

# DIET FOR GALACTOSAEMIA



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### WHAT IS GALACTOSAEMIA?

Galactosaemia is a rare, inherited, metabolic disorder. Galactose is present in lactose, the sugar found in all animal milks. People with galactosaemia lack the enzyme needed to break down galactose.

Usually, when a person eats or drinks a product containing lactose, such as milk, cheese, or butter, the body breaks the lactose down into two sugars, glucose and galactose.

Glucose is used by the body for energy, while galactose is converted into more glucose. In galactosaemia, the enzyme that converts galactose into glucose is missing. This causes too much galactose to build up in the blood.

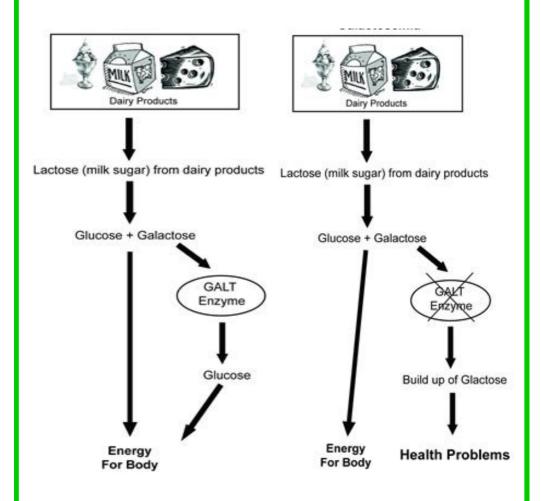
The build-up of galactose can cause serious complications including;

- enlarged liver
- kidney failure
- cataracts
- speech problems
- brain damage

### WHAT IS GALACTOSAEMIA?

### Person without Galactosaemia

### Person with Galactosaemia



# WHAT IS THE TREATMENT FOR GALACTOSAEMIA?

The treatment is a low galactose diet. The main source of galactose is lactose, so lactose has to be excluded from the diet. It is recommend that dietary treatment is for life.

# WHAT TYPES OF FOOD CONTAIN LACTOSE?

Lactose is found in 4 main types of food:

- 1. Cow's milk
- 2. Products made from cow's milk
- 3. Manufactured foods which contain cow's milk
- 4. Any mammalian milk including breast milk, goat's milk or sheep's milk

### THE TRAFFIC LIGHTS



The galactosaemia diet can be split into 3 main groups. A traffic light system is often used to help explain the groups.

RED	STOP!	Avoid these foods
ORANGE	CAUTION!	May contain lactose so check the label
GREEN	GO!	These foods are allowed

It is recommended that you check the food labels before consuming processed products. There is more information on page 18.

These foods are not allowed as they contain lactose or galactose.

### Milk and milk products

- All cow's milk including full fat, semi-skimmed, skimmed, UHT milk and milk shakes
- \* All lactose free milk and milk products e.g. Lactofree
- Any mammalian milk including goat, sheep or breast milk
- Dried milks e.g. Marvel, Coffee mate and other coffee creamers
- Evaporated and condensed milk
- Yoghurt and yoghurt drinks
- Ice-cream
- Fromage frais, crème fraiche, sour cream
- Buttermilk
- Cream double, single, whipping, clotted and artificial

### Cheese

- All cheese, cheese spreads and cottage cheese with the exception of the 6 permitted cheeses in the green food section
- Vegetarian cheese

### **Fats**

- Butter
- Vegetable spreads most contain milk products
- \* These products still contain galactose and must be avoided

These foods are not allowed as they contain lactose or galactose.

<u>Sauces</u> - made with any milks other than the suitable milks listed (See page 13 for a recipe).

- White sauce
- Parsley sauce
- Butter sauce
- Cheese sauce

### **Bread**

 Milk bread e.g. brioche, soda and naan bread, any breads containing milk as an ingredient

### **Desserts**

- Milk puddings
- Instant desserts made with milk
- Mousse
- Custard made with milk
- Ready made custard/instant custard powder
- Pies, crumbles and sponges made with butter or margarine
- Milk jelly
- Ice-cream
- Pancakes / crepes

### **Pastas**

Macaroni cheese or pasta in a creamy sauce

These foods are not allowed as they contain lactose or galactose.

