



Living life with PKU

Preparing to see your child's PKU specialist

Questions for your PKU specialist

- My child has recently switched from a Phe-free formula to a Phe-free supplement *or substitute*. Are further adjustments likely?
- My child's Phe blood levels are tested every week. How long before we can expect Phe levels to stabilise? Can I still breastfeed?
- Increasingly, my child is becoming upset when I go to collect a blood sample. How do I prevent it from becoming a bigger source of conflict?
- As my child becomes more mobile I'm increasingly worried that I won't be able to control everything that goes into his mouth. What if he/she eats something he/she shouldn't?
- Now that our child is older, is there any medication we can consider?
- Is it safe for my child to be taking medication from such an early age?
- Is medication something that could be a permanent part of our child's disorder management?
- How do I go about teaching my child which foods are safe to eat?
- I worry about leaving my child with a babysitter. Are there any additional precautions I should be taking?
- How strictly do we need to adhere to the diet? Can it be relaxed for special occasions like birthdays or family celebrations?
- Can the damage caused by high Phe levels in the blood be reversed?
- I understand PKU can be classified as *moderate or classic*. When will our child's status become clear?
- I've read that children with PKU are more likely to have fair hair. Why is that?
- Are there any other outward symptoms or signs of PKU?



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- Will my child's intolerance to Phe in food protein change over time?
- My child is about to begin nursery school. How much should I explain to my child's carer's about PKU?
- I've heard that children with PKU are more vulnerable to tooth decay. Why is that?
- Additional questions
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Health information

- My child's date of birth
- My child's blood type
- My child's last blood Phe level reading
- PKU specialist
- Our next appointment
- Dietitian or nutritionist
- Our next appointment