

CEO Message on International XLH Awareness Day 2026

Today, October 23, marks International XLH Awareness Day.

For many people living with XLH, life can mean years waiting for a diagnosis, symptoms mistaken for something else and care that can depend on where you happen to live.¹⁻³

These are the barriers the XLH community continues to face. At Kyowa Kirin, our *KABEGOE* Principles embody the spirit of leaping over barriers, with patients at the center.

This is strengthened by *Wa*, Kyowa Kirin's *spirit of harmony*. No one organization can do this alone, so we listen to the community, combine our strengths and move forward together.



A united commitment

To mark International XLH Awareness Day, I'm joined by Julie Dehaene-Puype, Steve Schaefer and Tomohiro Sudo, who lead our work across EMEA, North America and Japan and Asia Pacific, to share what our commitment to the XLH community means in practice.

<https://lnkd.in/p/gFVPY3zF>

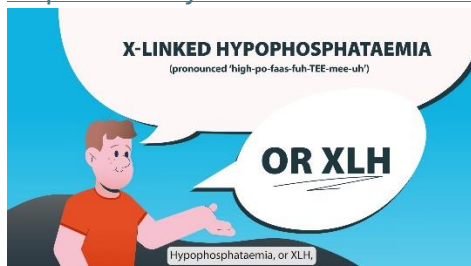


XLH hides in plain sight

Because XLH is so rare, for many people receiving an accurate diagnosis can take years.

¹ It's also easy to think of XLH as a childhood condition, when many adults are living with it undiagnosed. Our new animation explains what XLH is, how it can affect people at different stages of life, and why understanding it matters.

<https://www.youtube.com/watch?v=iyGF0yN9Mws>





We're working to build a clearer picture of life with XLH over time. We sponsor three long-term studies that together follow more than 2,000 people living with XLH across three regions.⁴⁻⁶

Listening first, then building together. We conducted a Community Impact Survey with a patient organization to understand life with XLH. We also launched the XLH Community Guidebook. The Guidebook was created with the community, for the community, shaped by the voices, experiences and needs of people living with XLH and the families that support them every day.

Care that looks beyond medicine. Living with XLH can mean lifelong, coordinated care, and access to that care can vary.³ We work with patient organizations, healthcare professionals and health systems to advance the recognition of this need.

All month, colleagues around the world have put the community's voice at the center, from watching short films made by people living with XLH themselves to conducting XLH Café events across Japan.

Attending the recent XLH Patient Day in Indianapolis gave me the privilege of hearing directly from patients about their XLH journeys and the difference our work is making in their lives. For us at Kyowa Kirin, "making people smile" is much more than words or a slogan. Listening directly to patients and their families is a powerful reminder of the very real difference our work can make in people's lives, and why we must continue listening, learning, and partnering with the community.

International XLH Awareness Day is just one day, but we work for this community every day. Together, we will continue working to help break down barriers and create life-changing value for people living with XLH around the world.

Abdul Mullick

President and CEO, Kyowa Kirin

References

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