

— THE — ABCs — OF — XLH



Ruby and Alejandro,
both living with XLH

Affects children
throughout life

X-linked hypophosphatemia (XLH) is a **rare, lifelong condition**. Symptoms often start during childhood and **change or progress** over time.

Begins on the X
chromosome

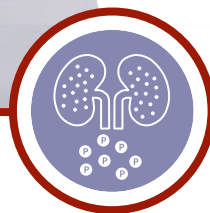
Children are born with XLH. The “X” stands for “X-linked” because the condition is due to a change (a variant) on the X chromosome. In most cases, XLH is **inherited** within families. However, children can sometimes be born with XLH, even if there’s no family history: this is called a **spontaneous case**.

Causes issues with bones,
muscles, and teeth



Increased FGF23

When someone has XLH, their body makes too much of a protein called **fibroblast growth factor 23 (FGF23)**. FGF23 plays a role in controlling the amount of phosphorus present in the body.



Phosphorus wasting

Too much FGF23 causes **phosphorus wasting**, which is the loss of phosphorus through the urine.



Weak and soft bones

Phosphorus wasting leads to low levels of phosphorus in the blood (called **hypophosphatemia**), causing various symptoms of XLH.

THERE'S NO CURE FOR XLH, BUT IT IS MANAGEABLE WITH PROPER CARE.

XLH: WHAT IT MAY MEAN FOR YOUR STUDENT



Possible symptoms of XLH in children

- Waddling gait
- Bone and joint pain
- Dental issues and tooth abscesses
- Bowing of the legs
- Short stature
- Rickets: softening and weakening of bones
- Craniosynostosis: when the bones in the skull join together too early, causing an unusual head shape and/or larger-than-usual head size



Potential challenges

- Depression; anxiety
- Teasing or bullying; feeling different from their peers
- Fatigue; tiredness due to trouble sleeping
- Having enough time to get from class to class
- Carrying heavy books in their backpack, especially after surgery
- Taking their XLH medicine
- Frequent absences for appointments (eg, doctor, dentist, physical therapy, mental health professional)
- Difficulty running
- Not being able to participate in regular gym class activities
- Not being able to keep up with other kids
- Sitting at their desk in class for a long time
- Standing in line for lunch

Learn more about how XLH affects your student

Talk to their parent or caregiver to better understand your student's personal journey with XLH and how to work together to support their needs at school.

Student's name: _____ Grade: _____ Teacher: _____

Parent's/caregiver's name: _____

Phone: _____ Email: _____



Learn more about XLH at [XLHLink.com](https://www.xlmlink.com).