2022 Review & 2023 Plan
for our supporters

Sarah Mitson
Oliver Gardiner
15th December 2022
Topics for today

• Review of 2022

• Our challenges

• Plan for 2023
Achievements in 2022
Advocating for patients across UK

Northern Ireland
HTA
Payer

Scotland
HTA
Payer

Republic of Ireland
HTA
Payer

England
HTA
Payer

Wales
HTA
Payer

National Institute for Health and Care Excellence

All Wales Medicines Strategy Group

Glyfy Bryngerol Medrhyngoeth Cymru Cynhyrchiad

GIG CYMRU NHS WALES

Scottish Medicines Consortium

An Roinn Sláinte
Mòranpìd A’ Pìsdie
Evidence of lived experience

PATIENT EXPERIENCE SURVEY 2022: Living with X-Linked Hypophosphataemia (XLH)

XLHuk.org

XLHuk.org/survey
Patient stories
Family Day in Manchester
Sharing the news online

Our Latest News

Latest news from NICE’s Topic Selection of using burosumab in XLH adults (September 2022)

September 16, 2022

XLH UK Family Day, Sunday 2nd October 2022. Don’t

September 2, 2022

International XLH Alliance Patient Group Meeting

July 27, 2022

The day before the 3rd International XLH Symposium took place in Dublin, we had a meeting of XLH patient groups from around the world, hosted by International XLH Alliance. Oliver Gardiner led several sessions...

July 24, 2022

3rd International XLH Symposium

The 3rd International XLH Symposium took place on the 1st July at University College, Dublin. The final session of the day was ‘Global Health Disparities and Access to Care’, where Oliver Gardiner presented...
Welcome to XLH’s first newsletter called ‘Navigator’. XLH UK was set up to help those with XLH and related disorders within the UK through research, support and advocacy. We hope that a regular newsletter will help you to navigate your way through some of the challenges that XLH presents.
Our challenges
Our Strategic Goals

• Make a meaningful contribution to improving the quality of life of XLH patients and their families

• Build a high-performing sustainable organisation
XLH UK and IXLHA

• Setting up XLH UK as a CIO and separating out IXLHA by Feb 23

• Primary objective for XLH UK – supporting UK patient group
• Primary objective for IXLHA – collaboration between national patient groups
Our plan for 2023
Our Purpose

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

We... *Listen*
*Represent*
*Inform*

---

Events
Submissions
News

Research
Patient stories
Webinars
Strategic Priorities 2023

1. Awareness & standards of care
2. Access to new treatments
3. Information and support
4. Research and evidence generation
5. High performing, sustainable organisation
XLH UK
A Charitable Incorporated Organisation

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

XLH UK © 2022. Registered Charity (England and Wales) 1196811.
Thank you and Happy Christmas!

This Photo by Unknown Author is licensed under CC BY
Our mission is to help those with XLH and related disorders within the UK, through research, support and advocacy.