### <u>Eggs</u>

- Scotch egg
- Quiche
- Scrambled egg if made with milk or butter

### **Spreads**

Chocolate spread

### Confectionary

- Milk chocolate / White chocolate
- Toffee
- Fudge
- Caramel

### <u>Beverages</u>

- Milk, milk shakes
- Bournvita, Horlicks, Ovaltine
- Instant cappuccino coffee / instant hot chocolate
- Instant white tea
- Cream liqueurs e.g. Bailey's, Irish Mist

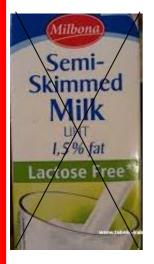
These foods are advertised as lactose free however they are <a href="NOT">NOT</a> suitable for people with galactosaemia as they contain galactose. Remember to check all food labels for the list of ingredients















THESE ARE SOME OF THE CURRENTLY AVAILABLE "LACTOSE FREE" PRODUCTS.

MORE ARE LIKELY TO BE DEVELOPED. CHECK THE LABELS AND ASK YOUR DIETITIAN IF YOU ARE STILL UNSURE IF THE PRODUCT IS SUITABLE

### ORANGE FOODS = CAUTION

These foods are manufactured and therefore may contain lactose or galactose. The ingredients list need to be checked regularly to make sure it is suitable.

### Fat

Margarines or low fat spreads

### Meat, poultry and fish

- Processed and pre-packed meat and fish
- Sausages, burgers, hot dogs, meat balls, meat pies, sausage rolls
- Chicken nuggets, chicken burgers, chicken tenders or any meat in batter or breadcrumbs
- Tinned fish
- Fish fingers and other fish in batter and breadcrumbs

### <u>Vegetables</u>

- Mashed potato check if any ordinary milk or butter added
- Instant mash, potato salad
- Tinned vegetables in sauce
- Baked beans
- Flavoured potato crisps, low fat crisps
- Coleslaw
- Potato waffles, potato shapes
- Vegetables in batter or breadcrumbs

### ORANGE FOODS = CAUTION

These foods are manufactured and therefor may contain lactose or galactose. The ingredients list need to be checked regularly to make sure it is suitable.

### **Desserts**

- Sorbets and ice Iollies
- Instant desserts

### Sauces, soups and spreads

- Dried or ready to use cooking sauces
- Gravy mixes, stock cubes and browning
- Tinned, packet or fresh soups
- Sandwich spreads including salad cream, mayonnaise
- Peanut butter
- Meat and fish paste
- Lemon curd
- Fruit mincemeat used for mince pies

### Confectionary

- Plain chocolate
- Chewy sweets
- Popcorn

### **Beverages**

Drinking chocolate

### ORANGE FOODS = CAUTION

These foods are manufactured and therefore may contain lactose or galactose. The ingredients also needs to be checked regularly to make sure it is suitable.

### Fruit and nuts

- Fruit pie
- Coated nuts, dry roasted nuts

### **Pasta**

Tinned spaghetti in sauce, pasta shapes in sauce

### **Breads**

- Wholemeal, granary, white, soda, naan and crisp breads
- Croissants
- Chapatti
- · Crumpets, pancakes
- Muffins

### Breakfast cereals

Breakfast cereals and cereal bars

### Biscuits and cakes

- Manufactured biscuits and cakes
- Doughnuts

### Eggs

 Scrambled egg or omelette - check if made with ordinary milk and butter

These are allowed as they do not contain lactose or galactose.

### Milk and milk products

- Soya powdered infant formula e.g. Wysoy
- Soya milk e.g. Alpro, Provamel, Tesco, Aldi, Lidl
- Soya yoghurts
- Soya ice-cream
- Soya desserts
- Soya Cream
- Rice milk not suitable under 5 years/during pregnancy
- Oat milk
- Oat cream
- Nut milks e.g. Hazelnut, Almond, Coconut

### Fats and Oils

- Vegan margarine e.g. Pure or Suma
- Kosher margarine
- Lard, dripping
- Vegetable oil including olive oil

### <u>Cheese</u>

- Gruyere
- Emmental
- Italian Parmesan / Grand Padano
- Jarlsberg
- French Comte

These are allowed as they do not contain lactose or galactose.

