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# News release

## Kyowa Kirin to Present New Research Spotlighting Global Efforts to Advance Science and Patient Care in X-linked Hypophosphatemia at ASBMR Annual Meeting

- *Two oral presentations and ten posters will shed light on real-world experiences of people living with XLH and the impact of burosumab treatment*

**Tokyo, September 25, 2024** — Kyowa Kirin Co., Ltd. (Kyowa Kirin, TSE:4151) will share new research that enhances understanding about the use of burosumab (CRYSVITA) in real-world clinical practice as well as the burden of those living with X-linked hypophosphatemia (XLH), a rare genetic metabolic bone disease. The findings will be presented at the American Society for Bone and Mineral Research (ASBMR) 2024 annual meeting, which takes place September 27-30 in Toronto, Ontario, Canada.

The first oral presentation of **"Patient reported outcomes (PRO) from a real-world study of burosumab treatment in adults with X-linked hypophosphatemia in the UK"** will be made by Judith Bubbear, MD, Royal National Orthopaedic Hospital (UK) on Saturday, September 28, 11:30 am EDT (Presentation #1022).

Whilst the second oral presentation, **"BurGER study: A Phase IIIb Study to Investigate the Efficacy and Safety of Anti-FGF23 (Burosumab) in Adults With X-Linked Hypophosphataemia (XLH) in Germany"** will be made by Lothar Seefried, MD, University of Würzburg, Orthopaedic Hospital KLH (Germany) on Sunday, September 29, 12:00 pm (Presentation #1064).

"As we learn more about XLH and how it impacts people's lives, real-world evidence can provide much-needed insight into potential strategies for managing this debilitating disease," said Angela Williams, PhD, Vice President, Global Head of Health Economics and Outcomes Research at Kyowa Kirin. "The breadth of our ASBMR data reflects our continued focus on advancing the science and understanding of XLH and improving the lives of people living with XLH."

ASBMR XLH poster presentations:

**Real-world impact of burosumab treatment in people living with XLH:**

"Effectiveness of burosumab versus conventional therapy in adults with X-linked hypophosphatemia in a real-world setting from the XLH Disease Monitoring Program" (Poster#SAT-430)
- Lead author: Pablo Florenzano, MD, Pontificia Universidad Católica de Chile
- Poster Session I; Saturday, September 28, 2:15 – 3:45 pm EDT

"Biochemical measurements according to age group in burosumab-treated patients with X-linked hypophosphatemia (XLH) in a real-world setting: an analysis of the XLH Disease Monitoring Program" (Poster #Fri-424, #Sun-424)
- Lead author: Leanne M. Ward, MD, Children's Hospital of Eastern Ontario
- Welcome Reception/Plenary Poster Session; Friday, Sept. 27, 5:30 – 7:30 pm EDT
- Poster Session II; Sunday, Sept. 29, 2:15 – 3:45 pm EDT

"Symptoms experienced by adolescents living with X-linked hypophosphatemia at the end of skeletal growth (EOSG) treated with burosumab—a mixed methods analysis" (Poster #SAT-445)
- Lead author: Vrinda Saraff, MD, Birmingham Women's and Children's Hospital (UK)
- Poster Session I; Saturday, Sept. 28, 2:15 – 3:45 pm EDT

"Efficacy and safety of burosumab in adult Chinese patients with X-linked hypophosphatemic rickets/osteomalacia (XLH): an open-label, multi-center, single-cohort, post-marketing phase IV study" (Poster#SUN-119)
- Lead author: Wei Liu, MD, Peking Union Medical College Hospital
- Poster Session II; Sunday, Sept. 29, 2:15 – 3:45 pm EDT

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"Efficacy and safety of burosumab in pediatric Chinese patients with X-linked hypophosphatemic rickets/osteomalacia (XLH): an open-label, multi-center, single-cohort, post-marketing phase IV study" (Poster#SAT-121)

- Lead author: Xiaoping Luo, MD, Tongji Medical College, Huazhong University of Science and Technology
- Poster Session I; Saturday, Sept. 28, 2:15 – 3:45 pm EDT

