

# Your Child's Doctor Discussion Guide

[XLH](#) [LINK](#)

Are your child's symptoms related to X-linked hypophosphatemia (XLH)? Fill out the guide below and bring it with you to your child's next appointment. Together, you and the doctor can figure out the best way to manage your child's symptoms.



Emily and her daughter Isla  
Both living with XLH



## Let's start with the basics. Have you or any of your family members been diagnosed with XLH?

Yes

No



## Everyone experiences symptoms differently. Let the doctor know if your child has any of the following symptoms:

Shorter than children their age

Rickets/bowed legs

Bone and joint pain

If so, how severe is your child's pain?

Dental problems (tooth abscesses, etc)

If so, how many dental problems has your child had?

Mild    Moderate    Severe    Very severe

1-3    4-6    7-9    10 or more

Muscle weakness

If so, how weak does your child feel on a daily basis?

Fractures

If so, how many fractures has your child had?

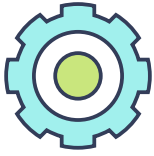
Not weak    Mildly weak    Weak    Very weak

1-3    4-6    7-9    10

Other:



## How old was your child when you first noticed these symptoms?



**Let your doctor know how you've been managing your child's symptoms so far. Please note which of the following you've tried.**

Rest

---

Physical therapy

---

Orthopedic care

---

Exercise/stretching

---

Vitamins/supplements:

---

Medications:

---

Other:



**It's understandable that these symptoms can affect your child's life. Please mark which areas are impacted and discuss with your child's doctor.**

Nursery/school

---

Home

---

Not at all

Very much

Not at all

Very much

Hobbies

For example: sports, after-school activities, crafts

---

Social life

Including feeling left out or not being able to participate in activities

---

Not at all

Very much

Not at all

Very much

Emotional well-being

---

Other:

Not at all

Very much



**Make sure you're getting all the answers you need. At your child's next appointment, go over this discussion guide with the doctor. The following questions may also help:**

- What tests are available to diagnose XLH?
- I understand that there are different tests that can help diagnose XLH. One of these is a fasting serum phosphorus test. Would this test be appropriate for my child?
- How is XLH managed?

**My notes:**



[kkna.kyowakirin.com](http://kkna.kyowakirin.com) | © 2023 Kyowa Kirin, Inc.  
All rights reserved. COMM-US-RDS-0092 March 2023



[XLHLink.com](http://XLHLink.com)