

Setmelanotide for treating obesity and hyperphagia in Bardet-Biedl syndrome

Information for the public

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Setmelanotide (Imcivree) is available on the NHS. It is a possible treatment for obesity and hyperphagia in genetically confirmed Bardet-Biedl syndrome in people 6 years and over, only if they are aged between 6 and 17 years when treatment starts. These people can carry on having setmelanotide as adults until they need to stop.

If you are not eligible for setmelanotide 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. See [our webpage on 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

[Bardet-Biedl Syndrome UK \(admin@bbsuk.org.uk\)](mailto:admin@bbsuk.org.uk) can give you advice and support.

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.

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