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PRESS RELEASE
For immediate distribution

NICE recommends access to burosumab for treating X-linked hypophosphataemia (XLH) in eligible adults

Burosumab will be available on the NHS in all UK nations

London, England, June 21st, 2024.
XLH UK is delighted to report that the National Institute for Health and Care Excellence (NICE) has revised their recommendation from the draft guidance issued in November 2023. On the strength of evidence submitted by clinicians, XLH UK and the patient community, the guidance now recommends access to burosumab (marketed as Crysvita) to treat adults who have a confirmed diagnosis of X-linked hypophosphataemia (XLH).

The recommendation means that adults with XLH in England, Wales and Northern Ireland will join those in Scotland in being able to access this treatment on the NHS, if this treatment is advised by their clinician. Children with XLH already have access to this treatment and may no longer have to stop the treatment at puberty.

XLH is a rare genetic condition inherited as an X-linked dominant trait. If untreated, it can cause significant skeletal deformities in children from a young age, with lifelong disability, pain, and fatigue. It is a progressive and debilitating condition which can require patients to have multiple surgeries in their lifetime.

The news is truly life-changing for patients and their families with XLH, as burosumab is the first and only treatment that targets the underlying mechanism of their hypophosphataemia. This breakthrough therapy shows improvements in the areas that matter to patients, including reductions in daily pain and stiffness. In addition, improvements in healing of fractures limit the need for invasive, corrective surgeries and reduce lifelong pain and disability.

Commenting on NICE's decision, XLH UK trustee Oliver Gardiner explained *"This is fantastic news for adults with XLH in UK. This life-changing treatment is the first to tackle the underlying problem and will lessen the significant physical and emotional challenges that adults with XLH face on a daily basis."*

We commend NICE, NHS England and Kyowa Kirin for their efforts, dedication and commitment to understand the impact that this rare, hereditary and lifelong disorder has on individuals and their families. We would like to thank all the patients and families who shared their experiences with NICE and with us through our research using patient surveys, interviews and case studies. These were invaluable to the process, allowing decision-makers to understand the impact of XLH on patients and their families.

NICE Guidance
More about burosumab
XLH UK
Kyowa Kirin International