

## FIRST STEPS

# Information For Caregivers

This leaflet should be given to anyone who is looking after your child. It provides basic information about PKU and is designed to supplement the information provided by you and your dietitian about your child's diet.

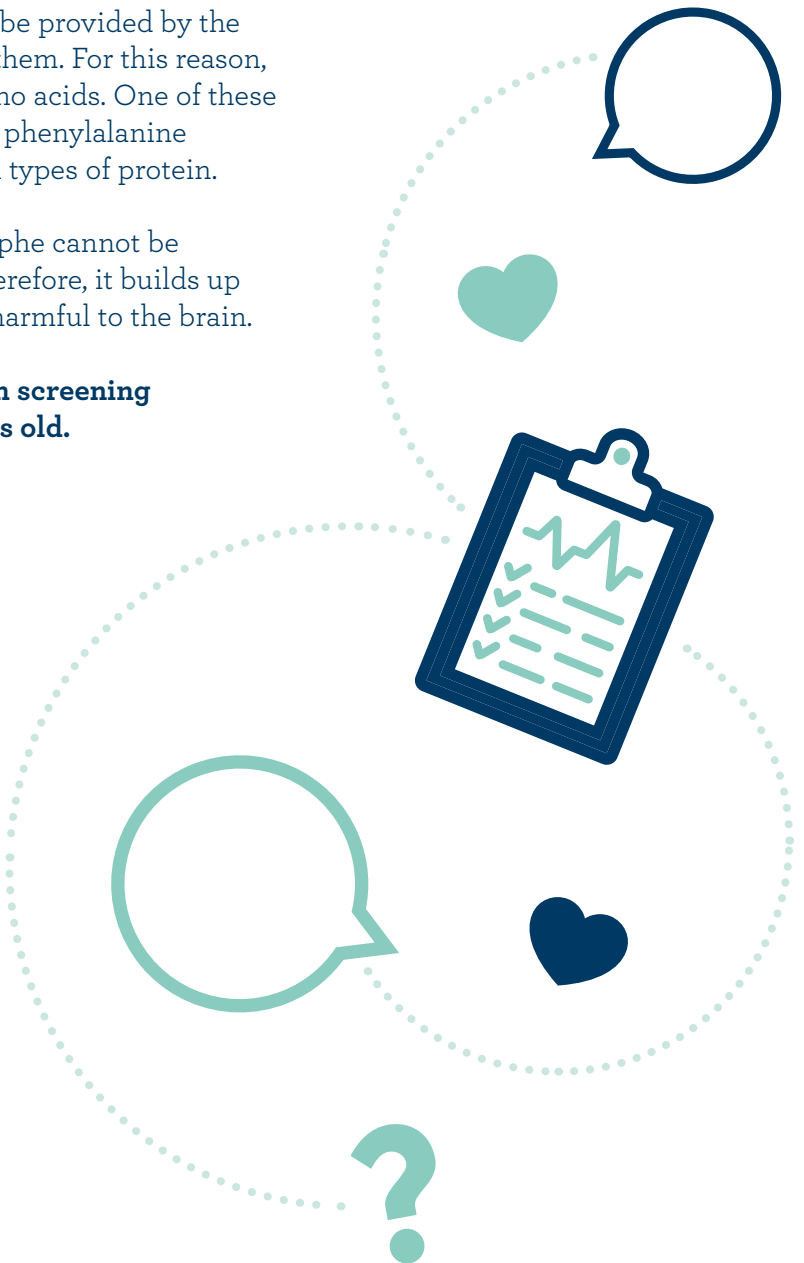
## What is PKU?

**PKU stands for Phenylketonuria. PKU is an inherited condition – a disorder of protein metabolism.**

Protein is made up of small units or building blocks called amino acids. There are about 20 different amino acids, and some of these must be provided by the diet as the body cannot make them. For this reason, they are called “essential” amino acids. One of these essential amino acids is called phenylalanine (phe) and is found in nearly all types of protein.

If an individual has PKU then phe cannot be used properly by the body. Therefore, it builds up in the blood to levels that are harmful to the brain.

**PKU is identified via newborn screening when a baby is about five days old.**



## Further questions

### How can we make sure we recognise a child's dietary needs without making them feel singled out?

You may find it easier to manage a child's specific dietary needs by using a different colour plate, bowl or cutlery so it's clear to others a child has a specific dietary requirement. This may help to prevent mix-ups.

It is likely there will be other children with specific dietary needs too, perhaps a milk or nut allergy for example and you may be familiar with accommodating situations like these already.

### What happens if there are celebrations involving food?

Whilst children with PKU often cannot eat the standard cakes or biscuits the other children will be, there are many low protein alternatives available. Ask parents to provide you with a supply of these for such events. Most importantly, make sure the child is involved in any celebrations.

