

# Parents' Guide to Galactosemia



## Part 2: Your Child Six Months and Older

## To Parents

This booklet was written for parents of children with galactosemia. It is written in two parts. Part 1 is for new parents. It answers the questions that most new parents ask about galactosemia and the diet. Part 2 has more details on the diet and how to follow it.

As you read this booklet, write down any questions that are not answered. There is space to do this on pages 48-49. Take this booklet with you and discuss these things with your baby's doctor and the staff at the genetic/metabolic center. A list of genetic/metabolic centers is on pages 51-52.

Share this booklet with grandparents and other family members, teachers and babysitters so that they can better understand the importance of your child's diet. Ask the Genetic/Metabolic Center for extra copies, or write to us at the Genetic Disease Branch. Our address is on the back cover.



**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 child. 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 child 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.



**Foods containing milk and milk products  
cannot be eaten.**

## Are Milk Intolerance, Milk Sensitivity or Allergy, and Galactosemia the Same?

No. They are all different.

The body normally changes lactose found in milk and other foods into glucose and galactose. The body then changes the galactose into glucose.

People with milk intolerance cannot break down the sugar lactose or fat or protein found in milk. This is a common condition. The usual cause for milk intolerance is due to the lactase enzyme being missing or deficient, so the sugar lactose is not broken down. About 80 to 90 percent of adults in the general population are deficient in the lactase enzyme. This enzyme is not missing in people with galactosemia.

People who have milk sensitivity develop allergic reactions when they drink milk. Symptoms vary from asthma to stomach problems to hives. An antigen antibody reaction produces these allergic symptoms.

People with galactosemia can break down lactose into glucose and galactose. But they cannot change galactose into glucose because an enzyme is missing.

The diets for galactosemia, milk intolerance, and milk sensitivity are similar because milk products cannot be used. However, there are some milk products made for people with milk intolerance that are not safe for people with galactosemia.

## 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, such as vomiting, diarrhea and weight loss begin.

Galactosemia is found through a simple blood test. The test measures the amount of 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 soon after birth.**

## What Causes Galactosemia?

Galactosemia is inherited. A child 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 child 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 see pages 43-44.

Your child 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 child.



**Your child cannot give galactosemia to another child.**

## 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 cheese, butter, yogurt, cream, ice cream, and any other foods that contain milk or milk products. They must follow this diet for their entire lives.**



**These foods cannot be eaten.**

## How Can I Make Sure Foods Are Safe?

Read the label on all packaged foods. Many packaged and processed foods 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**
- **whey or whey solids (milk proteins)**
- **lactose (milk sugar)**
- **casein (milk protein)**

If there is no label or the contents are not listed, do **not** give the food to your child.



**Read the label to be sure the food is safe.**

## 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 child 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. All children grow the most 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 soon 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 give you the latest research findings.

Be sure to keep all of your child's appointments. They include immunizations, well child visits and visits to the genetic/metabolic center. 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. Together you can provide the best care for your child.

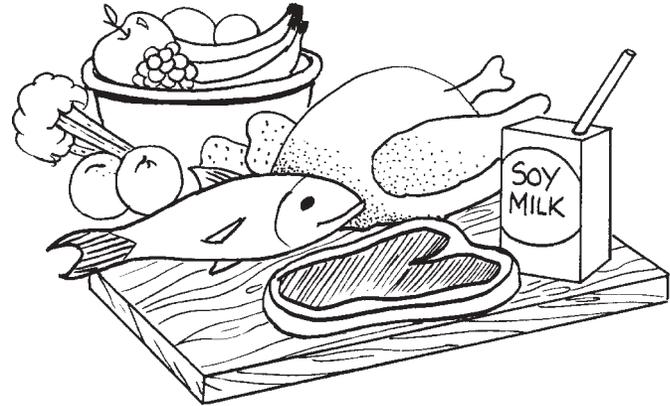


**Take your child for well child and genetic visits.**

## The Modified Diet

Most foods are safe for your child to eat. Milk and milk products are **not** safe. Any food can become unsafe if milk or a milk product is added to it. Always check the label on packaged foods to make sure they do not contain any harmful ingredients. Also, be careful when eating at fast food or other restaurants. (See pages 31-33 for tips on meals away from home.)

You can buy the foods for your child's special diet at your local store. These foods are listed by groups on pages 34-35 to help you plan the meals for your child and family. The staff at the genetic/metabolic center can also answer your questions and tell you more about these foods.



**These foods are usually safe.**

## Milk and Milk Substitutes

Do **not** give your child with galactosemia breast milk, cow's milk, goat's milk or milk products such as cheese, yogurt, and ice cream. Instead a number of fortified soy milk products can be used.

