DOCTOR DISCUSSION GUIDE FOR CHILDREN

XLHLink
Bringing people and ideas together

A GUIDE FOR DISCUSSING XLH MANAGEMENT WITH YOUR CHILD'S DOCTOR*

XLH symptoms can progress over time, and it can be difficult to understand how they may be impacting your child's day-to-day life. The following questionnaire can help you prepare and identify talking points to discuss with the doctor during visits.

Be as honest as you can. There are no right or wrong answers. Complete this questionnaire before each primary care provider and XLH specialist appointment, and see how the answers change over time.

*Parents and caregivers, encourage older children to answer the questions themselves if they have the ability to do so. Share this information with your child's primary care provider (pediatrician) and their XLH specialist (endocrinologist, nephrologist, or other).

Since their last appointment, has your child expressed disinterest in or avoidance of social or school activities due to:

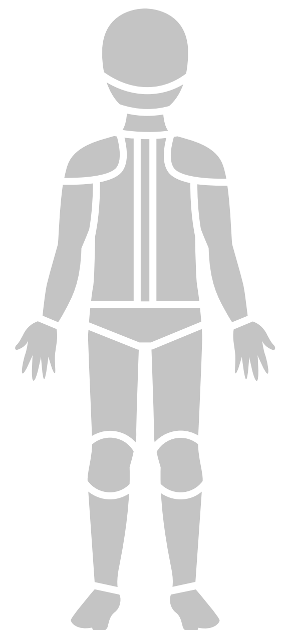
Feeling tired or a lack of energy?	☐ Yes	☐ No
Difficulty moving?	☐ Yes	☐ No
Experiencing teasing for being short or for their physical appearance?	☐ Yes	☐ No

Since their last appointment, how often has your child complained of pain?

- ☐ Never
- ☐ Seldom (once in a while)
- ☐ Occasionally (a few times a month)
- ☐ Often (daily or several times a week)

If your child has experienced pain, where in the body is their pain located?
(check all that apply or indicate where on the image of the body)

☐ Head	☐ Hands / wrists	☐ Knees
☐ Teeth / jaw	☐ Spine	☐ Feet
☐ Neck	☐ Torso	☐ Other
☐ Shoulders	☐ Hips	
☐ Arms	☐ Legs	



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Since their last appointment, has your child needed assistance to move due to pain or corrective surgeries?

☐ Yes ☐ No

Please describe. *(optional)*

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Since their last appointment, has your child had any dental complications?

☐ Yes ☐ No

How often have you had to take your child to the dentist?

☐ Once ☐ Less than 5 times ☐ 5 times or more

Describe the type of dental complications. *(optional)*

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How recently have you discussed options for managing your child's XLH with their doctor?

☐ Within the last 3 months ☐ More than a year ago

☐ Within the last year ☐ Never

Describe how your child's XLH is managed on a daily basis and any concerns you may have about XLH management. *(optional)*

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List any additional questions or notes to discuss with your child's doctor at their next appointment. *(optional)*

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DOCTOR DISCUSSION GUIDE FOR ADULTS

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A GUIDE FOR DISCUSSING XLH MANAGEMENT WITH YOUR DOCTOR

XLH symptoms can progress over time, and it can be difficult to understand how they may be impacting your day-to-day life. The following questionnaire can help you prepare and identify talking points to discuss with your doctor during visits.

Be as honest as you can. There are no right or wrong answers. Complete this questionnaire before each primary care provider and XLH specialist appointment, and see how the answers change over time.

In the past 6 months, have you had to make any adjustments to your home, work, or social life due to tiredness, lack of energy, and/or difficulty moving?

☐ Yes ☐ No

If yes, where have you had to make adjustments? *(check all that apply)*

☐ At work ☐ At home ☐ Socially ☐ Other

Please describe the types of adjustments. *(optional)*

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In the past 6 months, how often have you felt recurring or new pain?

☐ Never

☐ Seldom (once in a while)

☐ Occasionally (a few times a month)

☐ Often (daily or several times a week)

If you have experienced pain, where in the body is your pain located?
(check all that apply or indicate where on the image of the body)

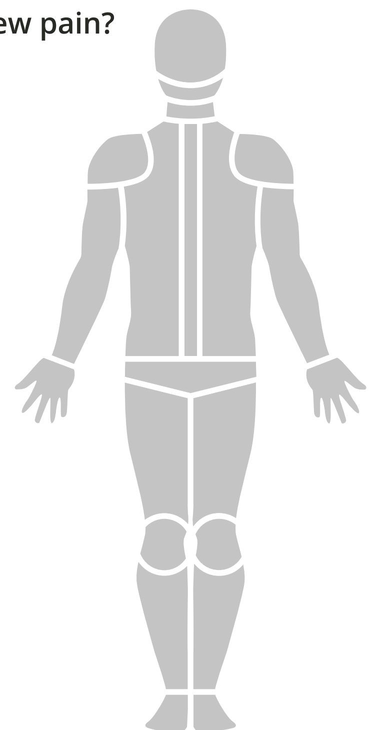
☐ Head ☐ Hands / wrists ☐ Knees

☐ Teeth / jaw ☐ Spine ☐ Feet

☐ Neck ☐ Torso ☐ Other

☐ Shoulders ☐ Hips

☐ Arms ☐ Legs



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DOCTOR DISCUSSION GUIDE FOR ADULTS

In the past 6 months, how often have you had to take steps to manage your pain?

- ☐ Never
- ☐ Seldom (once in a while)
- ☐ Occasionally (a few times a month)
- ☐ Often (daily or several times a week)

Describe how you managed your pain. *(optional)*

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Do you have any hearing issues?

☐ Yes ☐ No

Describe the hearing issues. *(optional)*

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How recently have you discussed options for managing your XLH with your doctor?

- ☐ Within the last 6 months
- ☐ Between 6 months and 1 year ago
- ☐ More than a year ago
- ☐ Never

Describe how your XLH is managed on a daily basis and any concerns you have about XLH management. *(optional)*

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List any additional questions or notes to discuss with your doctor at your next appointment. *(optional)*

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