## Where can I find additional information about PKU?

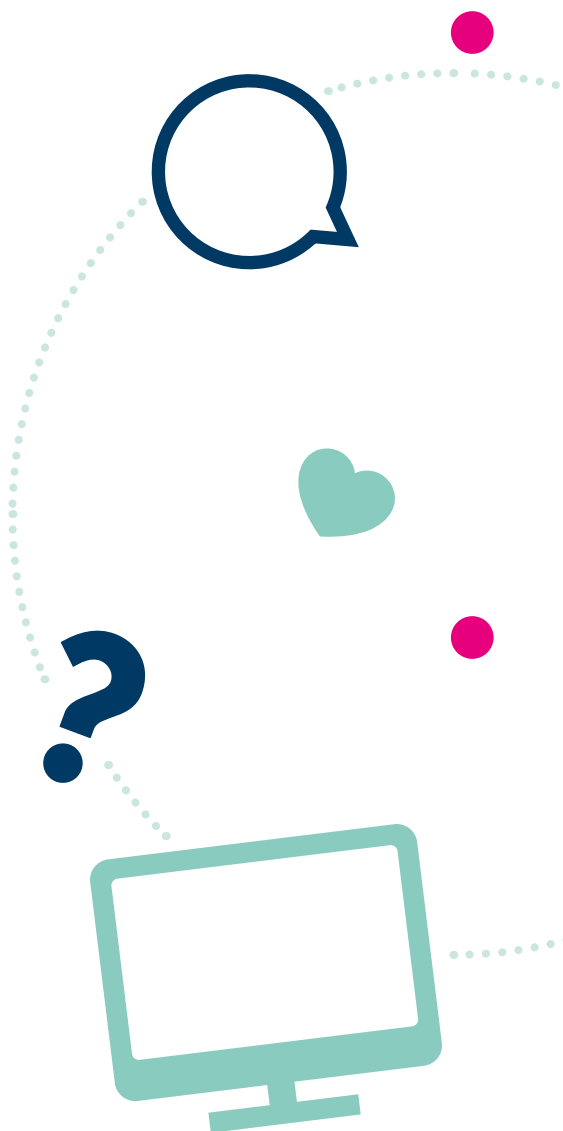
### Reliable sources of information include:

**The National Society for Phenylketonuria (NSPKU)**  
[www.nspku.org](http://www.nspku.org)

**Children Living with Inherited Metabolic Diseases (CLIMB)**  
[www.climb.org.uk](http://www.climb.org.uk)

**PKU UK & Ireland Facebook page**

If you require additional copies of this information, please email [vitafriends@vitaflo.co.uk](mailto:vitafriends@vitaflo.co.uk) and quote the code **KES0023A**



## How is PKU managed?

**PKU is managed by a low protein diet, supplemented with protein substitutes to meet their nutritional needs. A child with PKU will be seen by a dietitian on a regular basis to help manage their condition.**

### **What is a low protein diet?**

Individuals with PKU must avoid high protein foods. These include:

- Meat
- Fish
- Quorn
- Eggs
- Cheese
- Nuts & Seeds

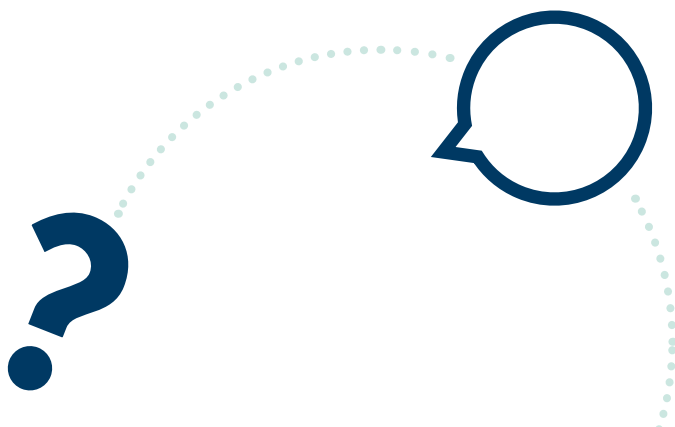
Foods like bread, pasta and cakes also need to be avoided as these contain small but significant amounts of protein. Specially made low protein versions of these foods are often prescribed and parents will provide you with a supply of these.

Exchange foods (measured amounts of protein) need to be provided and may come from foods such as potatoes, breakfast cereal or rice and certain vegetables such as sweetcorn, peas and spinach. Parents, with the help of their dietitians, will make sure you are completely familiar with what is permitted in the diet.

### **What happens if a child with PKU accidentally eats a food containing high of amounts protein?**

Accidents can and will happen and there will be no immediate reaction if a child eats a food not permitted in their diet. This is different to the instant reaction that a child with a nut allergy may have. There is no need to seek medical attention.

However, it is very important to make sure that mistakes do not happen often and it is always important to let a child's parents know if they have eaten something in error, as they will need to let their dietitian know.



# What is a protein substitute?

Individuals with PKU still need protein to support their growth and development.

A protein substitute provides “safe” protein, without the phe. It is often taken 3 times per day and should be treated as though it is medicine.

## Can I mix the protein substitute with food or drinks?

No. Protein substitutes **must not be mixed into foods or drinks**. This is because if the child does not finish their meal or drink it is impossible to know how much of the protein substitute they did not manage.

## What happens if a child with PKU won't take their protein substitute?

The protein substitute needs to be treated like a medicine and taken in the full amount each day. There may be times a child does not want to take their protein substitute or feel unwell, but missing a day is not an option as this may become a habit and break their routine. Make sure you inform the parents immediately if their child is refusing to take their protein substitute.

# Hints and tips

Some hints and tips for encouragement include:

- Lots of praise – smiling and encouragement gives a positive message about the protein substitute
- Try to make sure the same person gives the second stage protein substitute in the same way each day

