XLH LINK

XLH AND YOUR FAMILY

XLH (X-linked hypophosphatemia) is a genetic condition that can be inherited, so it may affect other people in your family. Use this guide to understand XLH inheritance and support your family in taking the first step toward care.

JoBeth
Karabeth's mother

Karabeth
Living with XLH
(spontaneous)

XLH OFTEN RUNS IN THE FAMILY

XLH is a genetic condition. This means it can be passed from parents to their children through their genes.

“

My grandmother had XLH. She passed it on to my father, who passed it on to me.

Shannon

Living with XLH

XLH can also occur without a family history

This is called a spontaneous case. About 3 out of 10 people can develop a spontaneous case of XLH.

People with a spontaneous case of XLH can still pass the condition to their children.

Alice
Living with XLH

Lisa
Alice’s mother, Jason’s wife

Jason
Alice’s father, living with XLH (spontaneous)

WHY THE "X" MATTERS IN XLH

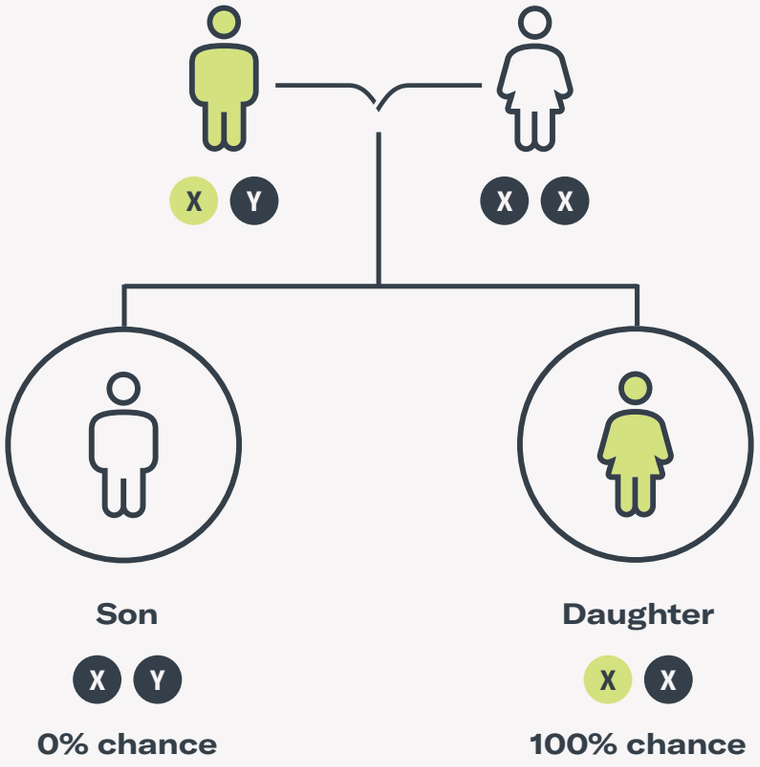
The X and L in XLH stand for X-linked, meaning the condition is passed down through the X chromosome

Chromosomes are structures that carry your genes:

- Men have an X and a Y chromosome (XY)
- Women have two X chromosomes (XX)

