

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		
	Yes	No	Not Sure	Yes	No	Not Sure
MY CONDITION: XLH						
I know what XLH is and I 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 understand that I can't give XLH to others.	<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.	<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.

	My Answers			Parent/Caregiver Assessment		
	Yes	No	Not Sure	Yes	No	Not Sure
TAKING CARE OF MYSELF						
I can explain to my teacher or others what I need to do for XLH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what my teachers and school nurses need to do to help me with XLH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what medicines I take for XLH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what days and times I take my XLH medicine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to take my XLH medicine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Write down the medicines you take for XLH.

When do you take them?

MY DOCTOR APPOINTMENTS

	My Answers			Parent/Caregiver Assessment		
	Yes	No	Not Sure	Yes	No	Not Sure
I know my doctors' names and how they care for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand why I have special doctors for XLH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know I can ask my doctor questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I ask my doctor to explain when I don't understand something they say.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I want to talk to my doctors more about XLH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

When I think about XLH, I wonder:

I want to ask my doctor about:

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 start the transitions discussion by 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**