



FOR IMMEDIATE RELEASE

## The International XLH Alliance Welcomes New Clinical Practice Recommendations for X-Linked Hypophosphataemia Published in *Nature Reviews Nephrology*

London, 27<sup>th</sup> January 2025 – The International XLH Alliance (IXLHA), a leading global advocate for individuals affected by X-linked hypophosphataemia (XLH), celebrates the publication of the latest [clinical practice recommendations for the diagnosis and management of XLH](#) in the prestigious journal *Nature Reviews Nephrology*. This landmark publication represents a significant milestone in providing updated and comprehensive guidance for care for patients living with this rare genetic disorder.

### Key Highlights of the Recommendations:

- **Early and Accurate Diagnosis:** Emphasis on the importance of early genetic testing and clinical assessment to ensure timely diagnosis and intervention.
- **Importance of Transitional Care:** Continuing treatment throughout transition into adult care is fundamental during a critical time of skeletal maturity.
- **Multidisciplinary Approach:** Guidance on integrating care from endocrinologists, orthopaedists, dentists, and other specialists to address the complex needs of XLH patients.
- **Treatment Advances:** Recommendations on the use of new treatments like burosumab, which target the underlying causes of XLH, and is progressively gaining ground over conventional treatments.
- **Patient-Centred Care:** A focus on individualised treatment plans that consider patient specificity, quality of life, and long-term outcomes.

The International XLH Alliance commends the authors for prioritising patient perspectives in developing these guidelines. The recommendations highlight the value of shared decision-making between patients and healthcare providers, aligning with the organisation's mission to empower individuals and families affected by XLH.

## Call to Action

While this publication marks a significant step forward, much work remains to ensure these recommendations translate into real-world benefits. IXLHA calls on healthcare systems, policymakers, and the pharmaceutical industry to urgently:

- Align pricing strategy based on patient needs. Too often, patient focus is remaining a slogan and is not translated into real measures.
- Improve access to genetic testing and specialised treatments, particularly in underserved regions.
- Support ongoing research to address remaining gaps in knowledge and develop novel therapies.

“The release of these guidelines is a testament to the power of collaboration between researchers, clinicians, and the patient community,” said Pol Harvengt, IXLHA Scientific Lead - “Together, we can ensure that every person with XLH receives the best care and support they need to live their fullest lives.”

## About XLH

XLH is a lifelong condition characterised by low phosphate levels in the blood, leading to bone deformities, pain, dental complications, and reduced quality of life. Despite advancements in understanding XLH, patients and their families have long faced challenges in accessing standardised care and effective treatments. These new guidelines, developed by an international panel of experts, aim to address these gaps by providing comprehensive, evidence-based recommendations for healthcare professionals.

<https://www.nature.com/articles/s41581-024-00926-x>

## About The International XLH Alliance

IXLHA is a collaborative nonprofit network of national patient groups. Currently, 27 countries are members of the Alliance.

For more information or to access resources related to XLH, visit <https://xlhalliance.org/>

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