

Planning for your child's future with XLH

Tips to help your child with X-linked hypophosphatemia (XLH) take charge of their healthcare

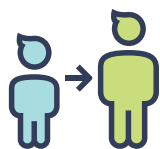


Arlene and her
daughter Gina

Living with XLH

Giving your child the tools to navigate their XLH journey

As a parent, you watch your child experience life changes as they get older. Having a lifelong condition like XLH can bring its own challenges. But with some planning, these changes don't have to feel so overwhelming for you or your child.



XLH symptoms can evolve over time and so should your child's care

How do you help your child plan for the future so that they can reach their full potential? Whether they're going off to college or just off your health insurance, this guide will help you and your child prepare for what's next in their XLH management journey. That way, they can continue to get the care they need.

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When I went away to college...it was challenging for me to find a new doctor for my XLH. Finding the right healthcare team is very important for anybody with any condition. You have to feel comfortable.”

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XLH is a progressive, lifelong condition

That means if left untreated—even temporarily—XLH symptoms can worsen over time. As adolescents with XLH become more independent, it is important that they continue their care without interruption.

Young people who need long-term care can fall through the cracks

>80% of young people in the US with lifelong conditions have not received adequate preparation for a successful transition to adult healthcare*

~60% of young people with lifelong conditions said that they never discussed a transition plan with their healthcare providers†

Challenges your child could face if their XLH care plan is interrupted:

- Worsening symptoms
- Worsened quality of life
- Delays in care from misdiagnosis

*Results from the 2016 National Survey of Children's Health, a nationally representative survey of parents.

†Results from the 2005-2006 National Survey of Children With Special Health Care Needs, with similar results found 10 years later.

Elizabeth and her son Simon

Both living with XLH



Building confidence and taking charge

Growing up can feel like there are a lot of unknowns ahead. Living with XLH, a lifelong condition, introduces its own unique hurdles. Building a healthy routine and lifestyle may help your child feel confident in handling more on their own.



Encourage your child to create healthy habits

- Make healthier food choices
- Exercise and stay active regularly
- Practice dental hygiene
- Avoid screens at least 30 minutes before bedtime to help with sleep
- Maintain a schedule to build time management skills



Empower your child to take more ownership

- Make sure your child understands the importance of being up-to-date on doctor visits and biannual (twice a year) checkups with their dentist
- Consider having your child take part in scheduling and keeping track of their own appointments
- Encourage your child to ask the doctor questions they may have about their health

Keeping track of important information

Living with XLH can mean seeing many different doctors and/or specialists. That's a lot of paperwork! These records are important for your child's new healthcare team to have—even if they aren't the doctor managing their XLH.

What their new healthcare team may need

Many healthcare practices have digital records on file so they're easier to access and share, including:



Medical history

- Age of diagnosis
- Family history
- Past lab results
- Genetic test results
- Surgery records (dates, types of surgeries)



Imaging

- Renal ultrasound
- Radiographic images and X-rays
- Dental records



Other records

- Hearing evaluations
- Growth chart
- Current medications
- Allergies
- Contact information for new and previous healthcare providers

Doctor's offices will need your permission to share your child's health records (unless your child is an adult).

Information found on their insurance card

1 Provider Logo

Member Name
Jane Doe

XXXXXXXX
XXXXXXX

2

Member ID
####

XXXXXXXX
XXXXXXX

3

####

- 1 Current insurance provider (medical and/or dental, as they may be different)
- 2 Policy number
- 3 Pharmacy benefit (ID/BIN)



TIP! Take a photo of the front and back of your insurance card(s) in case you lose it or don't have it on hand.



Does your child need a new specialist who knows and understands XLH? Start the search here. [Find a specialist](#)

Encourage your child to speak up

It's important that your child become comfortable communicating how they are feeling, both physically and emotionally, to their healthcare team.

XLH affects everyone differently, including children and adults. Symptoms can change as your child gets older. Your child should tell their doctor if symptoms change in any way or start impacting:

- Daily functioning
- Mental health
- Work or school
- Interpersonal relationships



Talk about mental well-being, too

With XLH, your child may be more likely to experience anxiety and depression. Encourage them to be honest—with both you and their doctors—about how they are feeling emotionally and if they need help.

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Continued management of XLH throughout your life is extremely important. It's going to change the older you get.”

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Elizabeth, her son Simon, and her mother Jean

Living with XLH



Tools to help start the process of transitioning to adult-focused care

Take the next step



Ask their current pediatric specialists if they can refer you and your child to adult specialists in their network



Find an adult specialist who knows and understands XLH



Ask your doctor about how to best manage your child's XLH symptoms

Below are some advocacy organizations and tools to support you and your child



[XLHNetwork.org](https://xlhnetwork.org)

A worldwide community of XLH patients, parents, caregivers, and medical professionals



[RareDiseases.org](https://rarediseases.org)

The National Organization for Rare Disorders is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them



[GlobalGenes.org](https://globalgenes.org)

A globally connected community committed to eliminating the challenges of rare disease and providing information, resources, and connections to all communities affected by rare diseases

Navigating XLH from childhood to young adulthood



Ruby
Living with XLH



Speak to their pediatrician about what you can do to prepare for your child's transition to adult-focused care.

Visit [XLHLink.com](https://www.xlhl.com) to learn more.