"BurGER study: A Phase IIIb study to investigate the efficacy and safety of anti-FGF23 (Burosumab) in adults with X-linked Hypophosphatemia in Germany"

- Lead author: Lothar Seefried, MD, University of Würzburg, Orthopaedic Hospital KLH (Germany)
- Poster Session II; Sunday September 29, 11:15 am–12:30 pm EDT

**XLH burden on multiple aspects of patients' lives:**

"Association between pain medication use and patient-reported outcomes in adults with X-linked hypophosphatemia: an exploratory analysis of a phase 3 study" (Poster #Sat-025)

- Lead author: Angela Williams, PhD, Kyowa Kirin International
- Poster Session I; Saturday, Sept. 28, 2:15 – 3:45 pm EDT

"Individuals with hereditary hypophosphatemia are not prone to early death despite significant earlier development of co-morbidities: a retrospective Danish register study" (Poster #Sun-024)

- Lead author: Signe Sparre Beck-Nielsen, MD, PhD, Aarhus University Hospital (Denmark)
- Poster Session II; Sunday, Sept. 29, 2:15 – 3:45 pm EDT

"X-linked Hypophosphatemia Community Impact Survey: psychosocial health, symptoms, and self-care" (Poster #SAT-LB 543)

- Lead author: Jill Simmons, MD, Vanderbilt University Medical Center
- Late Breaking Poster Session I; Saturday, Sept. 28, 2:15 – 3:45 pm EDT

**Bridging evidence gaps to improve clinical decision-making in XLH:**

"Advancing Patient Evidence in XLH (APEX): rational and design of real-world XLH global data unification program" (Poster #SAT-427)

- Lead author: Maria Luisa Brandi, MD, PhD, FIRMO Foundation, Florence, Italy and the University Vita-Salute San Raffaele, Milan, Italy
- Poster Session I; Saturday, Sep 28, 2:15-3:45 pm EDT

**About X-linked hypophosphataemia (XLH)**
XLH is caused by a genetic mutation which leads to overexpression of the protein FGF23, a protein involved in the regulation of phosphate concentration in the blood. In XLH, FGF23 is produced in excess leading to depletion of phosphate in the blood, known as hypophosphataemia.[1]

Individuals living with the disease may display a multitude of symptoms including short stature, limb deformities, bone and joint pain, oral abscesses, and hearing loss.[2] To manage this wide variety of symptoms, the disease is managed through multi-disciplinary teams.[3]

**About CRYSVITA (burosumab)**
CRYSVITA (burosumab) is a recombinant human monoclonal antibody (mAb) that binds to the protein fibroblast growth factor 23 (FGF23). This has the impact of inhibiting the action of FGF23, allowing phosphate regulation in the body to be restored.[4]

**About Kyowa Kirin**
Kyowa Kirin aims to discover novel medicines with life-changing value. As a Japan-based Global Specialty Pharmaceutical Company, we have invested in drug discovery and biotechnology innovation for more than 70 years and are currently working to engineer the next generation of antibodies and cell and gene therapies with the potential to help patients affected by severe and rare diseases. A shared commitment to our values, to sustainable growth, and to making people smile unites us across our four regions—Japan, Asia Pacific, North America, and EMEA/International.

You can learn more about the business of Kyowa Kirin at: https://www.kyowakirin.com

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## References

[1]Beck-Nielsen SS, et al. 2019. FGF23 and its role in X-linked hypophosphatemia-related morbidity. Orphanet Journal of Rare Diseases. 2022;14:1-25.
[2]Kubota T. X-linked hypophosphatemia transition and team management. Endocrines. 2022;3(3):411-418.
[3]European Medicines C. Summary of product characteristics, Crysvita 10 mg solution for injection. 2023. Available here. [Last accessed September 2024].
[4]Electronic Medicines Compendium. Crysvita 10 mg solution for injection. Available here. [Last accessed September 2024]