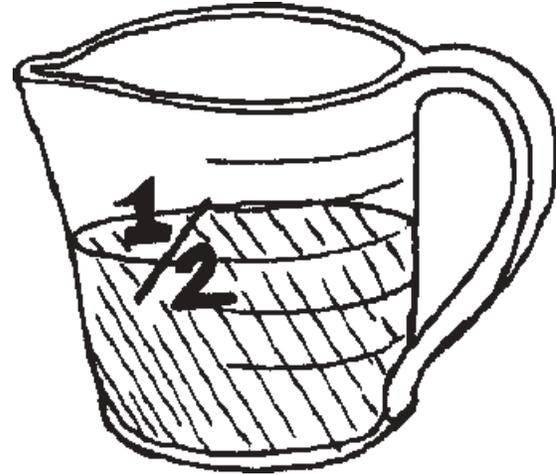
You can buy soy milk beverages for older children and adults at special food stores. They are **not** made for babies and you should talk with your doctor or nutritionist before you give them to your baby.



## What about Non-Dairy Products?

Non-dairy products can be used on cereal or in cooking. They should **not** be used to replace the soy milk formulas. They do not have the nutrients found in soy milk.

**Some products which are labeled “non-dairy” have casein or caseinate in them.** Casein and caseinate have a small amount of lactose in them. They can be used in small amounts in the diet of a child with galactosemia. **Do not let your child have more than a total of  $\frac{1}{2}$  cup per day of liquids with casein or caseinate.**



**No more than  $\frac{1}{2}$  cup of liquids with casein.**

# Milk and Milk Substitutes

## Safe

Infant soy formulas: Isomil®, Prosobee®, I-Soyalac®, Nursoy®

Soy milk

Nutramigen® (only up to 1 quart per day)

Casein hydrolysates (without lactose added)

Non-dairy cream substitutes which have soy protein

Non-dairy substitutes with caseinate (in small amounts)

## Harmful

Human milk, all animal milks, Lactaid® lactose-reduced milk

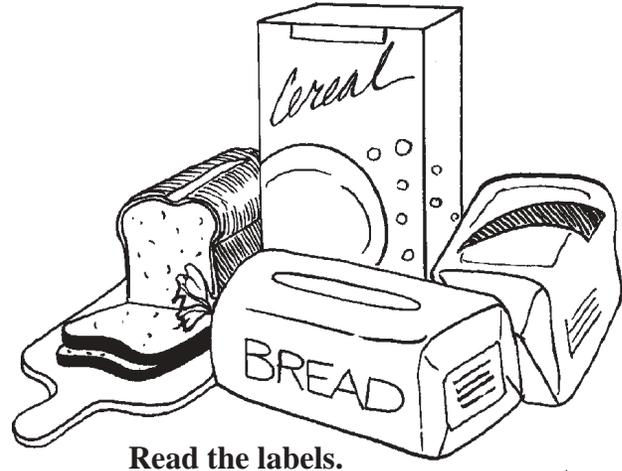
Casein, milk solids, whey, milk fat, lactose

Milk products: buttermilk, cream, whipped cream, sour cream, yogurt, ice cream, ice milk, sherbet, butter

Processed cheese, cottage cheese, cream cheese

## Grains and Breads

Grains and many breads are safe for your child. But breads and dry cereals that have milk or milk products are unsafe. **Check the label to see if milk or milk products are listed.** Local bakeries often do not label their products. Ask them for a list of what ingredients they use to bake their foods.



**Read the labels.**

### Safe

Infant cereals, cooked or dried cereals (without milk, milk products or lactose)

### Harmful

Infant cereals, dry or in a jar, which have milk or milk products

Macaroni, spaghetti, other noodles

Rice and other grains

Bread, rolls, and buns (**without** milk or milk products or lactose added)

Graham crackers, saltines, biscuits, and cookies (**without** milk or milk products, lactose, whey, or casein added)

Flour or corn tortillas, and tortilla chips (**without** milk, or milk products)

Dry cereal **with** added whey, casein or milk solids

Teething or “bitter” biscuits, arrowroot or animal cookies **which contain** milk, milk products, whey, or butter

All breads, rolls and buns **which have** butter, milk solids, whey, milk, milk products or lactose

Prepared mixes such as cake, pancake, waffle, muffin, biscuits **with** milk or milk products\*

Tortillas or corn chips **with** cheese, cream, or whey

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\* Some brands of mixes are safe. Check with your nutritionist for an up-to-date list.

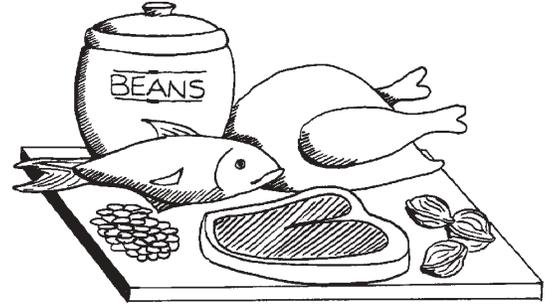
## Protein Foods

Almost all meats, fish, beans, and nuts can be eaten. Read the labels carefully on processed and packaged meats and cold cuts, such as hot dogs and bologna, to avoid milk, milk products or lactose. Do **not** give your child animal brains or mussels (a seafood). They contain galactose and should **not** be eaten by your child.