### Meat, poultry and fish

- Fresh meat, chicken or turkey
- Fresh fish or shell fish.
- Tuna, sardines or pilchards in brine

### **Eggs**

Eggs cooked with milk substitute and milk-free margarine

### Fruit and nuts

- All fresh, frozen and dried fruit
- Tinned fruit in juice or syrup
- Plain, roasted or salted nuts

### Flours, grains and pasta

- Wheat, rye, barley, oats, sago, corn flour, semolina, tapioca
- Rice
- Spaghetti and other plain boiled pasta

<u>Bread, biscuits and cakes</u> — homemade with milk-free ingredients

These are allowed as they do not contain lactose or galactose.

### Vegetables

- All fresh, frozen or dried vegetables
- Pulses e.g. red kidney beans, chick peas or lentils
- Mashed potatoes with milk substitute and milk-free margarine

### **Desserts**

- Jelly
- Custard and other milk puddings made with milk substitute
- Pies, crumbles and sponges made with milk free ingredients

### Sauces, soups and spreads

- Homemade soup without milk or cream
- Homemade sauces made with milk substitutes
- Homemade gravy made with milk-free gravy mix e.g. Marmite and Bovril

### Sugar, preserves and confectionary

- Sugar, glucose, honey, jam, marmalade, syrup and treacle
- Boiled sweets

These are allowed as they do not contain lactose or galactose.

### **Beverages**

- Fruit juice, squash
- Fizzy drinks
- Mineral water
- Tea, coffee and cocoa made without milk or with milk substitute

### **Miscellaneous**

- Baking powder, bicarbonate of soda, cream of tartar, yeast
- Herbs, pure spices
- Mustard
- Vinegar, salt, pepper
- Tomato ketchup
- Colouring and essences

WARNING: Even if a manufactured food is lactose free the first time you buy it, always recheck the label the next time to make sure it still is lactose free. Sometimes the manufacturer's change the ingredients they add to food.

### WHAT ABOUT CHEESE?

In Ireland, we have recently analysed the lactose and galactose content of a number of processed foods including cheese. Prior to this we recommended the avoidance of all cheeses. However we are now pleased to recommend that the following cheeses are suitable for people with galactosaemia;

- Gruyere
- Italian Parmesan. Note: American Parmesan is NOT suitable
- Jarlsberg
- Emmental
- Grana Padano
- French Comte

These cheeses are a very good source of calcium and should be included in the diet to achieve adequate calcium intake (see section on bone health).

There are also a number of alternatives including vegan or vegetarian cheeses available from health-food shops. These include a range by "Violife" (www.violife.gr), Vbites (www.vbitefoods.com) and Tofutti Cheese (www.tofutti.com). These vegan and vegetarian cheeses do not contain calcium. Your dietitian can provide you with a full list of products available.

### **READING FOOD LABELS**

The following are a list of ingredients that contain milk and are therefore **NOT** suitable:

- Skimmed milk powder, milk solids, milk protein, non-fat milk solids, separate milk solids
- Margarine or shortening containing skimmed milk or whey
- Whey, hydrolysed whey protein, whey syrup sweetener, hydrolysed whey sugar, vegetarian whey
- Casein, caseinates, hydrolysed casein, sodium caseinate, calcium caseinate
- Cheese powder
- Buttermilk, butterfat, butter oil, milk fat, animal fat, ghee, artificial cream
- Lactose
- Artificial sweetener called Tagatose and Lactitol

## We have a wallet sized card with this information — ask your dietitian for a copy

Products which state they have been "made in a factory where milk products are made" or "may contain traces of milk" <u>are safe</u> to use.

Some ingredients sound as though they contain lactose but they do not contain lactose– these foods ARE suitable

Lactic Acid E270	Stearoyl lactylates
Sodium lactate E325	Potassium lactate E325
Calcium lactate E327	Lysacin
Monosodium glutamate	Cocoa butter
Glucona delta lactone	

These foods ingredients **ARE** suitable to use in galactosaemia.

