

Your Doctor Discussion Guide



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



Actor portrayal



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

Yes

No



Everyone experiences symptoms differently. Let your doctor know if you have any of the following symptoms:

Below average height for your age

Bowed legs

Bone and joint pain

If so, how severe is your pain?

Dental problems (tooth abscesses, etc)

If so, how many dental problems have you had?

Mild Moderate Severe Very severe

1-3 4-6 7-9 10 or more

Fatigue/exhaustion

If so, how difficult is it for you to perform daily tasks?

Fractures

If so, how many fractures have you had?

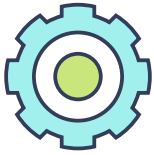
Not difficult Somewhat difficult Difficult Very difficult

1-3 4-6 7-9 10 or more

Other:



How old were you when you first noticed these symptoms?



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

Rest

Walking or mobility aid (cane, walker, etc)

Physical therapy

Orthopedic care

Medications:

Vitamins/supplements:

Other:



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

Work/school

Home

Not at all Very much

Not at all Very much

Hobbies

For example: sports, dance, 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 next appointment, go over this discussion guide with your 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 me?
- How is XLH managed?

My notes:



kkna.kyowakirin.com | © 2023 Kyowa Kirin, Inc.
All rights reserved. COMM-US-RDS-0091 March 2023



XLHLink.com