

# **Tourist Guide for Galactosaemians**

## **Germany**

**March 2008**

## What is this guide about?

Traveling foreign countries has become a commodity and not an event which you can only afford ones in your life. The world is moving closer and closer. People from all nationalities have the opportunity to explore the world, whether for holidays, a brief trip, or on business. Looking at people with Galactosaemia this is no different. What we realize is that Galactosaemians as well as their parents become more and more self-sufficient in handling the diet and start visiting foreign countries. This guide is meant to help and support anyone who wants to travel Germany. You get useful tips on the diet, shopping places, restaurants, contact information and more; a brief intro to the most important things. In addition we'd suggest using the German Diet Passport that was created by the European Galactosaemia Society (EGS). It is written in German and is a great help, especially if you need to visit a doctor or for the kitchen team of your hotel. You can download it from the internet at <http://www.galactosaemia.com/diet-passport/german-print.html>.

**Disclaimer:** We the authors of this document don't take responsibility for any information in here. What you find in here is close to what the German Galactosaemia society suggests to its members but as you know some people take the diet more or less strict than others and information changes very quickly.

## Useful diet tips

### Product declarations and other names for milk

In Germany food has to be labeled according to rule 2003/89/EC of the European Union. That means that **lactose has to be indicated on the label of the products except on products without package.**

In most cases the goods are sold in multiple countries, therefore labels often contain a list of ingredients written in multiple languages. There are some hidden names and synonyms used instead of milk or lactose making it difficult for non-native speakers to understand the list of Ingredients. The German name for Ingredients is **Zutaten**. As such you'd always try to find the word "Zutaten" first and check the list of ingredients underneath it.

The most important German names referring to lactose are:

- Laktose, Galaktose
- Milch. Milch can be labeled in various ways, such as Milchpulver, Magermilch, Buttermilch. We'd suggest not buying any goods with composed words containing Milch in it.
- Molke, Molkenpulver, Butter, Joghurt, Käse, Rahm, Sahne, Quark, Topfen, Kefir, Creme fraiche, Schmand, Kaffeeweißer
- Laktolit, E966
- Kaseine or Kaseinate can contain traces of lactose

As a rule of thumb you'd

1. Check if there's an ingredients list written in your native language and use it.
2. Try to find the German word **Zutaten** on the label.
3. Check if there's any of the words, synonyms from the list above
4. If not then it should be safe to eat it.

**Attention:** Often you'll find products that are labeled as **laktosefrei** (=lactose free). Almost always that means that the lactose is split into glucose and galactose. Those products are not allowed for Galactosaemians. Examples are product brands from **Minus-L**.

### **Supermarkets and other shopping places**

In Germany there's no special lactose free brand; therefore you'll always have to follow the rules about food labeling of packaged food as mentioned above.

Soya products are available in almost every supermarket. You might want to check for one of the following brands:

- **Alpro** soya products
- **Natumi** soya products
- **GranoVita** soya products

Often non-packaged meat or bread is sold in supermarkets as well. Some shops such as **TeGut** have lists of ingredients for them which you can use instead.

If you need baby milk you'd want to watch out for **Milupa SOM** or **Humana SL**.

### **Restaurants, butchers, bakeries**

In Germany you'll hardly find shops that label non-packaged food as lactose free. When you want to get lactose-free food in a restaurant, at a butcher or a bakery you always have to speak with the people working there. It depends on their knowledge and understanding of a diet and sometimes also on language skills if you can be sure to get lactose-free meals or not. The German diet passport mentioned above might help as well. Certain restaurants do have ingredient lists that you can use. These are **Mc Donalds**: McDonalds has a list of allergens at the backside of the paper on the tray. You have to check the last column of the table on there. Number 7 means that there's lactose in it. You can check it yourself or might ask the personal for help. In addition you can check for allergen data on the German Web page at <http://www.mcdonalds.de/html.php?&nt=N%E4hrwert>.

**Burger King**: McDonalds has a list of allergens at the backside of the paper on the tray. You can check it yourself or might ask the personal for help. In addition you can download allergen data from the German Web page at [http://www.burgerking.de/content/pdf/bk\\_allergieinformation.pdf](http://www.burgerking.de/content/pdf/bk_allergieinformation.pdf). The document is in English and you have to check for the word "Dairy".

**Kentucky Fried Chicken (KFC)**: KFC has a list of allergens at a brochure which you can get at the restaurants. You can check it yourself or might ask the personal for help. In addition you can download allergen data from the German Web page at [www.kfc.de/userfiles/file/nutrition.pdf](http://www.kfc.de/userfiles/file/nutrition.pdf). The document is in German and you have to check for the column "Milch".

### **Doctors and hospitals**

Galactosaemia is one the rare diseases; therefore most doctors, hospitals and pharmacists have little knowledge about it. Especially if they give you medicine you should always ask them to **double check for lactose** first! In case of problems you might want to contact the Competence Center Galactosaemia at the hospital in Düsseldorf (see contacts below).

## Contacts

For **general information** on how Galactosaemia is handled in Germany we'd suggest to call the International contact. In most cases we're able to handle your questions. In case that you need immediate **help at the location** you're visiting we might be able to get you in touch with a family that is living in that region.

**International contact** (German Galactosaemia society):

Anton Fuchs

Phone: +49 (0)6151 957515

For **detailed dietary information** and questions you can as well contact our dietary advisor for Galactosaemia.

**Dietary Advisor contact** (University hospital Hannover):

Uta Meyer

Phone: +49 (0)511 5329230

For **clinical information** and first contact for doctors we'd advice to call the Competence Center Galactosaemia.

**Competence Center Galactosaemia** (University hospital Düsseldorf):

Prof. Dr. P. Schadewaldt

Phone: +49 (0)211 81 16970 or 16969

## Further information

Further information on Galactosaemia can be found on the internet:

- The web pages of the German Galactosaemia Society (written in German language) at [www.galaktosaemie.de](http://www.galaktosaemie.de).
- The web pages of the European Galactosaemia Society at [www.galactosaemia.eu](http://www.galactosaemia.eu).