### **BONE HEALTH**

### HOW MUCH CALCIUM DO I NEED?

- Calcium is necessary to build strong, healthy bones. Usually, milk and milk products provide the main source of calcium. The amount of calcium needed depends on your age. The table below provides you with the recommended amount of calcium needed.
- Infants will need a soya based formula to provide all of their calcium until weaning starts between 4-6 months of age. Infants will need between 360 - 780mls of soya formula prior to weaning to meet their calcium requirements. \*Once solids are started, their calcium requirements will be met from a combination of both milk free food and soya based infant formula. Your dietitian will help calculate the amount of formula and food required.

<b>Age</b> (years)	Calcium requirement (mg/day)	No of portions
Infants 0 - 6 months 6 - 12 months	240 - 525 525	Soya formula 360 - 780mls *780mls
(1-10 years)	800	8
(11-18 years)	1200	12
Adults	800	8
Pregnancy	1200	12
Lactation	1200	12

FSAI Guidelines, 1999

• For infants, it is vital that a soya formula (or another formula which is recommended by your dietitian) is used and that dairy free products fortified with calcium are used for children and adults. Note that all organic soya milks do not contain added calcium.

### **BONE HEALTH**

Certain foods which are naturally lactose free are high in calcium and should be included in your daily diet. The calcium content of food has been divided into portions in the tables on pages 21 to 24.

100mg of calcium = 1 portion.

Use the tables on pages 21—24 to work out how much calcium you are taking each day and get some tips on how you can achieve your goal.

### For example:

A twelve year old girl needs 1200mg calcium each day. Here's a sample meal plan showing how she can get this amount.

MEAL	AMOUNT	CALCIUM PORTION
BREAKFAST		
Readybrek	1 bowl (35g)	4
Made with calcium enriched soya milk	100ml	1 1/4
Calcium Enriched Orange juice	100ml	1
MORNING SNACK		
Calcium enriched soya yoghurt	1 pot (125g)	1½
LUNCH		
Wholemeal bread	2 slices	3/4
Emmental Cheese and salad	30g	3
AFTERNOON SNACK		
Apple	1	0
Popcorn	1 bag	0
DINNER		
Potato	2 medium	0
Mixed vegetables		0
1 salmon cutlet	210	1/2
TOTAL CALCIUM INTAKE	AKE 12 PORTIONS = 1200mg	

Food type	Calcium Portion	
SOYA & NON DAIRY PRODUCTS		
INFANT FORMULA		
210ml - 7oz SMA Wysoy	1½	
SOYA MILK		
200ml Alpro Soya /Light Soya Milk	2½	
200ml Alpro Soya Junior 1+	2½	
200ml Alpro Wholebean Unsweetened	2½	
200ml Organic / Non calcium enriched	0	
200ml Holland & Barrett Soya Alternative with Calcium	2½	
200ml Tesco Free From Soya Sweetened Milk	3	
200ml Provamel Sweetened	2½	
200ml Milbona Soja Soya Milk (Lidl)	2½	
200ml Soya Delight Sweetened / Unsweetened (Aldi)	2½	
200ml Soya Soleil with Calcium & Vitamins	2½	
SOYA YOGURT		
1 Pot (125g) Calcium Enriched e.g. Alpro / Xotic	1½	
1 Pot Organic Yogurt	0	
Coyo Coconut Yogurt	0	
SOYA, ALMOND & COCONUT DESSERTS		
250ml Alpro Soya Custard (½ carton)	3	
1 pot Alpro Dessert (Caramel, Chocolate, Vanilla)	1½	
Almond Dream Mint-Chocolate Chip Ice-cream	0	
Booja-booja Ice-cream (Coconut, Vanilla & Chocolate)	0	
Nobó Ice-cream	0	

