



XLH

LINK

PLANNING FOR THE FUTURE WITH XLH

A caregiver guide for helping your teen
transition from pediatric to adult care

XLH=X-linked hypophosphatemia.

XLHLink.com

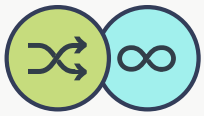
Arlene and her
daughter Gina

Living with XLH

Preparing for a healthcare transition

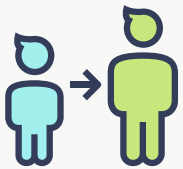
Help your teen take control of their healthcare as they get older

Provide support for your teen as they transition out of childhood and learn to manage their XLH journey into adulthood.



XLH is lifelong and progressive

Early and accurate diagnosis and management of XLH is critical in both children and adults.



Common myths about managing XLH

- XLH is only a childhood disease
- Mild symptoms never worsen over time
- Adult patients will not benefit from ongoing disease management

These misconceptions can lead to gaps in care for adult patients.



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

GINA
LIVING WITH XLH

Continuing care into adulthood

Your teen could face unnecessary challenges if their XLH plan is interrupted

XLH symptoms impact both children and adults. As teens with XLH become more independent, it is important to continue care without interruption. **Planning now can help your teen better prepare to manage their XLH into adulthood.**

Two US surveys of parents with children who have special healthcare needs

~78% of those parents reported that their children did not receive healthcare transition planning^a

76% of those parents reported that their child's pediatric provider did not discuss a shift to providers who treat adults^b



Continuing to manage XLH beyond childhood can help improve health outcomes.

^aResults from the 2019-2020 National Survey of Children's Health.

^bResults from the 2021-2022 National Survey of Children's Health.

Transition of care recommendations for caregivers¹



Encourage your teen to use the checklist within this brochure as they begin seeing new doctors.

Transitioning to a new healthcare team

As your teen gets older, they will need to start going to doctors who treat adults.

Here are some ways to get started:



Ask your teen's current doctor how long they can continue to treat your teen.
Some pediatric doctors will treat their patients until they are 21.



Ask your teen's doctor if they recommend another doctor who specializes in adult care of XLH.



Ask members of the XLH community for doctor recommendations.



Find an XLH specialist near you.

Managing XLH as an adult

Keeping up with regular doctor visits can help patients track any potential disease progression or complications.

Young adults should have **checkups every 6 to 12 months**, depending on their treatment plan or as recommended by their care team.

These checkups might include:



Bloodwork



Urine tests



Mobility tests



Dental exams

XLH affects everyone differently. It is important that young adults communicate how they are feeling both physically and emotionally with their care team.



Mindful tip: As your teen becomes a young adult, encourage them to speak to their doctors about healthy habits related to managing their XLH, such as:



Eating a balanced diet



Maintaining a healthy dental routine



Getting proper sleep



Managing their mental and emotional health

Managing medical records over time

As a young adult, your teen will be in charge of their medical records and providing that information to new doctors. Help your teen compile this information.



Basic information

This includes information about their insurance company, the names of current and previous doctors, and current medications they are taking.



Medical history with XLH

This might include previous lab results, X-rays and other imaging results, dental records, and surgical records.



Symptom history

Many doctors have digital records, which can make it easier to share with other doctors. But it is a good idea to encourage your teen to keep track of this information themselves through a written history to share with any new doctors they will see as they get older.



Mindful tip: Help your young adult learn where to access their personal health information in their online patient portal.

Understanding health insurance

Young adults can usually stay on their parents' health insurance plan until they turn 26; however, once your teen reaches a certain age, there can be limitations on what information parents can access.

Help your teen understand their insurance information and how to advocate for themselves with insurance companies. This can include:

- ✓ What their insurance plans cover
- ✓ How to connect with insurance agents
- ✓ How to navigate their online patient portal

Also, make sure your teen understands the information on their insurance cards:



- Current insurance provider (note: medical and dental may be different)
- Policy number (for doctor visits)
- Pharmacy plan (for medication)



Mindful tip: Encourage your teen to keep a digital copy of their insurance cards so their information is readily available.

Your XLH checklist¹



This checklist is for your teen when they take the next step of transitioning from pediatric to adult care.

Items to bring with you to your doctor visits:

- ☐ List of current medications, supplements, and treatment history
- ☐ Insurance card

List of past XLH symptoms and complications

- | | | | |
|---|-------------------------------|---|---|
| ☐  | Fractures and pseudofractures | ☐  | Craniosynostosis and/or Chiari malformation |
| ☐  | Dental abscesses | ☐  | Lower limb deformity |

Other _____

- ☐ Emergency contact information
- ☐ Names and contact information for current and past:
 - ☒ Specialists
 - ☒ Healthcare providers
- ☐ Medical and surgical records, lab results, and images from past visits with other doctors and specialists
- ☐ Detailed family history and genetic testing results
- ☐ Any other information you would like your doctor to know



Mindful tip: Work with family or caregivers to gather a complete record before seeing new doctors. Include current and past symptoms and complications.

Notes

TEAR HERE

XLH may be rare, but you are not alone

Reach out to the advocacy organizations and support groups below, and encourage your teen to do so as well.



XLHNetwork.org

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



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

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



Learn more about XLH.



Visit us on social media

Reference: 1. Dahir K, Dhaliwal R, Simmons J, et al. Health care transition from pediatric- to adult-focused care in X-linked hypophosphatemia: expert consensus. *J Clin Endocrinol Metab.* 2022;107(3):599-613. doi:10.1210/clinem/dgab796



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