Experts have different opinions on the use of green peas, lima beans, organ meats and legumes. Some experts do **not** recommend them for children with galactosemia, while others feel that they are acceptable. Discuss these foods with your nutritionist and doctor at the genetic/metabolic center to see what they think is best for your child.

### Safe

Strained or junior infant meats (**without** milk or milk products)



### Harmful

Strained or junior infant meats **with** milk or dried milk

Meat dinners or toddler foods (**without** milk or milk products)

Eggs (made **without** milk, cream, butter, or margarine that has milk products)

Plain meat, chicken and other poultry, and all-meat sausages

Fish

Cold cuts and hot dog (**without** milk products)

Nuts, peanut or other nut butters, and coconut

Legumes, dried beans such kidney, pinto, navy, black-eyed, etc. (**unless** they are made with milk or milk products)

Meat dinners for toddlers or finger meat sticks **with** nonfat dry milk, or cheese

Cream, sauces and breadings should **not** be used with these protein foods unless they are milk-free

Beef brain or other animal brains

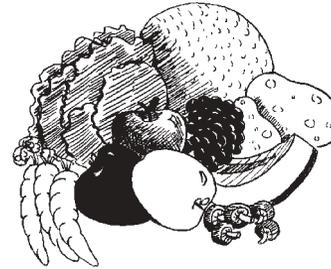
Mussels (a seafood)

Processed meats and cold cuts **with** added milk products or lactose

Fermented soybean products such as miso, natto, tempeh, or fermented soy sauce in which enzyme processing is used

## Fruits and Vegetables

Almost all fresh fruits and vegetables are safe. They are unsafe if milk, lactose or other milk products are added to them. Please read information on green peas and lima beans on page 16.



### Safe

Homemade or store bought infant strained, junior or toddler foods (**without** milk or milk products)

Any vegetables, fresh, frozen, canned, dried (**unless** processed **with** lactose or milk products)

Plain potato chips (**without** milk products)

Red beets

### Harmful

Infant strained, junior or toddler foods **with** cream, non-fat milk, or butter added

Vegetables **with** sauces that have cream, milk, butter, casein, whey, or cheese

Potato chips **with** cheese, sour cream, or whey

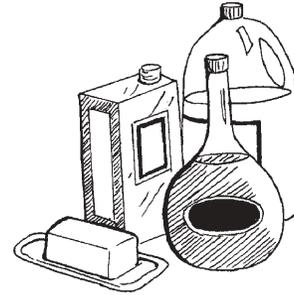
Sugar beets\*

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\* Note: Refined sugar made from sugar beets is safe. It **does not** have galactose.

# Fats

Fats that **do not** contain milk or milk products, such as whey or casein are safe to use. Animal fats, such as lard or suet (beef fat), can be used since they are not made from milk.



## Safe

Margarine (**without** milk or milk products added)

Vegetable oils, such as soybean, corn, olive, cottonseed, safflower, and peanut oil

Salad dressing (**without** milk products added)

Mayonnaise

## Harmful

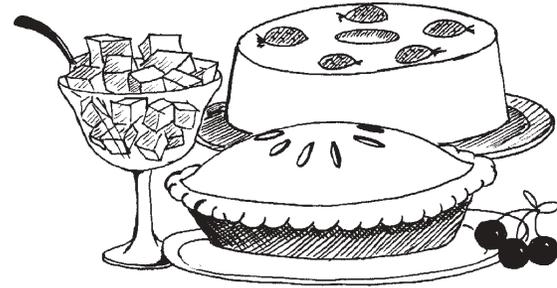
Milk fat, cream, butter, sour cream, margarine **with** milk, whey, or casein added

Salad dressing **with** milk, milk products, yogurt or cheese added

## Desserts and Sweets

Your child can have milk-free desserts and sweets. Frozen desserts that are milk-free can also be used.

**Do not let your child have any dairy or milk desserts, such as puddings and ice cream. Some cake and cookie mixes and most candies also contain unsafe ingredients. Read labels carefully.**



### Safe

Fruit and flavored ices, gelatin desserts

Homemade pudding **without** milk or milk products

Non-dairy whipped toppings or liquids (use only small amount if contains caseinate)

### Harmful

Dairy and milk desserts: ice cream, ice milk, yogurt, sherbet, pudding, custard, and parfait

Desserts made **with** caseinate

Whipped toppings or liquids that **contain** milk, whey, or cream

## Safe

Frozen desserts made with soy protein or tofu that are **milk-free**. **Milk product-free** sorbets and Mocha Mix® frozen desserts

Cakes, pies and cookies made with **milk substitutes** and other safe items

Clear candies, gumdrops, marshmallows, chewing gum

Carob

Bittersweet, semisweet, unsweetened, dark sweet, white, or baking chocolate and cocoa

## Harmful

Frozen desserts made with **milk or milk products**

Cake, cookie or muffin mixes that contain milk or milk products

Candies that do not list ingredients. Also, Caramels, butterscotch or any candies such as taffy, toffee that **contain** milk, milk products or lactose