Food type	Calcium Por- tion
SOYA & NON DAIRY PRODUCTS (continued)	
RICE MILK	
200ml Rice Dream Original + Calcium	2½
200ml Provamel Rice Drink with Calcium	2½
200ml Alpro Rice Milk Original / Light	2½
NUT MILK	
200ml Alpro Almond /Fresh Almond Drink	2½
200ml Alpro Hazelnut/Fresh Hazelnut Drink	2½
200ml Blue Diamond Almond Breeze Original	2½
200ml Tesco Free From Almond milk	2½
OAT MILK	
200ml Oatly Oat Drink Calcium Enriched	2½
250ml Oatly Oat Chocolate Drink	2½
200mls Oat Dream Milk Original + Calcium	2½
COCONUT MILK	
Alpro Coconut Milk	2½
Koko Dairy Free Original & Calcium	2½
Marks & Spencer Made Without Dairy Coconut Drink	2½
VEGETABLES	
1 small can baked beans	1
½ can kidney beans (120g)	1
½ can chick peas (100g)	1/2
60g Spinach	1
70g Curly Kale	1
80g Okra	1

Food type	Calcium Portion
BREAD & CEREALS	
2 Medium Slices White Bread	1
2 Medium Slices Wholemeal Bread	3/4
1 Average Bowl Readybrek (35g)	4
1 Average Bowl All Bran (45g)	1½
1 Average Bowl Cheerios (45g)	2
1 Average Bowl Coco-pops (45g)	2
1 Average Bowl Frosties (45g)	2
1 Average Bowl Rice Krispies (45g)	2
MEAT, FISH & EGGS	
1 Average tin Sardines in Brine (120g)	6 ½
1 Average tin Sardines in Oil (120g)	6
1 Average tin Sardines in Tomato Sauce (120g)	5
1 Small Tin Anchovies (50g)	2
½ Tin Pilchards (77g)	3
1 Average Salmon cutlet (210g)	1/2
1 Average Portion Prawns (100g)	1
I Average Portion Scampi* (150g)	3
½ Tin Crab meat (85g)	1
3 Sausages*	1
2 Eggs Boiled	1/2

Food type	Calcium Portion
NUTS & SEEDS	
18 Whole Almonds (36g)	1
20 Hazelnuts (35g)	1/2
13 Walnuts	1/2
6 Whole Brazil Nuts	1/2
Peanuts (135g)	1/2
Mixed Nuts (55g)	1/2
1 Tbsp. Sesame seeds (15g)	1
2 Tbsp. Milled Flaxseed (18g)	1/2
1 Heaped Tsp. Tahini (10g)	1/2
WARNING: NUTS ARE NOT SUITABLE IN CHILDREN UNDER 5	

YEARS DUE TO THE RISK OF CHOKING

FRUIT	
150mls Calcium Enriched Orange Juice	2
7 dried Apricots (54g)	1/2
1 Medium Orange (160g)	3/4
1 Bowl Blackcurrants (stewed) - 140g	3/4
1 Dried Fig	1/2
1 Fresh Fig	1/2
3 Heaped Tbsp. Mixed Dried Fruit	1/2
CHEESE (SUITABLE)	
30g Jarlsberg	2
30g Italian Parmesan/Grana Padano	3
30g Gruyere	3
30g Emmental	3
30g Comte	2

### **DIETARY SUPPLEMENTS**

### IS AN EXTRA CALCIUM SUPPLEMENT NECESSARY?

- If you or your child are not taking enough calcium enriched foods, your dietitian may recommend that your doctor prescribes a calcium supplement.
- If you have been prescribed two calcium tablets per day, it is better to take one in the morning and one in the evening
- If you have been prescribed one calcium tablet per day, it is better to take it in the evening as this may prevent bone loss that occurs at night.
- Do not take the calcium supplement at the same time as a multivitamin tablet or any other tablet which contains iron. Calcium and iron can interfere with each other and lower their absorption.
- Smoking, alcohol and caffeine can also decrease the absorption of calcium.
- Some calcium supplements contain lactose, your dietitian will recommend suitable ones for you.

