

Tourist Guide for Galactosaemia

Germany

March 2008

What is this guide about?

Traveling to foreign countries has become easier and is no longer an event which you can only afford once in your life. Areas are becoming more accessible and people from all nationalities have the opportunity to explore the world, whether for holidays, a brief trip or on business. This is no different for people with Galactosaemia and we realise galactosaemics, as well as their parents, are becoming more and more confident in handling the diet and visiting foreign countries. This guide is meant to help and support anyone who wants to travel to Germany. It includes useful tips on the diet, places to shop, restaurants, contact information and more; a brief introduction to the most important things. In addition we would suggest using the German Diet Passport that was produced 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 staff at 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, do not take responsibility for any information contained in it. The information included is what the German Galactosaemia Society advises to its members but we are aware some people follow a more or less strict diet 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. This means that **lactose has to be declared on the label of all products except those without packaging.**

In most cases the goods are sold in a number of countries, therefore labels often contain a list of ingredients written in different languages. Milk and lactose can be referred to as different names making it difficult for non-German speakers to understand the list of ingredients. The German name for ingredients is **Zutaten**. As such you would 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 would suggest not buying goods with any words containing Milch in the ingredients
- 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 would

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

Attention: Often you will find products that are labeled as **laktosefrei** (lactose free). This usually means that the lactose has been split into glucose and galactose. These products are not suitable for galactosaemics. Examples are product brands from **Minus-L**.

Supermarkets and other shopping places

In Germany there is no special lactose free brand; therefore you will always have to follow the rules regarding food labeling of packaged food as mentioned above.

Soya products are available in almost every supermarket. You might want to look 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 these which you can use.

If you need baby milk you should look for **Milupa SOM** or **Humana SL**.

Restaurants, butchers, bakeries

In Germany you will find very few 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 will have to ask the people working there. It will depend on their knowledge and understanding of a “special” diet and on their language skills as to whether you can guarantee a lactose-free meal or not. The German diet passport mentioned above might help as well.

Certain restaurants do have ingredient lists that you can use. These are:

MacDonalds: MacDonalds has a list of allergens on the back of the paper on the tray. You have to check the last column of the table on there. Number 7 means that there is lactose in it. You can check it yourself or you can ask the staff for help. You can also check for allergen data on the German web page at <http://www.mcdonalds.de/html.php?&nt=N%E4hrwert>.

Burger King: They also have a list of allergens on the back of the paper on the tray. You can check it yourself or ask the staff for help. In addition you can download allergen data from the German web page at 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 in a brochure which you can get at the restaurants. You can check it yourself or ask the staff for help. You can also download allergen data from the German web page at 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 a rare disease therefore most doctors, hospitals and pharmacists have little knowledge about it. You should always ask them to **double check for lactose** in any medication they prescribe. If there is a problem you may want to contact the Competence Center for Galactosaemia at the hospital in Düsseldorf (see contacts below).

Contacts

For **general information** on how Galactosaemia is handled in Germany we would suggest you get in touch with the International contact who will do their best to answer your questions. In the event that you need immediate **help at the location** where you are staying we will try to put you in touch with a family that lives in that region.

International contact (German Galactosaemia society):

Anton Fuchs

Phone: +49 (0)6151 957515

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

Dietary Advisor contact (University Hospital Hannover):

Uta Meyer

Phone: +49 (0)511 5329230

For **clinical information** and as the first contact for doctors we would advise calling the Competence Center for Galactosaemia.

Competence Center for 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 website of the German Galactosaemia Society (written in German) at www.galaktosaemie.de.
- The website of the European Galactosaemia Society at www.galactosaemia.eu.