Carob **with** milk products

Cocoa mixes or chocolate syrups **with** milk products

Fudge, milk chocolate or yogurt coatings **with** milk fat and/or whey, white chocolate **with** milk or milk products added

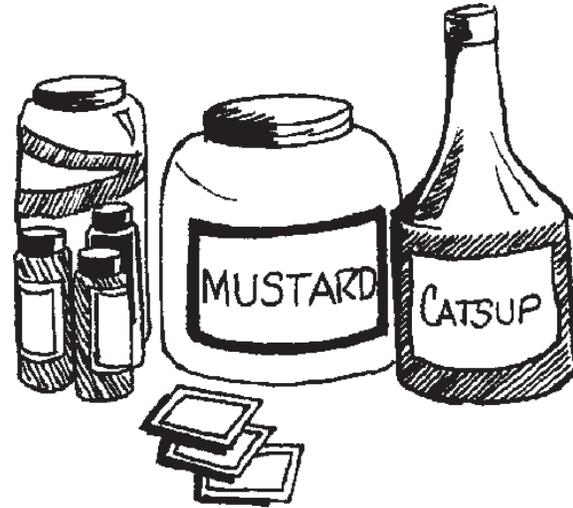
## Soups and Sauces

**All soups, sauces, and gravies that do not contain milk, milk products or other “unsafe” ingredients can be used.** If you make them at home, use a milk substitute or water. If you buy canned or dried soups, sauces or gravy mixes, be sure to read the labels.



## Other Foods

There are many foods or ingredients used daily that do not fit into any of the other groups. These include some beverages, condiments, sweeteners, seasonings, and spreads. As always, you should check the labels before using these foods.



### Safe

Tea, coffee, salt, pepper, pure spices and herbs, monosodium glutamate (MSG), pure flavorings

Catsup, mustard, and horseradish

### Harmful

Flavored coffees with sodium caseinate

Condiments **that contain** cream, lactose, milk or milk products

## Other Foods (continued)

### Safe

Vegetable gums do not contain free galactose nor release galactose within the digestive system

Agar, acacia (gum arabic), carrageenan, locust bean (carob) gum tragacanth, and guar gum

Sugar, molasses, sorghum

Sweeteners **that do not** contain lactose such as aspartame, also known as NutraSweet®

Honey for children over 1 year old\*

Corn syrup

### Harmful



Honey for children under 1 year of age\*

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\* Never give honey to **any** baby under 1 year. Honey can cause a serious illness in babies under 1 year.

## Hints to Following the Diet

This and the following sections give tips on planning meals, buying and preparing food, and eating away from home.

### Meal Planning

1. Use a food group plan to be sure the day's meals are well balanced. A sample plan is on pages 34-35. Include foods that differ in taste, color, and texture to make meals fun for the whole family. Always try to eat a variety of safe foods.
2. Plan menus for your family using recipes that do not have milk or milk products or lactose as much as you can.
3. Keep a file of recipes that do not use milk or milk products and star those that need milk-free ingredients. For a list of cookbooks, see page 50.



## Meal Planning (continued)

4. Keep milk substitutes on hand.
5. Involve your child in meal planning to encourage independence and allow a choice of foods, and in planning for holidays and birthdays.
6. Pick a similar but safe food for your child to have when the rest of the family is having food with milk or milk products.

### Examples:

- ◆ angel food cake instead of butter cake
- ◆ frozen fruit juice instead of ice cream or sherbet
- ◆ fruit juice instead of milk shake

7. Give a list of snacks or foods which your child can eat to teachers and babysitters.



**Involve your child in planning.**

## Preparing Foods

1. Prepare most of the foods for the family without milk or milk products.

Examples:

- ◆ gravies with water **instead of** milk
- ◆ milk-free margarine on vegetables **instead of** cream sauce or butter
- ◆ meringue or fruit topping **instead of** cream

2. Let your child help you prepare his or her food or formula. For example, he or she can choose between two fruits for lunch or measure soy formula and add the needed amount of water.



**Let your child help.**

# Grocery Shopping

1. Read the list of ingredients on the label when you buy any processed or packaged foods. Many of these foods are unsafe for your child.

## Harmful ingredients

Do **not** give your child any product that lists:

- ◆ milk
- ◆ butter, cream, yogurt, milk fat
- ◆ nonfat dry milk solids
- ◆ lactose (milk sugar)
- ◆ whey or whey solids (milk protein)
- ◆ cheese



### **Safe only in small amounts**

You can give your child small amounts of any product that lists:

- ◆ casein
- ◆ caseinate or “hydrolyzed protein”
- ◆ lactalbumin

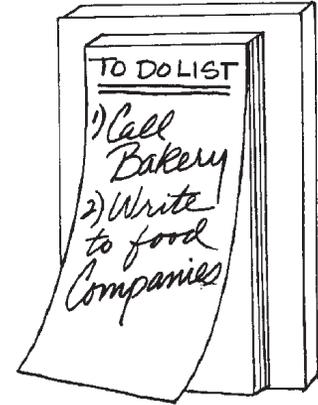
### **Safe ingredients**

You can buy and give your child any product that lists:

