

# Traveling to Brazil: PKU Toddler

---

*By PKU Toddler, Older Sister, and Parents -- California*

We took a three-week vacation to the North East of Brazil at the end of 2010. We expected this to be a challenging trip due to the unique needs of our PKU Toddler.

We read the travel stories on PKU News, which were helpful guidance. However, only one story featured a toddler. In that story, the family had the luxury of being near an AFB. We did not have this luxury. We hope sharing our experience will help you prepare for your own adventure!

## The Usual Diet

The staples of our PKU Toddler's diet are powdered Periflex Junior, powdered rice and oatmeal baby cereals, packaged pureed fruit/vegetable baby food, specialty rice and pasta, and Turtle Mountain So Delicious Cultured Coconut Milk "yogurt". I call this last one out specifically because it is low PHE and he loves it. He eats two cups of it a day. And it is perishable.

At this point, we were also introducing solid fruits and vegetables but they did not account for much of his diet. It is worth noting that we find the Cambrooke DietWell application for iPod/iPhone an indispensable tool for tracking our PKU Toddler's diet.

## The Preparation

Our goal was to avoid changing the diet of our PKU Toddler during the trip because we did not want to risk substantial swing in his PHE without ability to do a PHE test. So, we planned to sustain his Usual Diet for three weeks. We identified three areas of concern:

- Potential for trip-ruining loss of Periflex Junior due to lost bags
- Transporting four dozen servings of perishable "yogurt"
- The sheer bulk of items

We agreed that if our bags were lost, we would turn around and return home immediately. This meant we needed enough food in carry-on to make it to Brazil and back, if necessary. Although Brazil doesn't seem that far away, the indirect route from where we live was longer than taking a trip to China, nearly a trip to India. We needed four days of food in our carry-on.

We researched getting four dozen cups of "yogurt" to Brazil. We first contacted Turtle Mountain; unfortunately they did not have distribution in Brazil. We then looked at shipping; we were advised by several carriers that overnight shipping to Brazil will only get packages to Brazilian Customs overnight. It routinely takes weeks before the packages are released – not an option for perishables.

We concluded we'd pack our "yogurt" in our checked bags. We reused three 14x14x14 foam coolers with outer cardboard boxes from Cambrooke Foods, and about fifty small "freezer packs" we purchased from Uline. We found everything fit the coolers, with enough room to take a loaf of low-protein bread and low-protein fruit gel cups.

Fitting everything into luggage was another story. We could (barely) fit one cooler per carefully selected bag, and the cans of formula took up a lot of space. We consulted with friends and family in Brazil, who told us we could buy baby cereal and pureed baby food there. They also told us size seven disposable diapers for our hefty PKU Toddler were not available, so we'd need to bring our own.

Based on this information, we decided to buy the baby cereal and pureed baby food in Brazil but bring diapers. We packed four days' worth of everything, a digital scale, and bottles into our carry-on and three weeks' worth of everything except baby cereal and pureed baby food into our checked bags. In total and including our clothes, we had six carry-on and eight checked bags for three ticketed passengers and a "lap baby".

Our clinic provided us with a letter to use while traveling in case we were questioned about the supplies we carried. We also packed our copy of the Low Protein Food List for PKU, in the event our iPod were lost, broken, or stolen.

## **The Flight to Brazil**

We planned carefully and hoped for a good flight. We quickly got a nasty surprise when the airline check-in agent told us there was a seasonal "baggage embargo" to certain Latin and South American destinations and we had a hard limit at six checked bags, with no possibility of paying for extras.

The agent was not interested in accommodating our PKU Toddler's hidden disability, even when we offered the letter from our clinic. We volunteered to buy a full ticket for the "lap baby" to take the two extra bags, but the agent said no seats were available. We are very dissatisfied with this airline and will not fly them again. They were totally unwilling to help; this was inexcusable considering we had documentation of our need and had even volunteered to buy another ticket. The "baggage embargo" is an arbitrary policy of the airline and we are aware that business class passengers can take extra bags.

With everything planned, packed, and scheduled, we were looking at either cancelling our trip or leaving two bags behind. So we left two bags, uncertain of what was in them, other than knowing they did not contain supplies for our PKU Toddler. We never anticipated this turn of events. We had worried about security checkpoints and customs, but neither turned out to be an issue. We always declared our items and volunteered the letter from our clinic.

We arrived at our destination with all the supplies we brought for our PKU Toddler, the perishables still very cold. The "freezer packs" and the yogurt cups survived the pressure changes from four takeoffs and landings along the way. We were, however, missing many of our clothes – left behind!

## Welcome to Brazil

Shortly after we arrived, we set aside everything we would need for the return trip, and then went out to buy baby cereal and pureed baby food.

When it came to baby cereal, we needed plain rice and oatmeal cereals. There were similar cereals, but most were blends of two grains, and virtually all had added sugar. We didn't care for the added sugar, but the blending threw us for a loop because we had no way to determine the PHE content. We finally identified one product that was suitable:



We had worse luck with pureed baby food. Sure enough, it was available, but we found nothing we felt appropriate for our PKU Toddler. What we needed were fruit and vegetable varieties. What we found were “something and meat”, “something and beans”, and “something with milk”. As a local said, “The challenge here is to get protein into the people.” No beef, bean, and egg soup for you, PKU Toddler!



### Sopinha de Carne, Legumes e Gema de Ovos

Sopinha de carne, legumes, arroz e gema de ovos para lactentes e crianças de primeira infância.

We should have been much more specific when asking our friends and family to research the locally available products. After some stress, we resigned to make baby food every day by cooking and blending vegetables. Fortunately, where we stayed we had access to a kitchen. This worked out fine for our PKU Toddler but was an unexpected chore. Fortunately, after this rough start, we settled into a daily routine and enjoyed our vacation.

## The Return and Lessons Learned

As far as care and feeding of our PKU Toddler is concerned, the return trip was uneventful. We returned home and resumed our normal routine. We followed up with a PHE test and found it to be reasonably close to our target.

In addition to the excellent preparation advice in the travel stories on PKU News, we learned a few lessons which we won't forget anytime soon:

1. If you plan to take more than two checked bags per ticketed passenger, call the airline first to make sure it is allowed for your destination and the dates you are traveling.
2. Contact the airline in advance, and speak with their customer service agents to find the team that assists with travel for customers with disabilities. Although our family does not consider PKU a disability, you might be able to get special assistance or pointers from the airline. As far as traveling with supplies, PKU has things in common with other "hidden disabilities" such as diabetes.
3. If you have anyone doing local research on availability of products you need, make sure to be very specific. Don't ask, "Is pureed baby food available?" Instead, ask, "Is pureed squash available, without any added dairy, beans, eggs, or meat? Can you take a picture of the product label for me?"
4. Make backup plans. We thought we were prepared, and knew what we'd do if our bags were lost. However, we didn't consider what we'd do if our assumptions were wrong about buying products locally. The backup plan might be as simple as, "We are prepared for unexpected expenses..." If we hadn't had access to a kitchen, we would have needed to buy a portable stove, a pot, and a blender (we certainly didn't think to bring those in checked bags!)
5. If you plan to internationally ship items to your destination in advance, it takes longer than the carrier's shipping times indicate. For example, FedEx priority international might take only two days to get your package to customs in a foreign country. It might then take 3 weeks to clear customs. You need to ship well in advance depending on the destination. In an emergency situation, don't count on someone "at home" who can ship you items. The items could take so long to clear customs that they arrive long after you've returned home!