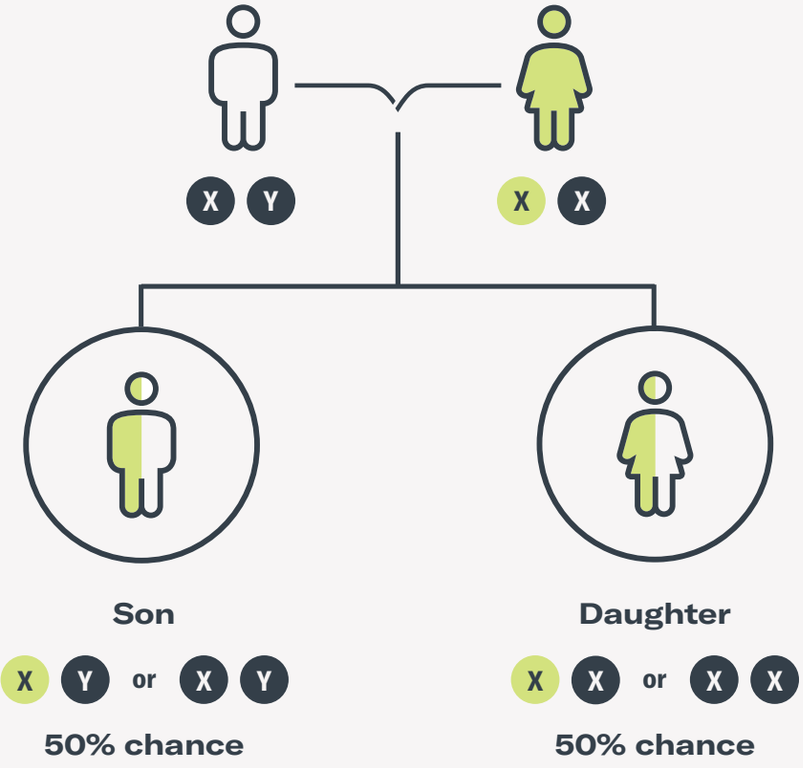
Chromosome with XLH

If a father has XLH and the mother does not:



All daughters will have XLH. No sons will have XLH. This is because **daughters inherit an X chromosome from their father**. No sons will have XLH because **sons get the X chromosome from their mother**.

If a mother has XLH and the father does not:



Both sons and daughters have a 50% chance of having XLH. This is because **all children inherit an X chromosome from their mother**.

THE SYMPTOMS OF XLH CAN VARY

Not everyone experiences XLH the same way. Some family members can have several symptoms, while others may only have a few. Even if XLH symptoms look or feel different, it's important to pay attention to all of them.

From left to right: **Karabeth, Alice, Jason, Sunindiya, Shannon,** and **Raquel.**
Alice and Shannon inherited XLH.
Karabeth, Jason, Sunindiya, and Raquel have spontaneous XLH.

There are several ways that XLH can affect the body

Do you recognize any of these symptoms in your family?

BONES, MUSCLES, AND JOINTS

- Bone and joint pain
- Shorter than average height
- Weakening of growing bones (rickets)
- Delayed walking or an unusual way of walking (gait abnormalities)
- Bowed legs and knock knees
- Muscle pain and weakness
- Weakening of mature bone (osteomalacia)
- Joint damage (osteoarthritis)
- Hardening of tissue attaching bones and muscles (enthesopathy)
- Broken bones (fractures) and areas of weakened bone that are not completely broken (pseudofractures)
- Unusual shape of the head (craniosynostosis)
- Narrowing of spaces in the spine (spinal stenosis)

DENTAL

- Issues such as abscesses and tooth loss
- Problems with the gums, like redness, swelling, or infection (periodontitis)

OTHER

- Hearing loss
- Fatigue

EXPLORE THE FAMILY RESOURCE CENTER

Could someone else in your family have XLH? The Family Resource Center offers tools and resources to help you better understand who else in your family may be affected and how to start meaningful conversations about XLH with your relatives.

Alice and her father, **Jason**.
Jason has spontaneous XLH.
Alice inherited XLH.

LEARN FROM EXPERTS AND FAMILIES

Explore videos that can help you better understand XLH inheritance and feel more prepared to talk with your family.

Get the facts from an XLH expert

Watch short videos featuring Dr. Nancy Dunbar, an XLH specialist with more than 20 years of experience helping families understand XLH.

Watch the expert videos

Hear how others started the XLH conversation

Listen to real people living with XLH share how they discovered XLH in their family and how those conversations encouraged others to speak with their doctor.

Watch real family experiences

Dr. Dunbar, Emily, and Connie speak on behalf of and receive compensation from Kyowa Kirin for their engagements.

DISCOVER WHO ELSE IN YOUR FAMILY MAY HAVE XLH

Build your family tree

Use an interactive XLH Family Tree tool to explore how XLH may have been passed through your family. See which relatives may have XLH and learn why sharing what you know can make a difference.

Start building your family tree

For educational purposes only. For diagnosis, please speak with your doctor.

ORDER YOUR FREE XLH CONVERSATION CARDS

Make the conversation feel easier

Use these cards to explore XLH topics like inheritance, symptoms, testing, care, and support. Each card includes a question or activity to help you talk about XLH with your family.

Order your XLH Conversation Cards

Shipping costs are included. These cards are for educational purposes only. For individual questions, please speak with your doctor.

FIND A DOCTOR WHO UNDERSTANDS XLH

XLH is a rare disease, so it helps to see a doctor who knows how to diagnose and manage it. Use the XLH Specialist Finder to help your family members find a doctor near them.

From left to right: **Karabeth, Jason, Alice, Sunindiya, Raquel,** and **Shannon.**
Alice and Shannon inherited XLH.
Karabeth, Jason, Sunindiya, and Raquel have spontaneous XLH.

Find an XLH specialist

Kyowa Kirin

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