- ◆ lactate
- ◆ lactylated fatty acid
- ◆ calcium compound
- ◆ glucono delta-lactone
- ◆ stearyl lactylate (dough conditioners)
- ◆ hydrolyzed vegetable protein

## Grocery Shopping (continued)

2. Watch out for low calorie and diabetic foods. The sweeteners in them or other items may contain lactose.
3. Bakery goods may not have labels. If they are made by a local bakery, check with the bakery to make sure the products do not have milk or milk products or other unsafe ingredients in them. Some food companies are willing to send you a full list of the ingredients in their products. If the ingredients are not listed you can write and ask them for a list before you buy or use the food. The company's name and address are given on the package.
4. Make a list of brand names of foods sold in your market that do not have milk or milk products. Re-check labels often for changes.
5. Buy food staples, such as lactose-free bread and margarine **without** milk, for the whole family.
6. Buy soy formulas in concentrated or powdered form and by the case when you can. This will help you to save both time and money.



# Meals away from Home

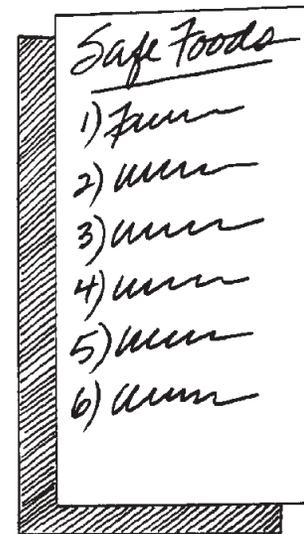
## School

It may be easier to send a lunch packed at home for the first year. Sharing in group meals is an important part of a child's being accepted, so encourage this when safe foods for meals or snacks are being served. Give your child's teacher a list of safe foods and/or a copy of this booklet. See the resource list for other suggestions.

Prepare milk-free and milk product-free snacks for school meetings and parties. Ask teachers and other parents to let you know in advance when food will be served so you can bring other foods.

## Restaurants

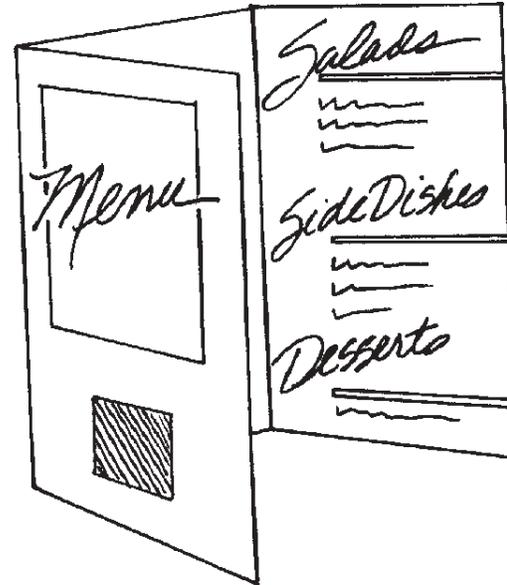
1. Select a restaurant where you know you can order milk-free foods. Some fast-food restaurants have ingredient lists for foods on the menu. Call in advance so there is time to get the information you need.



**Give your child's teacher a list of safe foods.**

## Restaurants (continued)

2. If necessary, bring milk-free rolls for hamburgers.
3. These foods that do not contain milk or milk products are often on menus:
  - ◆ **green salads (without cheese, cream, or yogurt salad dressings)**
  - ◆ **plain baked potatoes or french fries (without butter, cheese, or sour cream)**
  - ◆ **fresh fruits**
  - ◆ **fruit ice (instead of ice cream)**
  - ◆ **baked or broiled meat (without cream sauce, breading or coating)**



**Look for safe foods on menus.**

## Traveling

1. Take powdered soy formula with a measuring scoop and directions for a single serving. Concentrated canned liquid soy formula and the required water can also be used. But, the mixture and the opened can must be kept cold and used within 48 hours.
2. Take milk-free staple foods, such as bread, in extra amounts for an extended trip.
3. Plan meals noting which foods can be bought in markets along the way.
4. Check out restaurants ahead of time for a good selection of safe foods. Chain restaurants are more likely to prepare their food in the same way from city to city, but not always.



