INFORMATION FOR FAMILIES

2010

Minnesota Department of Health

Duarte Galactosemia

(doo-art-ay ga-lac-toe-see-me-ah)

It is important for you to understand the difference between **Duarte** galactosemia and **Classic** galactosemia. As you begin learning about galactosemia, you might read about health problems children with galactosemia can develop. Many of these problems develop **ONLY** in children with Classic galactosemia. Your child **DOES NOT HAVE** Classic galactosemia. Your child has Duarte galactosemia, which is **NOT** associated with the same medical problems as Classic galactosemia.

What is Duarte Galactosemia?

Galactosemia affects a special enzyme needed to break down a sugar that is part of all milk products and several other foods, including breast milk and most formulas. A person with Duarte galactosemia is only missing **SOME** of the enzyme that breaks down the milk sugar known as galactose. A person with Duarte galactosemia has **MORE** enzyme than a person with Classic galactosemia.

	Classic	**Duarte**
Medical Problems if Untreated	Liver failure Infections Bleeding problems Cognitive impairment Learning problems Cataracts	Usually none. May have learning problems.
Possible Long Term Problems	Speech problems Vision problems Poor growth Learning problems Fertility problems Decreased bone density Tremors/Balance problems	Usually none.

What is the Treatment for Duarte Galactosemia?

Some children with Duarte galactosemia are managed with a special diet low in the milk sugars, lactose and galactose. Often, children are on the diet only for the first year of life. Some children with Duarte galactosemia are not managed with a special diet at all. Your metabolic specialists will work with you to decide if your child should be managed with a special diet.

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How did my baby get Duarte Galactosemia?

All types of galactosemia are passed on, or inherited, through instructions in the body called genes. A child gets two copies of all genes in the body, one copy from the mother and the other copy from the father. One of our genes gives the instructions to make the enzyme needed to break down galactose. If a child receives two copies of this gene that are not working properly, he or she will have galactosemia.

Duarte galactosemia (DG) is caused when a person inherits either one copy of the Classic galactosemia gene (G) and one copy of the Duarte gene (D), or two copies of the Duarte gene (DD).

If a person inherits a normal copy of the gene (N) and a copy of the Duarte gene (D), then he or she is a carrier for Duarte galactosemia. Carriers are not affected and do not have symptoms of galactosemia, but they can pass on the Duarte gene to their children.

The amount of enzyme a person has depends on the genes that they have. The table below shows the different possibilities.

Genes	Amount of Enzyme	Type of Galactosemia	Treatment
N and N	100%	Unaffected	None
N and D	75%	Duarte galactosemia carrier	None
N and G	50%	Classic galactosmia carrier	None
D and D	**50%**	**Duarte galactosemia**	**Typically no special diet**
D and G	**25-50%**	**Duarte galactosemia**	**May or may not be treated with special diet**
G and G	less than 5%	Classic galactosemia	Needs special diet

Where can I get more Information?

Genetics Home Reference:
http://ghr.nlm.nih.gov

Parents of Galactosemic Children
www.galactosemia.org

Galactosemic Families of Minnesota
http://www.galactosemia-mn.com

MN Children & Youth with Special Health Needs
(651) 201-3650 or (800) 728-5420

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