ADVOCACY TOOLKIT

Be the LINK to Change

XLH NETWORK

Table of Contents


XLH Day 2023 Los Angeles

What is XLH

X-linked hypophosphatemia (XLH) is a hereditary, progressive, and lifelong rare genetic disease that affects up to 1 in 20,000 people, with approximately 12,000 - 16,000 in the United States. XLH can affect the bones, muscles, and teeth of both children and adults. Hypophosphatemia is a condition caused by a low level of phosphorus in the blood. XLH is often inherited, however 20% to 30% of people develop XLH as a result of a spontaneous mutation.

Who is the XLH Network

The XLH Network was founded in November 1996 as a volunteer group of people affected by or interested in XLH, or X-Linked Hypophosphatemia. Today we're incorporated as a 501(c)(3) tax-exempt charity - making all donations tax deductible to the fullest extent allowed by law. We are the first organization in the world specifically dedicated to XLH. The XLH Network is helping thousands of people who are affected by or interested in XLH and related disorders of phosphate wasting. Our website provides information to people around the world with up-to-date information on diagnosis, treatment and the very latest research.
XLH Network Inc. membership is growing daily, and members have available to them a variety of tools that help connect patients with each other, and with clinicians and researchers as well.

XLH Facts

- What does XLH mean? XL stands for X-linked which means that the condition is most often passed down through the X chromosome. H stands for hypophosphatemia.

- XLH is a hereditary progressive disease that affects up to 1 in 20,000 people.

- XLH is caused by a genetic mutation. This gene mutation causes the body to produce too much of a hormone called fibroblast growth factor 23 (FGF23).

- Extra FGF23 makes the body release too much phosphorus through the urine.

- When phosphorus levels in the blood drop too low, this is known as hypophosphatemia

- XLH is often passed down, but not always. 20% to 30% of people develop XLH as a result of a spontaneous mutation.

- XLH is a whole body/whole life disease.

- Some XLH childhood symptoms include: Rickets and osteomalacia, delays in walking, short stature, bowed legs or knock knees, irregularities in the shape of the head, dental abscesses or tooth loss, muscle pain and weakness, bone and joint pain, and fatigue.

- Some XLH adult symptoms include: Hearing loss, osteomalacia, hardening of ligaments or tendons, fractures and pseudofractures, muscle pain and weakness, bone and joint pain, and fatigue.

- XLH is diagnosed by your doctor collecting blood samples to measure phosphorus levels, genetic testing, or x-rays to evaluate the condition of the bones.

XLH NETWORK

XLH Awareness Day is recognized every June 23rd. This awareness campaign is meant to increase recognition of XLH and the symptoms, promote early diagnosis and treatment, and improve the quality of life for those living with this lifelong disease. This day is recogized in the United States, Canada, and many Latin American countries.

Whether advocacy work is second nature to you or you’re just getting started, you already have the most important tool you need, your personal story. As a partner, organization, patient, or caregiver, we are grateful for your participation. Your voice WILL be the LINK to change.

This toolkit is designed to assist you in your advocacy efforts to help raise awareness for XLH. It will provide you with the tools you need to get started, post to social media, reach out to the local media, host an event, and engage legislators.

If you have additional questions or need help finding a resource please email shannon.sharp@xlhnetwork.org

Ways to get involved

There are many ways to advocate and help raise awareness about XLH including:

- Sharing information about XLH through various channels like websites, blogs, newsletters, social media like Facebook, Instagram, and more. We have included tips, shareable graphics, and language you can use in this toolkit.

- Sharing this awareness campaign and toolkit with other advocates, health care professionals, and researchers and encouraging them to join the movement.

- Organizing an event during XLH Awareness Month. Look for the section in the toolkit on hosting an XLH meet and greet.

- Legislative Advocacy such as writing letters, making telephone calls, sending emails, attending town halls, or having personal meetings. These are all opportunities to share your story and struggles with living with XLH.

- Not all advocates are XLHers or caregivers. Healthcare facilities, other organizations, or businesses can become official partners.

Please email Shannon.sharp@xlhnetwork.org
for more information on how to join.

XLH Awareness Campaign Partners

There’s strength in numbers, so for your XLH Awareness Day outreach consider joining forces as an XLH Awareness Campaign Partner.

