

X-LINKED HYPOPHOSPHATEMIA (XLH) SELF-CARE ASSESSMENT

AGES 12 TO 14

Fill out this form with your parent or caregiver. Be as honest as you can. There are no right or wrong answers. Your answers will help you create a self-care plan for when you get older. You can fill out this form once a year and see how your answers change.

	My Answers			Parent/Caregiver Assessment		
	I know this	I am still learning this	I don't know/do this yet	They know this	They are still learning this	They don't know/do this yet
XLH KNOWLEDGE						
I know what XLH is and can explain it to my friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can describe how XLH makes my body feel, including the things that hurt me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know whether or not my parents have XLH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I will need to change my doctor to a different doctor as an adult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand that the ways XLH affects my body will change over time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Write down how you would explain or describe what XLH is to a friend or family member.

SELF-CARE

	My Answers			Parent/Caregiver Assessment		
	I know this	I am still learning this	I don't know/do this yet	They know this	They are still learning this	They don't know/do this yet
I know and can explain how I take care of XLH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can talk about my emotions with my parents or friends, like when I'm feeling sad or mad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to go for help when I feel sad or mad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my medication schedule and what to do if I miss a dose.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know the potential side effects of my medication.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what medicines I should not take and what medicines I am allergic to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to take care of XLH in school.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If the answer to any of the above questions was "I don't know / do this yet," talk about this with your parents or bring this form to talk about this with your doctor during your next visit.

My doctor's name is: _____

The medication I take for XLH is: _____

My medication schedule is: _____

USING HEALTHCARE SERVICES

	My Answers			Parent/Caregiver Assessment		
	I know this	I am still learning this	I don't know/do this yet	They know this	They are still learning this	They don't know/do this yet
I know my doctors' names and where to find their contact information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I make my own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can talk to my doctor about my concerns or questions about how I manage XLH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know to ask for an explanation when I don't understand something my doctor says.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can provide a summary of my medical history (such as dates and types of surgeries, family history, allergies, and medications).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what health information I should carry with me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my health insurance information (plan, coverage).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

To assist in planning for your next doctor's visit, you can also reference this toolkit's *Doctor Discussion Guide* for advice on speaking with healthcare providers and getting more out of your appointments.

When I think about my health in the future, I wonder about:

When I think about my future, these are the things I want to do:

NEXT STEPS

Bring this self-care assessment to your next appointment with your child's primary care provider (pediatrician) and their XLH specialist (endocrinologist, nephrologist, or other). You can discuss how best to teach your child these steps to self-care and start the transitions discussion with your doctor. Consider asking:

- When do you recommend my child starts to see you alone for a portion of their appointment?
- Does your office have a template for a medical transition plan?
- How will the transition plan be updated as my child grows?
- Can we review our transition plan with you on a yearly basis?



Download the full **XLH Transitions Toolkit** at [XLHlink.com](https://www.xlmlink.com)