

10⁺¹ Steps to **Success** with PKU

- 1. Adopt a positive attitude.** Do not let PKU stop you doing what you want to do as a family because with a bit of planning there is no limit. PKU is about a diet, everything else is normal. *Be open about it with friends but don't go overboard with detail unless they want it.*
- 2. Be consistent.** All family, extended family, friends and carers need to be consistent in their approach. It benefits no one if confusing messages are given.
- 3. Encourage and help children to do things for themselves to develop their confidence and independence.** Teaching and patience in the early years will be rewarded later on. Shop, cook and count exchanges together.
- 4. Eat together as a family as often as you can.** Eating is a social and enjoyable activity and for anyone on a special diet it is really helpful it remains so to support and encourage them. Never exclude children on a special diet and always ensure they have something tasty to eat. It helps to make the PKU meal similar to the family's e.g. low protein pasta and tomato based sauce and ordinary pasta with this sauce and added meat, fish or grated cheese for the normal diet.
- 5. Ensure enough calories for age, height and weight.** Too few calories may increase blood phenylalanine and if hungry there is a temptation to eat inappropriate foods - and it's also important to eat healthily.
- 6. Eat a varied diet and be open to trying new foods.** Try not to make the PKU diet more difficult than it needs to be. There is a wonderful range of fruit, vegetables and supermarket foods as well as ACBS foods on prescription to try – go for it.
- 7. Avoid developing a taste for normal foods for which there is a low protein equivalent such as bread and chocolate.** Once you have crossed this line it is difficult to go back to the prescribed low protein version and it adds a temptation which can be hard to resist.
- 8. Find a protein substitute which is acceptable and take it at least 3 times a day.** There is a vast range of protein substitutes to choose from including powders, gels, tablets, bars, ready to drink pouches and tasteless grains. It lowers blood phenylalanine and evens out levels in the day helping to avoid peaks and troughs.

9. **Develop a routine with protein substitute and blood tests.**

Other routines can slide but this one should hold

10. **Get organised.** There's extra to do with ordering/collecting prescriptions, appointments, shopping and cooking so help yourself as much as you can by considering home delivery. Developing good organisational skills can help in all aspects of life not just PKU.

Try the following:

- i) a good, clear calendar in the kitchen
- ii) a white board with pen attached to write all messages
- iii) a check list for times away from home – what are the essentials you need to take.

11. **Try not to be resentful.** PKU will not go away but there are far worse things than this and it is very successfully treated. There is no reason why you cannot make the most of every situation – life is for living!

Produced by the National Society for Phenylketonuria
and its Medical Advisory Panel.



The Society is a registered charity.
It offers support to families with PKU and all future publications.

Further information and details can be obtained by contacting:
The NSPKU Helpline on: 020 8364 3010
or writing to:
The National Society for Phenylketonuria (United Kingdom) Ltd.
PO Box 26642, London, N14 4ZF