose. Note that lactate, lactic acid, and lactylate do not contain galactose.
- Casein.
- Whey and whey solids.
- Milk solids and dry milk solids.
- Nonfat dry milk powder.
- Sodium caseinate.
- Calcium caseinate.
- Tragacanth gum.
- Lactostearin.
- Lactalbumin.
- Dough conditioners.
- Hydrolyzed protein.
- Monosodium glutamate (MSG). Some MSGs contain galactose, so it is best to avoid this ingredient.
- Children with galactosemia do not always get enough riboflavin, vitamin D, or calcium. Talk to your child's health care provider if you think your child is not getting the nutrients he or she needs, and ask if you should give your child supplements.

SEEK MEDICAL CARE IF:

- Your child's symptoms do not get better or get worse after following a galactose-free diet.
- Your child has a fever.
- Your child is losing weight.

SEEK IMMEDIATE MEDICAL CARE IF:

- Your child is unable to eat.
- Your baby who is younger than 3 months has a fever higher than 100°F (38°C).
- Your child has a seizure.

This information is not intended to replace advice given to you by your health care provider. Make sure you discuss any questions you have with your health care provider.

Document Released: 07/15/2015 Document Reviewed: 07/15/2015
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