## A Daily Guide for Young Children

Milk Group	Protein Group	Grains Group
<p><b><u>Use:</u></b></p> <p>24 ounces soy milk fortified with methionine casein hydrolysate without added lactose</p> <p><b><u>Do not use:</u></b></p> <p>cow's milk; any animal milks, butter, cream, milk fat, casein (hydrolyzed milk protein), cheese (fresh or aged), yogurt, <b>lactose</b></p>	<p><b><u>Use:</u></b></p> <p>4 cooked ounces of meat, fish, poultry, eggs, nuts, legumes (peas and beans), peanut and other nut butters, soybeans and soy products</p> <p><b><u>Do not use:</u></b></p> <p>mussels (seafood), brains (organ meat), creamed foods with sauce made with milk, butter, cream, <b>fermented</b> soy products</p>	<p><b><u>Use:</u></b></p> <p>4 servings (½ cup or 1 slice) of rice, oats, wheat, rye, corn, barley in breads or cereals</p> <p><b><u>Do not use:</u></b></p> <p>any made with milk or milk products</p>

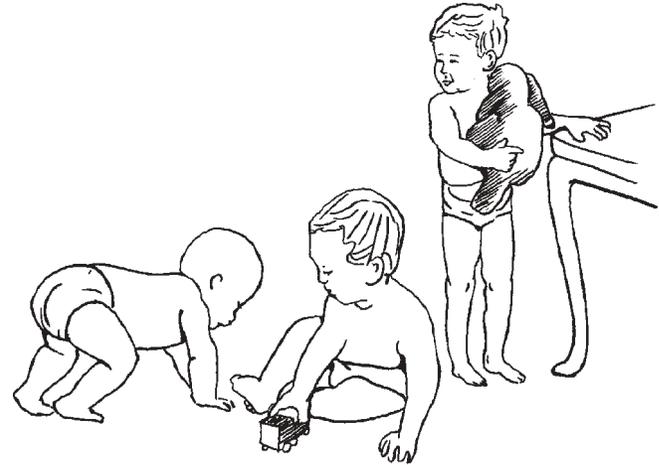
<b>Vegetable/Fruit Group</b>	<b>Fats</b>	<b>Sugars</b>
<p><b><u>Use:</u></b></p> <p>4 servings (½ cup or 1 piece)</p> <p>one citrus fruit</p> <p>one deep green or yellow fruit or vegetable, as raw, cooked, dried or frozen</p> <p><b><u>Do not use:</u></b></p> <p>sauces with milk, butter, cream, or margarine with milk</p>	<p><b><u>Use:</u></b></p> <p>at least 1 tablespoon or as need for calories</p> <p>oil, shortening, lard, milk-free margarines, milk-free salad dressing</p> <p><b><u>Do not use:</u></b></p> <p>butter, cream, milk fat, margarines with milk, cheese, cream or yogurt salad dressings</p>	<p><b><u>Use:</u></b></p> <p>as needed for extra calories</p> <p>sucrose (table sugar), glucose, honey, syrup, molasses, sorghum</p> <p><b><u>Do not use:</u></b></p> <p><b>lactose</b></p>

**\*Ask the nutritionist at your genetic/metabolic center for a plan for your child.**

## Growing up on the Modified Diet

For all children the most growth happens from birth to one year of age. During this time the average baby triples in weight and almost doubles in length. The modified diet, including the soy formula and foods, provide the nutrients and energy needed for this growth and development.

During the first few months, the soy based formula alone provides everything a baby needs. At around 4 to 6 months a baby is ready for some solid foods. You can buy these foods or make them yourself. For the infant with galactosemia, these foods must not contain galactose or lactose.



**The most growth happens during the first year.**

Babies soon learn to grasp and pick up foods. They enjoy feeding themselves. Encourage this but be careful. Babies and small children can choke easily. So do not give your baby or small child foods that are small, round, tough or sticky. This includes berries, nuts, hard candies, raw carrots, and peanut butter if spread too thickly.

Toddlers, ages 1 to 3 years, grow slower than infants. This will affect their hunger and interest in foods. Changes in appetite and food likes and dislikes are typical for this age group. They like to copy their parents and brothers and sisters. So set a good example by your eating habits. Most children are curious about new foods. Foods that contain milk or milk products will need to be stored out of reach.



**Toddlers grow slower than infants.**

## Growing up on the Modified Diet (continued)

The soy formula will continue to be an important part of the diet. It provides the needed calcium, riboflavin, and vitamin D. Toddlers will want to drink it from a cup.

After ages 3 to 4 years, there is a steady increase in food intake as growth increases. These changes in appetite are normal.

Other things, besides changes in growth, can cause a change in a child's appetite. When a child is sick, he or she may eat less than usual. As the child begins to feel better, his or her hunger should return. Eating too many sweets and "junk foods" or having too much milk substitute or other drinks can also decrease your child's appetite for healthy foods. You can change this by making healthy snacks and desserts for your child.



**Toddlers can drink soy formula from a cup.**

Your child may refuse to drink the soy mixture if it is either too watery or too thick. Also, if your child senses your dislike for the soy milk, he or she may not want to take it.

If your child seems hungry most of the time, more food may be needed. Measuring your child's growth can reassure you that he or she is getting enough to eat.

To encourage good eating habits, make meals pleasant and relaxing. It is best if you are not feeling tired or tense when you feed your child. Use utensils that are the right size for your child. Dishes, cups and any other items should be unbreakable. Make sure your child is seated comfortably. Give small amounts that can be easily eaten. This helps to provide a sense of accomplishment.



