

Parents' Guide to Galactosemia



Part 1: Your Baby's First Six Months

To Parents

This booklet was written for the parents of a baby with galactosemia. Your baby can be treated with a modified diet. That means giving your baby a formula that does not contain lactose, instead of breast milk or other formulas with milk. As your child gets older, there are certain foods that he or she cannot eat.

As you read this booklet, write down any questions you have. There is space to do this on page 19. Take this booklet with you and discuss your questions with your baby's doctor and the staff at the Genetic/Metabolic Center. A list of Centers is provided on pages 18-19.

Once your baby starts eating solid foods ask the staff at the Genetic Metabolic Center for Part II of this booklet. It tells about the modified diet that your child will need to follow.



**Discuss this booklet
with your doctor.**

What Is Galactosemia?

Galactosemia is a disorder that causes a certain kind of sugar to build up in the body. This sugar is called galactose. A modified diet will help prevent the disorder from harming your baby. Your baby cannot have food that has galactose in it. Most galactose comes from milk sugar. Milk sugar is called lactose. It is in all foods that have animal milk in them. It is in breast milk and many baby formulas.

A baby with galactosemia doesn't have one of the enzymes that changes galactose into glucose. So galactose builds up in the body. This can cause damage to the brain, eyes, liver and kidneys. The damage can be reduced by taking galactose out of the diet.



Food containing milk and milk products cannot be eaten.

How Do We Know Which Babies Have Galactosemia?

A baby born with galactosemia may look healthy at birth. Only after the first few milk feedings do problems begin, such as vomiting, diarrhea and weight loss.

Galactosemia is found through a simple blood test. The test measures the amount of the enzyme in each baby's blood. All babies with galactosemia have decreased levels of this enzyme. The different amount of enzyme activity might account for some of the differences in the long-term problems seen between patients. In California, this test is done on babies soon after birth through the State Newborn Screening Program. Each year, about 6 to 9 babies are born in California with this disorder. It is found equally in both boys and girls.

Before testing began in 1980, most babies born with galactosemia died before they were a few months old. By testing all babies, those who have the disorder are found and treated when they are very young. This helps prevent death and many other severe problems in children.



Babies are tested shortly after they are born.

What Causes Galactosemia?

Galactosemia is inherited. A baby with galactosemia inherited it from both parents just as he or she inherited hair, skin or eye color. This is **not** something your child will outgrow. Your child will always have it. Therefore, your baby may have additional health needs as she/he grows older.

Galactosemia is **not** contagious. That means you **cannot** “catch” it like a common cold. Your child cannot “give” it to another child. For more information on how galactosemia is inherited please see pages 12 to 15.

Your baby cannot eat foods that have galactose in them. Most galactose comes from milk sugar called **lactose**. It is in all foods that have animal milk in them. It is in breast milk and many baby formulas. A modified diet will help prevent this disorder from harming your baby.



A baby inherits galactosemia from both parents.

How Is Galactosemia Treated?

Galactosemia is treated with a modified diet. This diet is called the **galactose-restricted diet**. It can help prevent severe damage from occurring to the brain, eyes, liver and kidneys. Children who start the diet as infants and stay on the diet are less likely to have these problems.

There are lots of foods that **can** be eaten safely. A child or adult on this diet can eat most protein foods, such as beef, poultry and eggs. They can also eat fruits, vegetables, grains, fats and many breads.

People with galactosemia cannot have milk or milk products. This includes breast milk, cheese, ice cream, yogurt, butter, cream, and any other foods that contain milk or milk products. They must follow this modified diet for their entire life.



Milk and breast milk are not allowed on the modified diet.

What Can I Feed My Baby?

Feed your baby a **soy** formula that does **not** contain lactose. Some of these are Carnation Alsoy®, Gerber Soy®, Isomil®, Nursoy®, Prosobee® and I-Soyalac®. They are safe to drink and alone they provide everything your baby needs to grow during the first few months. You can buy these formulas at your local stores.

If your baby will not drink one of these formulas or has loose stools, Nutramigen® can be used. Ask your doctor or nutritionist how much to give your baby.

Do not breast feed your baby. Do not give cow's milk, goat's milk or any formula that has milk or lactose in it.



These formulas are safe for your baby.

What Else Can My Baby Eat?

Solid food can be started at 4 to 6 months of age. Talk with your doctor, nurse or nutritionist about when to start and which foods to use. Infant rice, oat or barley cereals are usually the first solid foods. These are safe for your baby as long as they do not contain milk or milk products. Mix them with soy formula or water.

Cooked, strained or blended fruits and vegetables and fruit juices can be added to the diet as your baby grows older. You can make these yourself or buy them at the store. **These are safe unless they are made with nonfat milk, cream, yogurt, butter or other milk or milk products.**



Baby's first foods.

