



Galactosemia

What is it?

A person who has galactosemia cannot break down galactose (a sugar found in milk and milk products). The body breaks down galactose into energy it can use. People with galactosemia are unable to break down galactose, and it builds up in the body. When too much galactose builds up, it becomes toxic to organs and the brain. A special diet can prevent most problems.

What causes it?

Galactosemia is inherited when both parents pass an abnormal galactosemia gene to their child. This means both parents are carriers of galactosemia. Carriers do not experience any health problems related to galactosemia. When two carriers have children together there is a one in four (25 percent) chance for each child to have galactosemia.

How is it detected?

Newborn screening test is done on tiny samples of blood taken from the infant's heel 24-48 hours after birth. After a positive newborn screen, testing at special labs must be done to know for sure if a baby has galactosemia.

What problems can it cause?

Galactosemia is different for each child. People treated for galactosemia may still have problems with speech, language, hearing, fine-motor coordination, eyes, stunted growth, tremors, reproduction, and learning disabilities.

How is it treated?

Galactosemia can be treated. People with galactosemia cannot eat galactose and lactose. All milk and foods that have milk in them must

be avoided. This includes cow's milk, goat's milk, human breast milk, and dairy products like butter, cheese, and yogurt. Other foods that have small amounts of milk products in other forms such as whey, casein, and curds should not be eaten. The treatment is life-long.

Galactosemia in Children?

A primary care doctor, a pediatric metabolic specialist, and a dietician should care for the child. These health professionals provide the child with good medical care and educate the family about galactosemia.

Families are taught to read labels carefully when shopping for food. Many prepared foods have ingredients containing lactose or galactose.

Treatment for galactosemia is life-long and, and a child with galactosemia should see a doctor regularly.

Where can I find more information?

www.climb.org.uk

800.652.3181

www.galactosemia.org

925. 275.0372

www.rarediseases.org

203.744.0100

www.galactosemia-mn.com

jrvisuals@hotmail.com

bbense@banta.com

Children's Special Health Services (CSHS)

State Capitol Judicial Wing
600 E Boulevard Ave., Department 301
Bismarck, ND 58505-0269
Toll Free: 800.755.2714
701.328.2436
Relay TDD: 701.328.3975
CSHS website: www.ndhealth.gov/CSHS
North Dakota Department of Health website:
www.ndhealth.gov

Family support resources available from CSHS:

- Guidelines of Care Info
- Family Support Packet
- Financial Help Packet
- Insurance Fact Sheet

Family Resources

Family to Family Network
Center for Rural Health
University of North Dakota
School of Medicine and Health Sciences
P.O. Box 9037
Grand Forks, ND 58202-9037
Toll Free: 888.434.7436
701.777.2359
Fax: 701.777.2353
E-mail: NDF2F@medicine.nodak.edu
www.medicine.nodak.edu/crh

Pathfinder Services of ND
Pathfinder Family Center
1600 2nd Ave. SW, Ste. 19
Minot, ND 58701
Toll Free: 800.245.5840
701.837.7500
Relay TDD: 701.837.7501
E-mail: ndpath01@ndak.net
www.pathfinder.minot.com

Family Voices of North Dakota, Inc.
P.O. Box 163
Edgeley, ND 58433
Toll Free: 888.522.9654
701.493.2634
Fax: 701.493.2635
www.geocities.com/ndfv

**This fact sheet has general information. Every child is different and some of these facts may not apply to your child specifically. Certain treatments may be recommended for some children but not others. All children should be followed by a metabolic doctor in addition to their primary-care provider.

Acknowledgement

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Disclaimer

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