**Measure your child's growth.**

## **Growing up on the Modified Diet (continued)**

Do not use sweets as bribes to get your child to eat other food. Food should not be used as a reward.

Prepare foods in different ways to enlarge your child's experience. Add new tastes and textures slowly. Do not pressure your child to eat. Following these tips, whenever you can, will help your child to have a good attitude about eating.

Your child is like other children in many ways, except that he or she is not able to change

galactose into glucose. The modified diet is only one part of your child's care. Keep your child on the modified diet but treat him or her like a normal, healthy child as much as possible.

Create a caring, supportive and safe home where your child learns love and acceptance, discipline and independence. Each child is a unique person with many talents and special qualities. As parents, you will enjoy watching your child growing, being part of your family, and learning about the world.

## Teaching Others about Galactosemia

Siblings, grandparents and other family members, caregivers, neighbors, and school staff need to understand the importance of your child's diet. Since most people do not know anything about galactosemia, you will need to inform them. Tell them that your child needs to be on a galactose-restricted or modified diet for his or her health. Explain what is safe to eat on the diet. You may even want to share a copy of the diet with them. Getting the entire family and others involved in managing the diet can help a lot.

You should also tell them that galactosemia is **not** contagious. Your child **cannot** give it to them or anyone else like a cold or the flu.



**Teach others about the diet.**

## Teaching Your Child about Galactosemia

Just as a child learns about safety and other rules, your child will need to learn about the modified diet. You can start teaching your child about the diet as early as pre-school. Your child can learn which foods are safe and which are not by using simple terms.

Giving your child a variety of foods that do not contain milk or milk products at an early age can help avoid refusal of food later on. The young child can be taught to ask about unfamiliar foods. Children by age ten are able to ask questions about foods or milk content before accepting

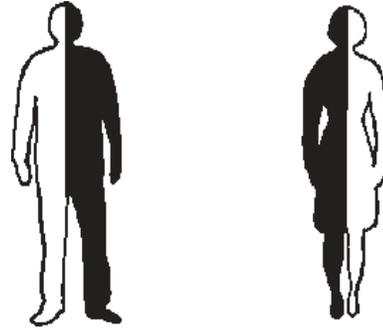
them. At this age they can grasp more complex explanations and understand how the body functions.

While growing up, all children test their parents' decisions. This will also happen with your children. You should not feel guilty that your child with galactosemia needs a modified diet. Do not give special favors to “make up” for the diet. Your child will learn to adjust to the diet if you and others use a consistent approach to the diet restrictions.

## More on How Galactosemia Is Inherited . . .

Galactosemia is inherited. That means 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.

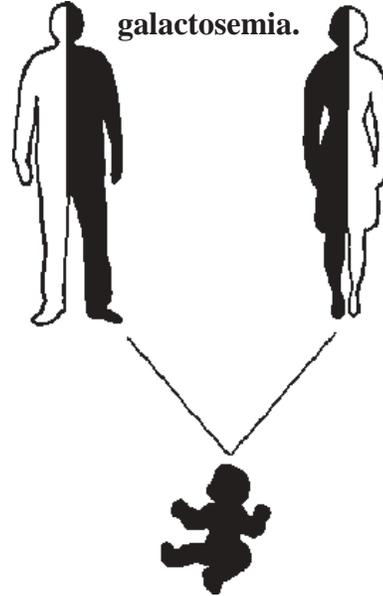
The parents of a child with galactosemia **each** have one gene for galactosemia and one non-galactosemia (or other) gene. People who have one galactosemia gene and one other gene are known as **carriers**. Carriers produce enough enzyme to keep galactose from building up in their bodies.



**Carriers have one gene for galactosemia and one 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. (See pages 45-46 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.**

## Can a Couple Have Another 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 a carrier couple decide to have.

Each time the couple gets pregnant, there is a:

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 galactosemia gene. (**Baby is a carrier.**)