Read the Labels on All Baby Foods

Check the label on the box or jar before buying any baby food. Some of the ingredients are unsafe. For example, “creamed corn” contains nonfat dry milk, which is unsafe. Do **not** buy foods that list any of these items:

- **Milk, butter, cream, yogurt**
- **Cheese**
- **Nonfat dry milk or milk solids**
- **Casein (milk protein)**
- **Whey or whey solids (milk protein)**
- **Lactose (milk sugar)**

The staff at the Genetic/Metabolic Center can give you a list of ingredients in baby foods.



Read all labels to make
sure the food is safe.

What About Other Foods?

Do not give any other foods to your baby during the first six months unless you are told to by the Genetic/Metabolic Center staff or the baby's doctor. Honey is unsafe for any baby under one year old.

Do not give honey for any reason. It can cause a serious illness which only babies under 1 year of age can get.

For information on which foods can be given after the first 6 months ask the staff at the Genetic/Metabolic Center for "Parents' Guide to Galactosemia Part II." You may also call or write us for a free copy.

California Department of Health Services
Newborn Screening Program
2151 Berkeley Way, Annex 4
Berkeley, California 94704
(510) 540-2534



**Never give honey to a baby
under one year old.**

Are Medicines or Vitamins Safe?

Not always. Lactose is often used as a “filler” in medicine, such as penicillin. Fillers are inactive ingredients and may not be listed on the container. Fillers may also be added to vitamin and mineral supplements. Labels will list nutrients, but may not list fillers. If a sugar is added, the type of sugar may not be shown. Remind your doctor that fillers cannot include lactose.

Talk with your doctor, nutritionist or pharmacist before giving your baby any medicines or food supplements. Your doctor may need to talk with the drug company to make sure the medicine is safe for your baby.



Check with your doctor.

Will My Child Grow Like Other Children?

Children with galactosemia who are on a galactose restricted diet can have normal physical growth. For all children, the greatest growth happens from birth to one year of age. During this time the average baby triples in weight and almost doubles in length.

Starting a lactose-free formula shortly after birth and following the modified diet carefully will help your child grow properly. Growth rate depends on a family's pattern of height and weight. It also depends on getting enough protein and calories.

Children with galactosemia are generally healthy and are **not** any more likely to get sick than any other children their age.



Your child should grow like other children.

Do Children With Galactosemia Have Any Special Problems?

Many children with galactosemia have problems with learning and/or speech even though they have stayed on the modified diet. Females may also have reproductive problems such as ovarian failure.

Right now we do not know why some children with galactosemia have problems and others do not. Researchers are trying to find out why these problems happen and what can be done to prevent them. Babies with galactosemia have variable enzyme levels. This may be a reason why some children have more problems than others. The genetics staff can provide you with the latest research findings. Be sure to keep all of your baby's appointments. These include well baby exams, immunizations, and visits to the genetic center. The well baby clinic will provide the routine care all babies need. The genetics staff will give you instructions for a modified diet. They will also observe your child's growth and development and arrange for any tests that are needed as your baby grows older. Together you can provide the best care for your baby.

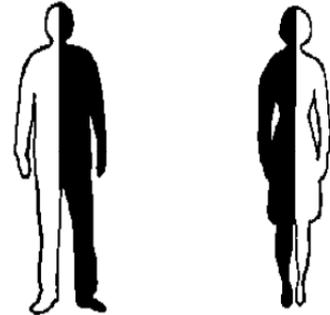


Take your baby for well baby and genetic visits.

More on How Galactosemia Is Inherited . . .

Galactosemia is inherited. That means that it is passed on from parents to children. We all carry traits that are found in our genetic material or “**genes**”. Each person has two sets of genes, one from the mother and one from the father.

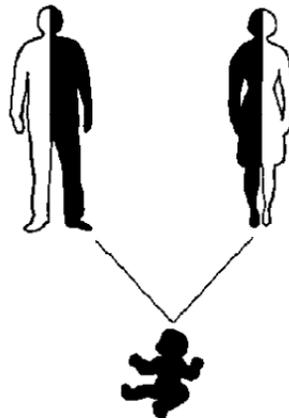
The parents of a baby with galactosemia **each** have one gene for galactosemia and one non-galactosemia (or other) gene. People who have one galactosemia gene and one other gene are known as “**carriers**”. Carriers produce enough enzyme to keep galactose from building up in their bodies.



Carriers have 1 gene for galactosemia and 1 other gene.

A baby with galactosemia received two genes for galactosemia. The baby inherited one gene from the mother and one gene from the father, who are both carriers. (See page 16 for the chances of having a child with galactosemia in a future pregnancy.)

Mother and father each have one gene for galactosemia.



Baby has two genes for galactosemia.

Women who are carriers of galactosemia and are pregnant should visit their genetic centers. They will be put on a galactose-restricted diet **before and during** their pregnancy.



Can a Couple Have More Than One Child With Galactosemia?

Yes. People who are carriers may pass on either their galactosemia gene or their other gene each time they get pregnant. For each pregnancy the chances or risk of having an infant with galactosemia is the same no matter how many children the carrier couple decide to have. Each time the couple gets pregnant, there is . . .

1 in 4 (25%) chance of having a baby without any galactosemia gene.
(Baby does not have galactosemia.)