This could include anyone interested in raising awareness about XLH such as private businesses, health professionals, hospitals, universities, research institutions, local community groups, non-profit organizations, and many more.

If you or your organization would like to join forces please contact shannon.sharp@xlhnetwork.org.

Why do you need an Advocacy story?

Real life stories are able to evoke a far more powerful response than bland facts because they touch our humanities; the same thing happens when you share your story. When you share your story with stakeholders, it helps them remember that when decisions about healthcare are being made, they affect real lives. Sharing your story puts a very real face on the issues that are important to our community.

How to tell your story

Be brief. Whether in writing or presented in a meeting, you want to be brief in sharing your story. The human attention span is not a long one.

Tell a story. Every book or movie has a great character that has a challenge they must overcome. Who are the characters in your story and what challenge must be overcome?

Ways to overcome the challenge. Everyone wants to see a happy ending. Share how the listener can take part in the solution in your story.

Be clear. Not everyone knows medical language or acronyms. When introducing your diagnosis or treatments offer an explanation to avoid any confusion.

Write it down. We can all get carried away when sharing our story. It helps to write it down before hand and practice all the important points that you think are necessary. When writing your story:

- Begin with who you are
- Set the stage of your story
- Include the challenge or obstacle that is preventing you from receiving your best care
- Finish with how that challenge or obstacle can be overcome and how the listener can help

Rare Disease Week on Capitol Hill 2024

Advocacy Outlets

XLH Network Website *xlhnetwork.org*

Share the XLH Network website with the community, friends, family, organizations, or healthcare professionals. By sharing this website they can learn more about XLH, what the organization does, how they can help further our mission, and raise awareness.

Social Media

Your social media accounts, whether they are on Facebook, Instagram, or LinkedIn, are the best places to feature your advocacy work online. Posting on social media is a key way to give your followers more insight to what challenges the XLH community faces.

- Use campaign graphics to give your post visual interest
- Link your post to www.xlhnetwork.org
- Use the official hashtags in your post #XLHDAY25

Sample posts:

- Approximately 12,000 to 16,000 Americans are living with X-linked hypophosphatemia (XLH).
- I advocate for the XLH community to help promote earlier diagnosis, treatment, and improve the quality of life for people living with XLH.
- Did you know that it is a myth that XLH is just a childhood disease? XLH is a whole body/whole life disease.
- The PHEX mutation which causes XLH is found on the 23rd chromosome. Because of this we celebrate XLH Awareness Day on June 23rd.

