



ESSENTIAL GUIDE TO TRAVELLING WITH

PKU



PACKING LIST ESSENTIALS

- **Protein substitute**, mixing equipment
- **Low protein food**, milks, low exchange snacks (take extra just in case!)
- **Accessories:** Sandwich bags, measuring jugs, scales, bowl, cool bag, ice packs
- **Protein calculator**, diet information, NSPKU food list
- **Blood testing equipment** (lancets, blood forms, envelopes with lab address) if going away for longer than 2 weeks
- Any other **medicines**
- Printed useful **translations** if travelling abroad
- **Letter from hospital and all travel documentation** needed if travelling abroad
- **Contact numbers** (hospital/Dietitian)
- **Mobile phone** & charger
- **Travelling with a baby?** Sufficient infant formula substitute, baby foods, jars, bottles, sterilising equipment

ADVICE FOR FLYING

- Check with the airline about how many and **what size bags you can take** on the plane with you
- If possible, **pack liquids in your hold baggage**. If you do take liquids in your hand luggage then:
 - Keep containers under 100ml
 - Place in clear plastic bag
 You may be able to take them over 100ml if you have approval from the airline and all supporting documentation
- **Divide your supplement into different bags** just in case you lose one



INSURANCE - EU

Within the EU you are **entitled to reduced or free emergency medical treatment** if you have an EHIC card. Call 0300 3301350 for more information.



INSURANCE - INTERNATIONAL

Outside of the EU, you can **purchase international travel insurance** with a number of providers.



TRAVELLING OUTSIDE OF THE UK

- **Letter** – Ask your Dietitian for a letter on headed paper listing all of the products you are taking and why you need them
- **Discuss blood level taking** with your Dietitian whilst you are away
- **Home delivery** – discuss with your home delivery provider if they ship abroad and your options
- If you are taking the product yourself, your **GP may need to prescribe extra products** in advance and contact the airline about extra baggage allowances
- If **staying in a hotel** pre-notify them of your food restrictions and see what options are available to you
- **If you have an infant, ensure there are suitable facilities** for making up feeds, e.g. a kettle or a container for sterilising bottles. Remember to take with you an up-to-date baby food list. All baby jars are allowed freely if they have less than 0.5 grams of protein in 100 grams.
- **Do not use tap water, always boiled water**

TRAVELLING WITHIN THE UK

- Contact your Dietitian to arrange **advance delivery of formula to UK location**
- If you are taking the product yourself, your GP may need to **prescribe extra products in advance**
- If staying in a **hotel pre-notify them of your food restrictions** and see what options are available to you
- **If you have an infant, ensure there are suitable facilities** for making up feeds, e.g. a kettle in the room. Remember to take with you an up-to-date baby food list. All baby jars are allowed freely if they have less than 0.5g of protein in 100g
- Speak to your Dietitian about **posting your blood sample** as normal



SCHOOL TRIPS

Contact your dietitian and inform them of the date, accommodation, catering arrangements and a named member of staff from school.

