Chapter 11: Traveling

A PKU Perspective
"There is no reason to let having PKU ever hold you back from going where you want to go and doing what you want to do. Traveling, be it by air or any other mode of transportation, opens new horizons and literally lets you look at things from a different perspective that should not be missed simply because you have PKU."

Traveling

Whether or not you have PKU, preparation and planning are important when you travel away from home. No matter if you are traveling near or far, you will find it easier to manage your diet and treatment if you do some research on the kinds of foods and resources you will have access to while traveling and once you reach your destination.

Air Travel

Going on a plane for a trip can make some people excited and others a little nervous or both. Having PKU should not stop you from traveling by plane. But it does mean you need to plan ahead and keep a few extra things in mind.

Flight delays are beyond your control. For this reason it is important to always pack your formula in your carry-on bag. Do not mix with liquid until past the security screening checkpoint. If you are traveling for an extended period of time, be sure to bring at least a week’s worth of formula in your carry-on, just in case your luggage gets lost or stolen.

Always bring a travel letter from your clinic explaining medical necessity when you travel, especially when you are traveling internationally. This letter should list the name of the PKU-related products you are carrying with you in your luggage, state why these products are needed, and who will be using them. If you have to carry liquid formula, such as for an infant, this letter should specifically mention this. It will help you handle any questions that may arise at security. A sample letter of medical necessity can be found in the resource chapter.

For ease of getting through security, it is also helpful to keep your medical formula in its original sealed containers (packages, cans or sachets) and take a copy of your prescription with you. If you are traveling domestically, you can also ship your medical foods to your destination in advance to reduce the weight of your luggage. Be sure to allow enough time for transit should there be any delays in shipping.

Have you packed these items?
- Medical formula
- A mixing container
- Scoops and measuring cups, if used
- Low protein foods
- A scale, if needed
- Food for your trip
- Your prescription
- Insurance card
- A medical foods necessity letter from your doctor

Traveling

Most domestic flights charge a fee for in-flight meals, and the foods are generally not PKU friendly. Be sure to pack (or purchase prior to boarding) any food or snacks you think you might need during the flight. Most international flights still offer meal service, so be sure to specify your need for a special meal when booking your international ticket. You may find that the only PKU-friendly meal option is a vegetable plate, salad or fruit plate (as even meals listed as low protein or vegetarian/vegan may not be low enough in protein for the PKU diet). Take plenty of snacks for the flight to cover the possibility of travel delays.

Call Hotels in Advance

To make your stay easier, call your hotel in advance to speak with management about your needs. Many hotels have rooms with a kitchenette where you can keep and prepare foods. Some hotels offer small refrigerators in each room where food or medical formula can be stored, but it is best to check prior to travel. If the hotel where you will be staying does not have kitchen facilities or a refrigerator, ask about having a mini-refrigerator brought to your room for use during your stay if you need one.

PKU Traveler’s Tips

When traveling, you may also find these tips to be helpful.

- If you are traveling overseas, ask your PKU team for information on where low protein supplies can be obtained in your destination country.
- If you are traveling on an organized tour overseas, ask your dietitian for a letter explaining your diet.
- Many hotel chains offer a free continental breakfast. In addition to coffee, fruit and cereal, many have a ‘make your own’ Belgian waffle option. If you bring low protein powdered pancake mix with you, you can easily make your own low protein waffle at the hotel. Just call ahead and ask.
- Disney World is also PKU-friendly as long as you call ahead to let them know you’re coming and what your dietary needs are.
- If you are shipping your formula or food to a hotel to arrive prior to your arrival, be sure to label the box clearly with your name and arrival date on the package. Call and alert the hotel that a shipment will be arriving for you.