Supporting those with XLH and related disorders

Who are we?
XLH UK is a charitable incorporated organisation, founded in 2017.

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

What is XLH?
X-Linked Hypophosphataemia (XLH) is a rare, chronic, progressive disease with an estimated prevalence of 1:100,000 new births.\(^1\) Typically it is passed from one generation to the next, but sometimes appears in an individual with no family history of XLH.\(^2\)

Image from Linglart A et al. Endocr Connect 2014;3:R13

Please contact us for more information:
e: contact@xlhuk.org  w: xlhuk.org

Registered Charity (England and Wales) 1196811

What are we doing?

Listening
Supporting research for public benefit into the causes, prevention, diagnosis and methods of treatment of XLH and related disorders and publishing the useful results of that research.

Representing
Providing a support network for families and patients suffering from the effects of XLH and related disorders.

Informing
Advocating the early diagnosis and well-managed treatment of XLH and related disorders.

How can you help us?
There are a number of ways you can work with XLH UK to help inform and support our work and lend your experience and expertise. Please contact us to find out more.

Who will benefit?
Individuals and families affected with XLH and related disorders such as Tumour Induced Osteomalacia (TIO) and Autosomal Dominant Hypophosphataemic Rickets (ADHR) in the UK and Ireland.