



WHO WE ARE

The XLH Network, Inc., a 501(c)(3) nonprofit corporation, works to connect affected families, clinicians, and researchers around the world with up-to-date information on the diagnosis, symptoms, and treatment of hypophosphatemic conditions in patients of all ages.

Our services include a moderated, peer-to-peer community forum; a physician referral database; educational literature and videos for patients and clinicians; a collaboratively sponsored, patient-focused natural history study; a speakers' bureau; and patient education and networking events, including Community Connections and XLH Days.



xlhnetwork



@xlh_network



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COMMUNITY. KNOWLEDGE.
COMPASSION.

COMMUNITY

The MISSION of The XLH Network, Inc.



Promote awareness and education for affected patients, families, medical professionals, and the community at large.



Support providers of medical care for better diagnosis and treatment.



Create resources and a community for affected families so they can understand and cope with the disease.



Foster the search for a cure.

If you would like to help us accomplish our mission, donations are tax-deductible and may be made online using the link at our website, **XLHNetwork.org**.



KNOWLEDGE

XLH is a whole-life, whole-body, potentially disabling disorder, affecting bones, teeth, muscle function, and energy levels. Symptoms include, but are not limited to, lower limb deformities, short stature, and spontaneous dental abscesses.

Early diagnosis and life-long treatment are critical to the bone, dental, muscle, and emotional and social health of patients.

Treatment has traditionally included multiple doses of phosphorus and calcitriol. Burosumab, a new FDA approved treatment, marketed as Crysvisa®, improves the kidney's reabsorption of phosphate by inhibiting the action of the FGF23.

COMPASSION

The XLH Network, Inc. provides online and in-person opportunities for patients and families to share their experiences with one another. After six decades of research, misconceptions about XLH persist, and treatment can be difficult to access. The XLH Network, Inc., is committed to connecting patients and doctors, educating them about XLH as a whole-life, whole-body disease, and advocating for additional research and the best medical care for our families.

"I am thankful each and every day for this group. They are supportive and very informative."