### **DIETARY SUPPLEMENTS**

### ARE THERE ANY OTHER MEDICATIONS NECESSARY?

- Vitamin D is also necessary for good bone health. It helps the body to absorb calcium and prevent your bones from becoming brittle. Vitamin D is often added into calcium supplements for this reason.
- There are a few foods that contain vitamin D e.g. oily fish, egg yolks, spreads and fortified foods e.g. certain milk alternatives.
- Vitamin D is also produced in the body when our skin is exposed to sunlight.
- In Ireland, we are not close enough to the equator to make enough vitamin D during the winter months. The sun rays are not strong enough. It has been suggested that a vitamin D supplement would be advisable for the general population. This can be discussed with your doctor and dietitian.

### DO MEDICINES AND SUPPLEMENTS CONTAIN LACTOSE?

- They may contain lactose as a filling or bulking agent (excipient) and so your doctor, chemist or dietitian can check this for you. Capsules and syrups are not usually a problem but still need to be checked for added lactose.
- Please note information about lactose content does not appear on drug labels unless large quantities are present.

### **RECIPES**

Always ensure that all ingredients are free from milk and milk products. Use your booklet and always check the ingredients list. If in doubt, leave it out.

### **Basic White Sauce**

- 1 heaped tablespoon (30g) milk-free margarine
- 1 heaped tablespoon (30g) plain flour
- 1 large mug (300ml) soya milk or other suitable milk substitute Seasoning to taste
- Place milk-free ingredients in pan
- Heat, whisking continuously until sauce thickens and it is cooked
- Season to taste

### **Pancakes**

4ozs (120g) plain flour

1 egg, lightly beaten

½ pint or 300mls soya milk or other suitable milk substitute Vegetable oil for frying

- Sift flour into a bowl.
- Add the egg then gradually add half the milk, beating well to make a smooth batter. Beat in the remaining milk.
- Heat a little vegetable oil in the frying pan.
- Pour in a little batter and tilt the pan so that the pan covers the base.
- Cook until the underside is golden, then turn and cook the other side.
- Repeat until all the batter has been used.

### **RECIPES**

### **Coconut Macaroons**

2 Egg whites

2 teaspoons corn flour

110g caster sugar

125g desiccated coconut

Grease proof paper

- Turn on the oven to Gas mark 4 / 180°C / 350°F.
- Line one or two baking trays with the grease proof paper.
- Place the egg whites in a bowl and whisk until frothy but not stiff.
- Stir in the corn flour and sugar, followed by the coconut.
- Drop in heaps onto the lined trays. Bake for about 20 minutes until firm and golden brown. Leave to cool.
- When cold, store in an airtight tin.

### Milk-free Mousse (2 servings)

½ packet of jelly cubes

½ pint milk substitute

50ml boiling water

- Dissolve jelly in a jug with boiling water
- Make up to ½ pint with milk substitute
- Place in a bowl in fridge for 15-20 minutes
- Whisk with an electric hand whisk until frothy.
- Divide into 2 empty yoghurt pots or ramekin dishes and leave to set in the fridge

### **RECIPES**

### Soya Custard (4 servings)

1 pint (600ml) soya milk

2 rounded tablespoons custard powder

1 tablespoon sugar

- Blend custard powder with 2-3 tbsp. of soya milk to make a smooth paste
- Gently heat the remaining soya milk and sugar until it begins to simmer
- Pour the blended custard mix into the simmering soya milk
- Return to heat and stir constantly until the custard thickens

### **Cheesecake** (4 servings)

500g soya yoghurt/dessert strawberry or banana flavour

6 milk-free digestive style biscuits

25g milk-free margarine

1 sachet quick-gel vegetarian jelly powder

8 strawberries, halved

1 banana, thinly sliced

- Melt the margarine, mix the crushed biscuits and then press into base of 4 x 6cm diameter ramekins
- Spoon the soya yoghurt/dessert evenly over
- Arrange fruit over the mixture
- Mix the gel according to instructions, and spread thinly over the fruit
- Refrigerate for about 30mins

For more recipes ask your dietitian or check out www.alprosoy.co.uk

www.godairyfree.org

www.dairyfreecooking.about.com

# **NOTES**



# The National Centre for Inherited Metabolic Disorders The Children's University Hospital Temple St 01 878 4317

Email: metabolic.dietitians@cuh.ie

**Updated October 2015** 