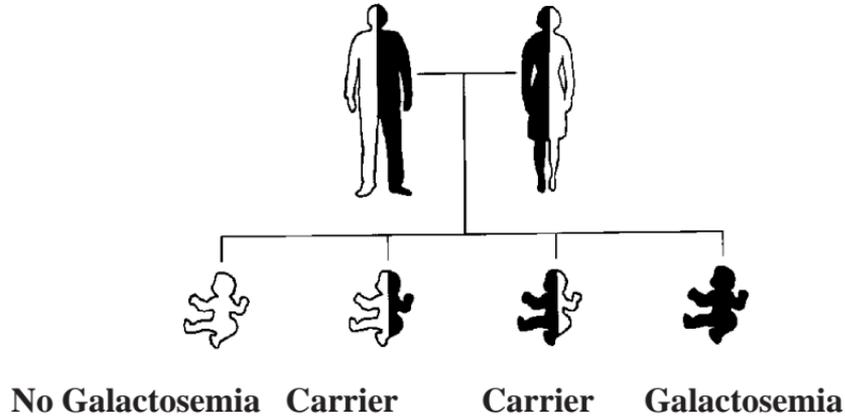
2 in 4 (50%) chance of having a baby with 1 galactosemia gene.
(Baby is a carrier.)

1 in 4 (25%) chance of having a baby with 2 galactosemia genes.
(Baby has galactosemia.)



Chance of Having a Baby With Galactosemia

Both Father and Mother Are Carriers



If you have any questions write them down on the following pages and then ask the staff at the Genetic/Metabolic Center or your doctor.

Notes and Questions for the Genetic Center Staff or Your Doctor

Other Important Names and Phone Numbers

Name_____ Telephone_____

Name_____ Telephone_____

Name_____ Telephone_____

Name_____ Telephone_____

Name_____ Telephone_____

List of Genetic/Metabolic Centers in California

Northern California

Children's Hospital Medical Center
of Northern California
Child Development Center
747 52nd Street
Oakland, California 94609
(510) 428-3351

U.C. Davis
Metabolic Clinic
Medical-Pediatrics
Davis, California 95616
(916) 752-7664

Valley Children's Hospital
Medical Genetics Department
3291 North Hilliard Avenue
Fresno, California 93726
(209) 243-6400

Stanford Medical Center
Pediatric Metabolic Genetics - H315
300 Pasteur Drive
Stanford, California 94305
(415) 723-6858

U.C. San Francisco
533 Parnassus Avenue
Genetics Clinic, Room U-100A
San Francisco, California 94143
(415) 476-2757

Northern California Kaiser
Permanente Medical Group
Regional Metabolic Center
280 West MacArthur Boulevard
Oakland, California 94611
(510) 596-6725

Southern California

Children's Hospital of Los Angeles
Medical Genetics-Metabolic Section
4650 Sunset Boulevard
Los Angeles, California 90027
(213) 669-2226 or 669-2178

Loma Linda University Medical Center
Pediatric Medical Group-Metabolic Clinic
11262 Campus (West Hall, Rm. 157)
Loma Linda, California 92354
(909) 478-8119

San Diego /Imperial Counties
Developmental Services, Inc.
Metabolic Disorders Clinic
4355 Ruffin Road, Suite 216
San Diego, California 92123-1648
(619) 576-2975 or 576-2851

UCLA Medical Center
Medical Genetic Division
MDCC-22-499
10833 Le Conte Avenue
Los Angeles, California 90095-1752
(310) 206-6581

Harbor/UCLA Medical Center
Division of Medical Genetics-E4
1124 West Carson Street
Torrance, California 90502
(310) 222-3751

Los Angeles County/USC Medical Center
Genetics Division-Metabolic Center
1240 North Mission Road, Rm. L-916
Los Angeles, California 90033
(213) 226-3816

U.C. Irvine Medical Center
Genetics Division, Pediatrics Department
Building 27, Route 81
101 City Drive South
Orange, California 92668
(714) 456-6878

Southern California Kaiser
 Permanente Medical Group
Regional Metabolic Services
1515 North Vermont, Rm. 860
Los Angeles, California 90027
(213) 667-6970

Additional Resources:

Parents of Galactosemic Children (PGC), Inc.
2871 Stage Coach Drive
Valley Springs, California 95252
(209) 772-2449
Contact Person: Gayle Dennis

Things to Remember

1. Your baby has galactosemia.
2. Do not breast feed your baby. Do not give cow's milk, goat's milk or any formula or food that has milk or lactose in it.
3. An infant soy formula is all your baby needs to eat to grow and develop for the first 4 to 6 months. Ask your doctor when to start solid foods and which ones are safe.
4. Your baby is like other babies except that she or he has to be on a modified diet.
5. Keep all your baby's appointments. Let your doctor and the Genetic/Metabolic Center know each time you move.
6. Remember, you are not alone. The clinic staff is there to help you. There is a parent's support group. Ask your area genetic center staff for the number of the support group's representative.

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