

# Strategic Review 2025

Our mission is to help those with XLH and related disorders within the UK, through research, support and advocacy.

---

10<sup>th</sup> Jan 2026

## Review of the year

---



## Our Purpose

---

XLH UK exists to help those with XLH and related disorders within the UK, through research, support and advocacy.

Events

Submissions

News

*We...*

*Listen*

*Represent*

*Inform*

Research

Patient stories

Webinars

## Achievements 2025

### Advocacy

- Monitoring and information about roll-out of burosumab for adults across England

### Research

- A new patient story about planning a family
- Partnership with Oxford University research program

### Support

- Community Day in Birmingham
- Support for Northern Ireland Family Day
- Connect online support meetings
- Peer to peer buddy system

## Advocating for patients across UK

**Northern Ireland**  
HTA

**Scottish Medicines Consortium**

**NICE** National Institute for Health and Care Excellence

Payer

Department of Health | An Roinn Sláinte  
Mánnystrie O Poustie

**Scotland**  
HTA

**Scottish Medicines Consortium**

Payer

**NHS**  
SCOTLAND

**Wales**  
HTA

All Wales Medicines Strategy Group  
Grŵp Strategaeth Meddyginiaethau Cymru Gyfan

**NICE** National Institute for Health and Care Excellence

Payer

GIG CYMRU  
NHS WALES

**England**  
HTA

**NICE** National Institute for Health and Care Excellence

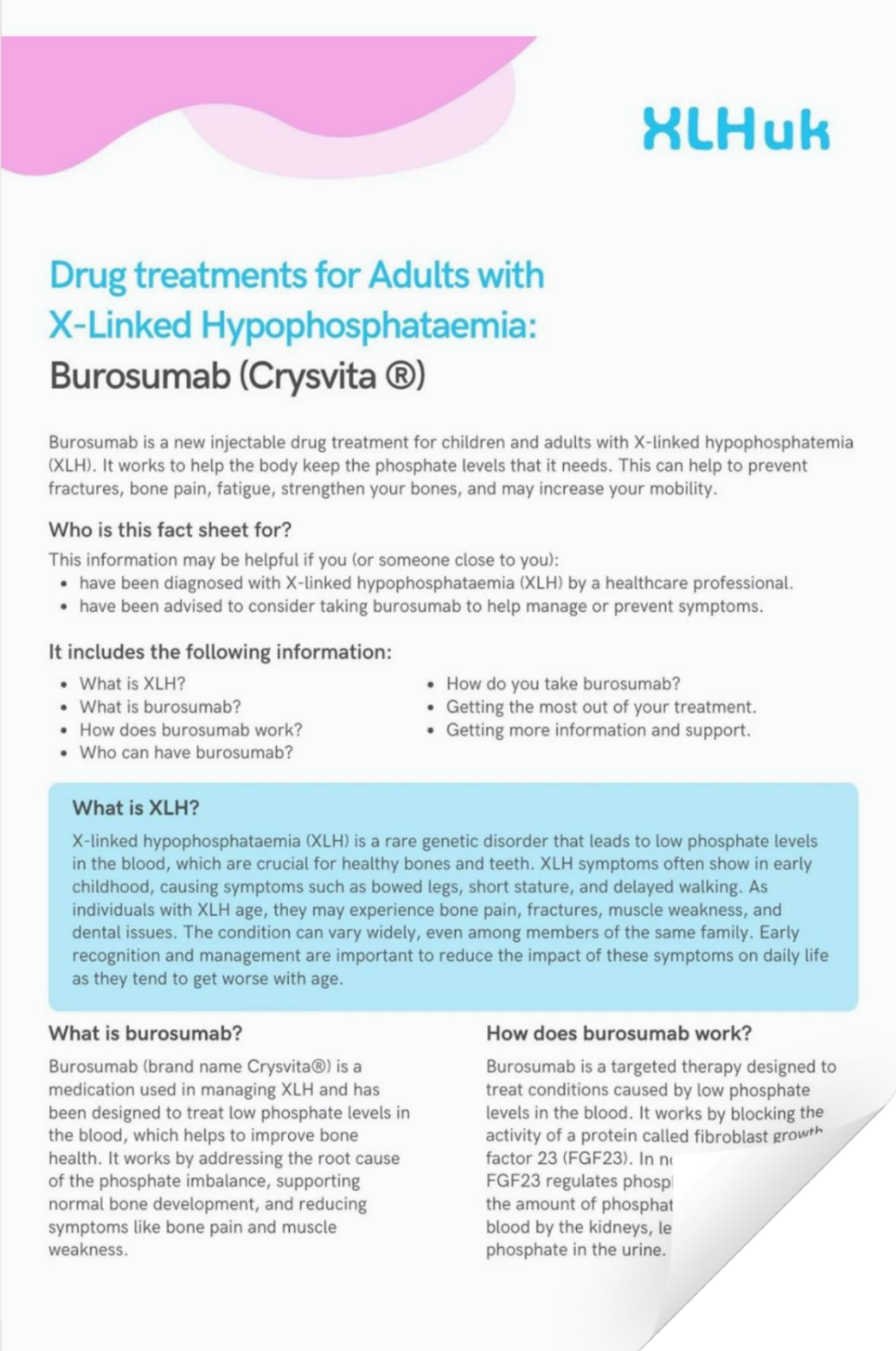
Payer

**NHS**  
England



## Information for adults starting burosumab

- XLH UK produced a patient fact sheet in partnership with the clinicians
- Information on the XLH website about the rollout and the arrival of pre-filled syringes



The image shows a patient fact sheet titled "Drug treatments for Adults with X-Linked Hypophosphataemia: Burosumab (Crysvita®)". The document is from XLHuk and provides information about the drug burosumab, including who it is for, what it includes, and how it works. It also includes a section on what XLH is.

**XLHuk**

### Drug treatments for Adults with X-Linked Hypophosphataemia: Burosumab (Crysvita®)

Burosumab is a new injectable drug treatment for children and adults with X-linked hypophosphatemia (XLH). It works to help the body keep the phosphate levels that it needs. This can help to prevent fractures, bone pain, fatigue, strengthen your bones, and may increase your mobility.

**Who is this fact sheet for?**  
This information may be helpful if you (or someone close to you):

- have been diagnosed with X-linked hypophosphataemia (XLH) by a healthcare professional.
- have been advised to consider taking burosumab to help manage or prevent symptoms.

**It includes the following information:**

- What is XLH?
- What is burosumab?
- How does burosumab work?
- Who can have burosumab?
- How do you take burosumab?
- Getting the most out of your treatment.
