



www.mi.gov/newbornscreening

Michigan Resources & Support

**Children's Hospital of Michigan
Metabolic Clinic**
Toll-free: 1-866-44CHMMC

**Children's Special Health
Care Services**
Family Phone Line
Toll-free: 1-800-359-3722

Early On® Michigan
Toll-free: 1-800-EARLY ON
www.1800earlyon.org

Michigan Genetics Connection
www.migeneticsconnection.org

Michigan Newborn Screening
Follow-up Coordinator
Toll-free: 1-866-673-9939
E-mail: MDCH-newbornscreening@michigan.gov

Michigan NBS Parent Liaison
Toll-free: 1-866-673-9939
E-mail: NBS-parent@michigan.gov

National Resources & Support

Family Village
www.familyvillage.wisc.edu

**Galactosemic Families of
Minnesota**
www.galactosemia-mn.com

GeneReviews
www.genetests.org

Genetic Alliance
www.geneticalliance.org

**Parents of Galactosemic
Children, Inc.**
www.galactosemia.org

What is Galactosemia?

Galactosemia is an inherited disorder that prevents a baby from digesting a sugar (galactose) found in milk and most infant formulas (except soy). Classic galactosemia occurs in about 1 in 41,000 Michigan newborns. If untreated, galactose can build up in a baby's body causing damage to the eyes, liver and brain. Galactosemia can be life threatening in the first few weeks of life. Milder variants of galactosemia (Duarte) are not associated with serious complications.

How may Galactosemia affect my child?

Classic Galactosemia

Signs of classic galactosemia are usually present in the first two weeks of life. These signs may include:

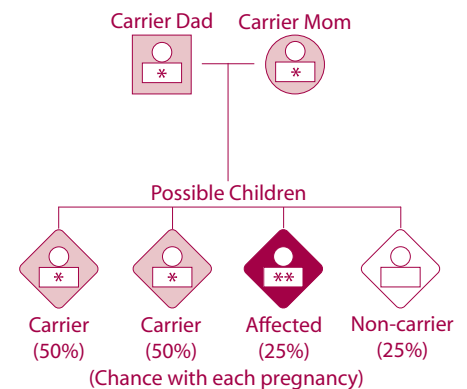
- Vomiting and diarrhea
- Poor weight gain or poor suck
- Jaundice (yellowing of skin or whites of eyes)
- Enlarged liver
- Cataracts
- Nervous system damage

Duarte Galactosemia Variant

Children with this form of galactosemia usually do not have any signs or symptoms. Follow-up in the Metabolic Clinic is recommended to monitor growth and development.

How does Galactosemia occur?

Galactosemia is a genetic disorder. Parents of an affected child carry a genetic trait that can cause galactosemia. Both parents pass the trait to a child with galactosemia. There is a 1 in 4 chance that each child will have galactosemia when both parents carry the trait for the disorder.



How is Galactosemia treated?

Newborns are placed on a special formula restricting galactose. This formula consists of a milk (lactose) substitute that is usually soy. Blood monitoring of galactose and strict avoidance of dairy products will allow for the best possible outcome in children with galactosemia. The Metabolic Clinic and your pediatrician will help you begin and keep your child on a diet that meets his or her metabolic needs.

For more information contact the Newborn Screening Program toll-free at 1-866-673-9939 or e-mail NBS-Parent@michigan.gov

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