Burosumab treatment for X-linked hypophosphataemia (XLH)

Information for children, families and carers

We have given you this factsheet because your child's doctor has recommended that they have a new type of treatment for their X-linked hypophosphataemia (XLH) called burosumab. It explains what burosumab is, what the treatment involves and what the potential benefits and risks are. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please speak to a member of our team.

What is burosumab?

Burosumab is a new type of treatment for the rare form of rickets called X-linked hypophosphataemia (XLH). XLH is a genetic condition that affects bones, muscles and teeth.

How does the treatment work?

Children with the condition XLH have too much of a hormone called fibroblast growth factor 23 (FGF23) in their blood. This hormone increases the amount of phosphate (a mineral that is essential for the normal growth of healthy bones and teeth) that is removed from the blood by the kidneys. As a result, the amount of phosphate in the blood of a child with XLH is lower than it should be. Without enough phosphate in their blood, a child's bones will not develop properly and will be too soft to support their own body weight without bending (bowed legs).

Burosumab is a medication that reduces the effect of the hormone FGF23 on the kidneys. This helps children with XLH to maintain a normal level of phosphate in their blood.

What are the benefits of this treatment?

In children, burosumab has been shown to:

- prevent irreversible bone damage
- help with healthy bone growth
- reduce bone pain
- improve quality of life (for example, being able to walk faster or play for longer)

Another benefit of burosumab is that your child will be able to stop taking their daily phosphate, calcium and activated vitamin D (such as calcitriol or alfacalcidol) medications and just have one injection every two weeks.

How should I prepare for my child's treatment?

Medications

Your child must stop taking their phosphate, calcium and activated vitamin D (such as calcitriol or alfacalcidol) medications one week before their first burosumab injection. They will not need to take these medications again while they are having their burosumab injections. They should continue their regular vitamin D supplements, such as colecalciferol.

Blood tests

Your child will need to have a blood test before some of their burosumab injections (injections one, two, three, five and seven). This will help us work out what dose of burosumab your child needs. The blood test will usually be done on the same day as your child's injection.

We will give you a **burosumab treatment card** which will contain a list of your child's upcoming appointments and blood tests. Please keep this card safe. On the dates when your child needs to have a blood test, please bring your child to the butterfly room (located in the children's outpatient department) for 8.30am.

After the first 12 weeks of treatment, your child will not need to have as many blood tests. We will contact you in advance to arrange future blood tests.

Eating and drinking

From midnight on the appointment days where a blood test is needed, your child must not eat or drink anything except water (this is called fasting). We recommend bringing some food with you to your child's appointment, so they can eat straight after their blood test.

What does the treatment involve?

A nurse will give your child a subcutaneous (just under the skin) injection of burosumab every two weeks into their upper leg or buttocks. If needed, we can apply a numbing cream or a cold spray to the area before injecting the medication to make this as comfortable as possible for your child.

For the first seven injections

- Injections one, two, three, five and seven will be given by a nurse at **Southampton General Hospital** in either the children's outpatient department or on the John Atwell day ward.
- Injections four and six will be given by a nurse at **your home**.

Please see your child's **burosumab treatment card** for the location of each of their injection appointments.

After the first injection, we may ask your child to stay in hospital for up to an hour. This is so we can make sure they do not have a reaction to the medication. If your child does not have a reaction to the medication, they will be able to go home immediately after having the following injections in hospital.

After the first seven injections

A nurse will give your child their injections at home every two weeks. This will be arranged by a homecare company called Alcura. We will ask for your consent to pass on your contact details to Alcura so that they can manage your child's injections going forward. A member of the Alcura team will then get in touch with you to arrange suitable dates and times for your child's injections.

If you have any questions for Alcura (the homecare company), please contact them using the details on page 4.

Can I give my child their injections?

If, in the future, you would like to receive training to give your child their burosumab injections yourself at home, please contact us. Some families find that this gives them more flexibility with the day and time of giving the injection. However, please note that this is completely optional. The homecare nurse can continue to give your child their injections long-term, if you prefer.

Are there any risks or side effects?

The most common side effects of burosumab include:

- redness, pain, or swelling at the injection site
- a tooth abscess (infection)
- a cough
- headaches
- nausea (feeling sick) or diarrhoea
- muscle pain
- a fever

If you have any concerns about side effects your child is experiencing, please contact us.

Contraception and pregnancy

The effects of burosumab on an unborn baby are unknown. If your child is sexually active, we advise that they use suitable contraception to prevent pregnancy. For more information on contraception, speak to your child's doctor or nurse. If you know or think that your child might be pregnant, contact us for advice as soon as possible.

Will my child need any follow-up care?

Children with XLH will need to have burosumab treatment until they finish growing (this is usually around age 16 in boys and 15 in girls). Your child will also be eligible to continue burosumab treatment as an adult. We will discuss this with you and your child in more detail when your child is ready to move on to adult services.

Contact us

If you have any questions or concerns, or if any of your child's appointment times are not suitable, please contact us as soon as possible.

Paediatric endocrine nurse specialists
Telephone: **023 8120 8719** (Monday to Friday, 9am to 5pm)
Email: **pens@uhs.nhs.uk**

Children's endocrine secretary
Telephone: **023 8120 6985** (Monday to Friday, 8am to 5pm)

Alcura (homecare company)
Telephone: **01604 433 500** or **0800 9800 686**
Email: **patientservices@alcura-health.co.uk**

Useful links

www.xlhuk.org

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