

*“One in
40,000 to 60,000
infants is born
with Classic
Galactosemia.”*

- Dr. Gerard Berry,
Vice Dean of Research
at Thomas Jefferson University
in Philadelphia
and one of the world's
leading galactosemia experts



Testing newborns' blood
can identify more than
50 health disorders,
including Galactosemia.
Early screening can save lives.



WHAT IS GANES?

The Galactosemia Association of the North Eastern States is a 501(c)(3) non-profit organization founded by families affected by galactosemia. Our goal is to raise awareness of galactosemia and support our mission:

To create and strengthen opportunities for networking among individuals and families affected by galactosemia and medical providers, and to support education and research related to the study, treatment, management, and a cure.

We serve 12 states (CT, DE, ME, MD, MA, NH, NJ, NY, PA, RI, VT, VA), and Washington, DC.

We are committed to helping others affected by this disorder, and we invite you to contact us:



CALL: 1-877-795-4895

WRITE: GANES, Inc., Box 479, Woodbury, NJ 08096

VISIT: www.galactosemia.com

EMAIL: galactosemia@ureach.com



HOW CAN I GET INVOLVED?

VOLUNTEER: Raise funds, plan networking events, create educational programs, organize outreach programs, or contribute to our website.

TURN TRASH INTO CASH: Volunteer to collect empty inkjet or laser toner cartridges. We recycle them for up to \$15 each! Every dollar helps those affected by galactosemia.

DONATIONS: GANES is a publicly supported 501(c)(3) organization. All donations are fully tax-deductible according to IRS regulations. Through your generosity, we can continue to work toward the study, treatment, management, and, best of all, a cure for galactosemia. Thank you for caring!



GANES

Galactosemia Association of
the North Eastern States, Inc.



WHAT IS CLASSIC GALACTOSEMIA?

Classic galactosemia is a rare genetic metabolic disorder inherited through a gene from both parents, who are carriers.

Normally, when a person consumes a product containing lactose, such as milk, cheese, or butter, the body breaks the lactose down into the sugars glucose and galactose. Glucose is used by the body for energy, while galactose is converted into usable glucose.

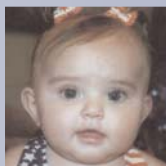
In galactosemia, the enzyme that converts galactose into glucose is missing. An excess of galactose accumulates in the blood. The build-up of galactose is a poison to the body, and can cause serious complications such as enlarged liver, kidney failure, cataracts, and brain damage.



HOW IS GALACTOSEMIA DIAGNOSED?

Diagnosis is usually made within the first weeks of life by a “heel prick” blood test that is part of the newborn screening process.

Early screening is literally a lifesaver for little ones with classic galactosemia. Up to 75 percent of infants with this disorder will die — within days — if untreated.



ARE THERE ANY EARLY SYMPTOMS?

An infant with classic galactosemia usually appears normal at birth.

If galactosemia is not detected at birth with testing, symptoms usually occur within the first few days or weeks of life after the baby drinks breast milk or a lactose-containing formula. Those symptoms may include jaundice, vomiting, poor weight gain, feeding difficulties, irritability, lethargy, and convulsions.

Another serious problem is susceptibility to *E. coli* sepsis, which has a 60 percent mortality rate. If the child is diagnosed before sepsis sets in, all symptoms should disappear.



HOW IS GALACTOSEMIA TREATED?

The only treatment currently available is the strict limitation of galactose in the diet. Milk sugar, lactose, is composed of galactose and glucose, so all products containing milk must be avoided.

Infants may be fed with soy formula, meat-based formula, or other lactose-free formula. Metabolic treatment providers have some variation in other items that should be limited or avoided. In general, products to avoid include milk, breast milk, dry milk solids, butter, cheese, cream, sour cream, buttermilk, margarine, lactose, milk chocolate, casein, curds, and whey. In addition, some fruits and vegetables may be limited, as well as fermented soy products, organ meats (liver, heart, kidney, brains, pancreas), hydrolyzed meat protein, legumes, and monosodium glutamate (MSG).

In addition, some medications and supplements have fillers that contain galactose or lactose; always review ingredients with a pharmacist.

To further ensure proper diet in case of emergency, some parents purchase a MedicAlert bracelet for their child to wear every day. The bracelets are engraved with a message such as “Galactosemia: No Dairy” or “Galactosemia: Lactose-Free Diet.”

Even with a special diet, galactosemic children have a high incidence of long-term complications involving speech and language, fine and gross motor skill delays, and specific learning disabilities. Ovarian failure may occur in girls.

However, through diet restrictions, medical advancement, and an increasingly wide variety of safe foods, many children are leading normal lives.

This document is intended to provide general information only. Always seek the advice of your physician or other qualified health professional for medical advice, examination, diagnosis, and treatment.