

Sapropterin for treating hyperphenylalaninaemia in phenylketonuria

Information for the public

Published: 22 September 2021

www.nice.org.uk

Sapropterin (Kuvan) is available on the NHS as a possible treatment for hyperphenylalaninaemia in people with phenylketonuria (PKU) who are under 22 or who are pregnant.

NICE's recommendation includes information about the dose you should get based on your age.

If you are not eligible for sapropterin but are already having it, you should be able to continue until you and your doctor decide when best to stop.

Is this treatment right for me?

Your healthcare professionals should give you clear information, talk with you about your options and listen carefully to your views and concerns. Your family can be involved too, if you wish. Read more about [making decisions about your care](#).

Questions to think about

- How well does it work compared with other treatments?
- What are the risks or side effects? How likely are they?
- How will the treatment affect my day-to-day life?
- What happens if the treatment does not work?
- What happens if I do not want to have treatment? Are there other treatments available?

Information and support

The [NHS website](#) may be a good place to find out more.

These organisations can give you advice and support:

- [The National Society for Phenylketonuria \(NSPKU\)](#), 0303 040 1090
- [Metabolic Support UK](#), 0845 241 2173

You can also get support from your local [Healthwatch](#).

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

ISBN: 978-1-4731-4263-3