- Getting more information and support.

**What is XLH?**  
X-linked hypophosphataemia (XLH) is a rare genetic disorder that leads to low phosphate levels in the blood, which are crucial for healthy bones and teeth. XLH symptoms often show in early childhood, causing symptoms such as bowed legs, short stature, and delayed walking. As individuals with XLH age, they may experience bone pain, fractures, muscle weakness, and dental issues. The condition can vary widely, even among members of the same family. Early recognition and management are important to reduce the impact of these symptoms on daily life as they tend to get worse with age.

**What is burosumab?**  
Burosumab (brand name Crysvita®) is a medication used in managing XLH and has been designed to treat low phosphate levels in the blood, which helps to improve bone health. It works by addressing the root cause of the phosphate imbalance, supporting normal bone development, and reducing symptoms like bone pain and muscle weakness.

**How does burosumab work?**  
Burosumab is a targeted therapy designed to treat conditions caused by low phosphate levels in the blood. It works by blocking the activity of a protein called fibroblast growth factor 23 (FGF23). In normal physiology, FGF23 regulates phosphate levels in the blood by the kidneys, leading to increased phosphate excretion in the urine.

## Patient stories

---

- We commissioned a patient story about planning for a family with XLH
- We also interviewed a fitness enthusiast with XLH who was running her first marathon



## University of Oxford partnership

---

- XLH UK has become a key patient partner for the research team at Oxford University, who are studying how burosumab is impacting quality of life for adults with XLH and their caregivers.
- This long-term study will provide ground-breaking insight into the impact of treating the cause of XLH, rather than the symptoms, for demographics who have not previously been investigated.

**RUDY**

## Community Day in Birmingham



Professor Kassim Javaid was keynote speaker...

...but there was plenty of fun for all the family!



## Supporting the community

- Bringing the value of shared experiences through virtual meetings for the XLH community
- Bringing the community together at events and through a buddy programme



## Fundraising

- In 2025 we have raised more than £4,000 in donations, thank you!
- We used a grant from the National Lottery to fund the 2025 Community Day, including travel bursaries to allow more of the community to attend



Thank you for your support!





# Contact Information

How to reach out

---

 <https://www.facebook.com/groups/xlhukcharity>

 <https://www.linkedin.com/company/xlh-uk>

 [https://www.instagram.com/xlh\\_uk](https://www.instagram.com/xlh_uk)

 [contact@xlhuk.org](mailto:contact@xlhuk.org)

 <https://xlhuk.org>