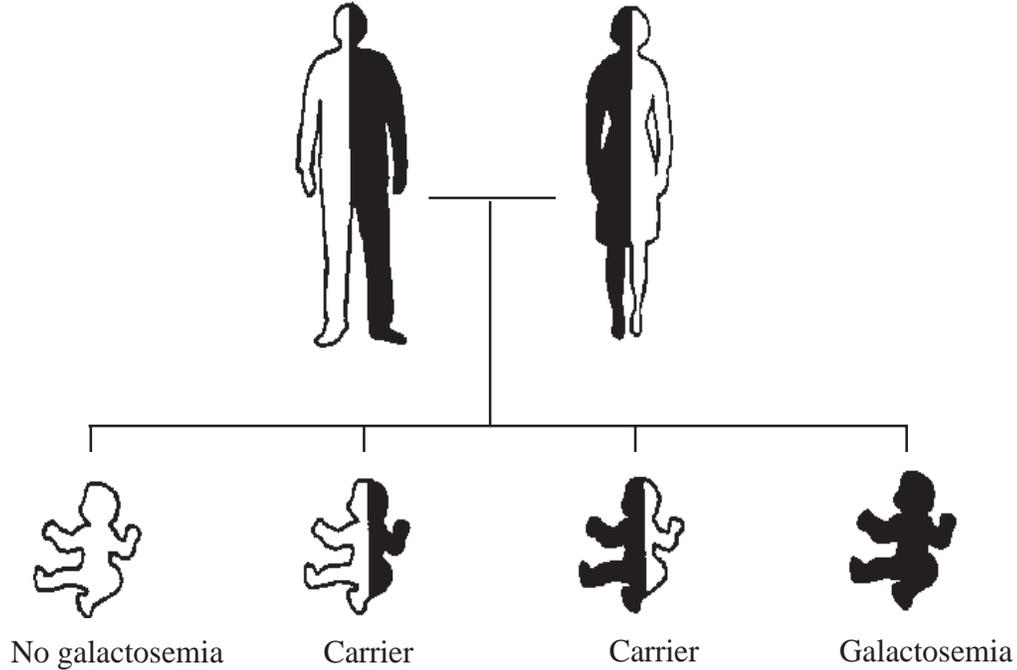


1 in 4 (25%) chance of having a baby with 2 galactosemia genes. (**Baby has galactosemia.**)



# Chance of Having a Baby with Galactosemia

## Both Father and Mother Are Carriers



## Can Babies Be Tested for Galactosemia before They Are Born?

Yes. Tests can be done during pregnancy to check for galactosemia and other genetic problems. One of these tests is called amniocentesis. It is done by inserting a needle in the womb and removing a small sample of fluid that surrounds the unborn baby.

If you are pregnant or thinking about having another baby, ask your genetic/metabolic center about prenatal diagnosis. The staff at the genetic/metabolic center can give you more details on amniocentesis and other tests and answer your questions. They will usually recommend that you be on a lactose-controlled diet before and during pregnancy. So it is a good idea to visit a genetic/metabolic center before becoming pregnant again.



**Talk with a genetic counselor.**

## Your Notes and Questions

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# Resources

These are some suggested readings. There are many other good resources.

## I. Cookbooks

- \* Meals without Milk, Mead Johnson
- \* Cooking with Isomil, Ross Lab
- The No Milk Cookbook, Barbara Newby Borgwardt

## II. Feeding

- \* Feeding Your Baby Prosobee: A Special Guide to Feeding the Infant Who Is Milk Sensitive, Mead Johnson.
- Special Diets and Kids: How to Keep Your Child on Any Prescribed Diet, J.F. Taylor and R.S. Latta; Dodd, Mead, & Co., 1987.

## III. Child Development and Parenting

- Between Parent and Child, H. Ginott Avon Books, New York, 1969.
- How to Discipline with Love, Fitzhugh Dodson, Signet Books, New American Library, New Jersey, 1977.
- Toddlers and Parents, T. Barry Brazelton, Dell Publishing Company, New York, 1974.
- The First Twelve Months of Life, Frank Caplan, Bantam Books, New York, 1981.
- The Second Twelve Months of Life, Frank and Teresa Caplan, Bantam Books, New York, 1980.
- Parent Magazine (newsstand or subscription)

## IV. Material for School Personnel

- A Teacher's Guide to Galactosemia, M. Nardella, MA, RD. Arizona Department of Health Services, Office of Nutrition Services, 1740 W. Adams, Rm 208, Phoenix, Arizona 85007. Single copy free upon request.

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\* You can get these from the staff at your Area Genetic Center.

## Genetic/Metabolic Centers in California

If you need help finding a genetic/metabolic center near you, ask your doctor, clinic or health care provider.

### Northern California

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

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

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

Valley Children's Hospital  
Medical Genetics Department  
3291 North Hilliard Avenue  
Fresno, CA 93726  
(559) 243-6400

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

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

## Southern California

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

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

Children's Hospital of Los Angeles  
Medical Genetics, Metabolic Section  
4650 Sunset Blvd., MS 90  
Los Angeles, CA 90027  
(213) 669-2226 or 669-2178

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

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

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

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

San Diego-Imperial Counties  
Developmental Services, Inc.  
Metabolic Disorders Clinic  
4355 Ruffin Road, Suite 216  
San Diego, CA 92123-1648  
(858) 576-2975 or 576-2851

# Other Important Names and Phone Numbers


## Things to Remember

1. Your child with galactosemia needs to be on a modified diet all of his or her life.
2. Most children who start the diet early grow up healthy.
3. Some children have problems. If you think your child might be having a problem, tell your doctor or the staff at the Genetic/Metabolic Center.
4. Let babysitters, teachers and other family members know which foods your child can eat. Explain the importance of the diet.
5. Read labels on products. These foods are not safe for your child:
  - milk, milk fat, or nonfat dry milk solids
  - butter, cream, yogurt
  - lactose (milk sugar)
  - whey or whey solids (milk protein)
  - cheese
  - casein (milk protein)

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