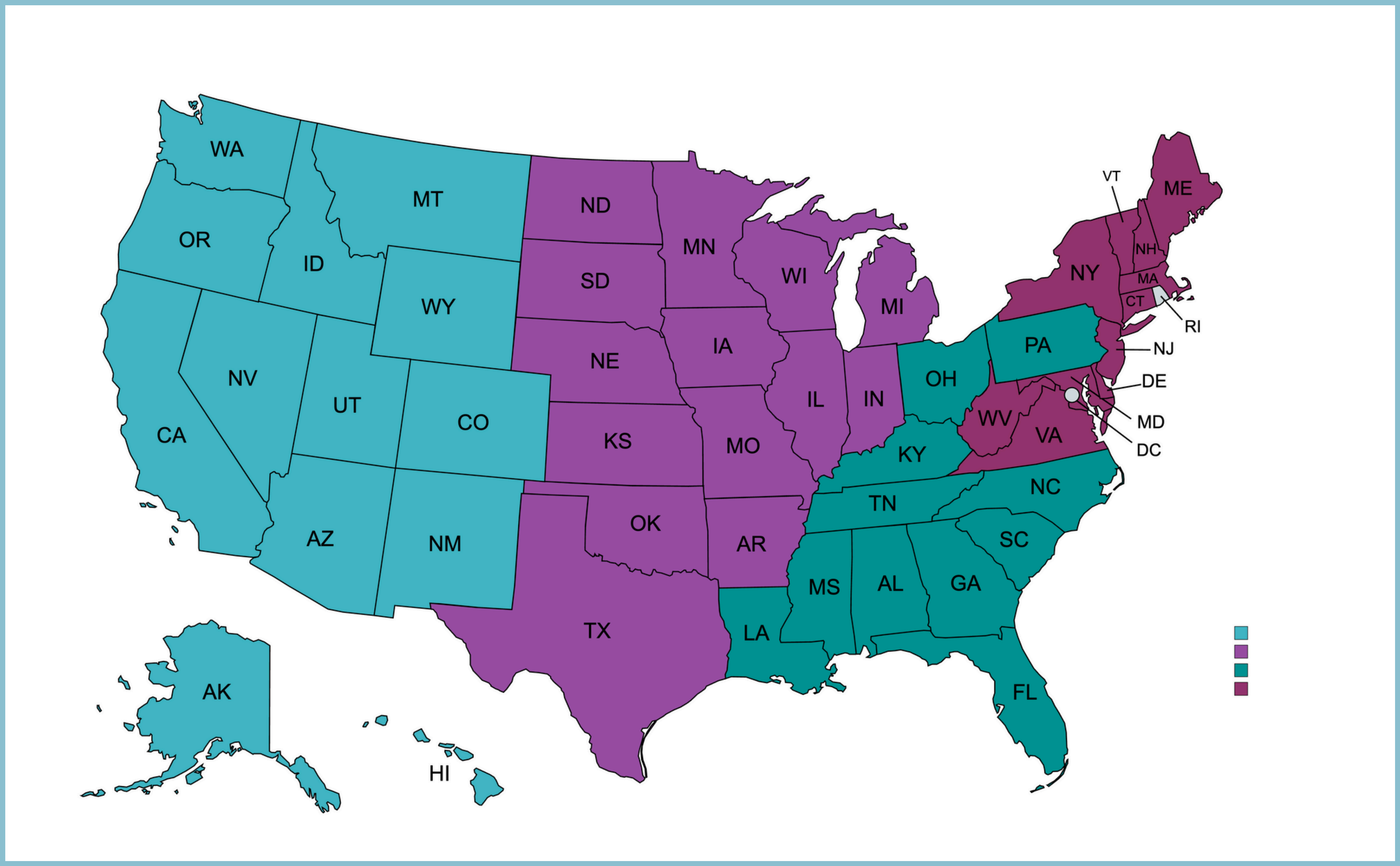
Videos

A video is a great way of sharing your XLH story. Post it on your social media page. Here are a few examples of things you can talk about.

- Tell how you were diagnosed
- Tell about XLH
- Share how you accomplish every day activities living with XLH

Host an Event in June

You can observe XLH Awareness Day on June 23 or on another day during XLH Awareness Month in June. Whether you already have events planned, or are looking for new opportunities to engage the community and press, this kit can help you increase the momentum of the campaign. Host a Regional Meet-and-Greet in your area and receive $250 to help pay for rent on a space, food for the event, or activities. Reach out to your Regional Lead for more details.



Region 1 - Logan Rath email: region1@xlhnetwork.org

Region 2 - Kathy Klase email: region2@xlhnetwork.org

Region 3 - Rebecca Fields email: region3@xlhnetwork.org

Region 4 - Shannon Sharp email: region4@xlhnetwork.org

Marketing the Event

Signage

Contact your Regional Lead to have a promotional poster customized for your regional meet-and-greet. The XLH Network will also advertise on social media and email all members in your area.

Regional Meet and Greet
XLH Awareness Month
Date and Time

Place: Location

RSVP : Regional Lead email

XLH patients, family, and caregivers please join us as we come together to get to know each other and offer support.

A light lunch will be provided. Please bring a side dish or dessert.

Place: Martin "Marty" L. Snook Memorial Park
Washington County Parks
1307 South Potomac Street
Hagerstown, MD

When: Saturday June 28, 2025

Time: 12p – 8p

Swimming pool will be open at a minimal additional costs:

- Adults $5
- K-12 $4
- Pre-K $3
- Senior Citizens $4

RSVP : Shirley.Brown@xlhnetwork.org

Engaging Traditional Media

Feature Story

Reach out to local journalists and ask them to feature your XLH story as a feature story for XLH Awareness Month/Day. A patient story will help readers relate to the disease and make them more willing to learn and share the information. Ask them to cover your XLH Awareness Month event if you plan one.

Example:

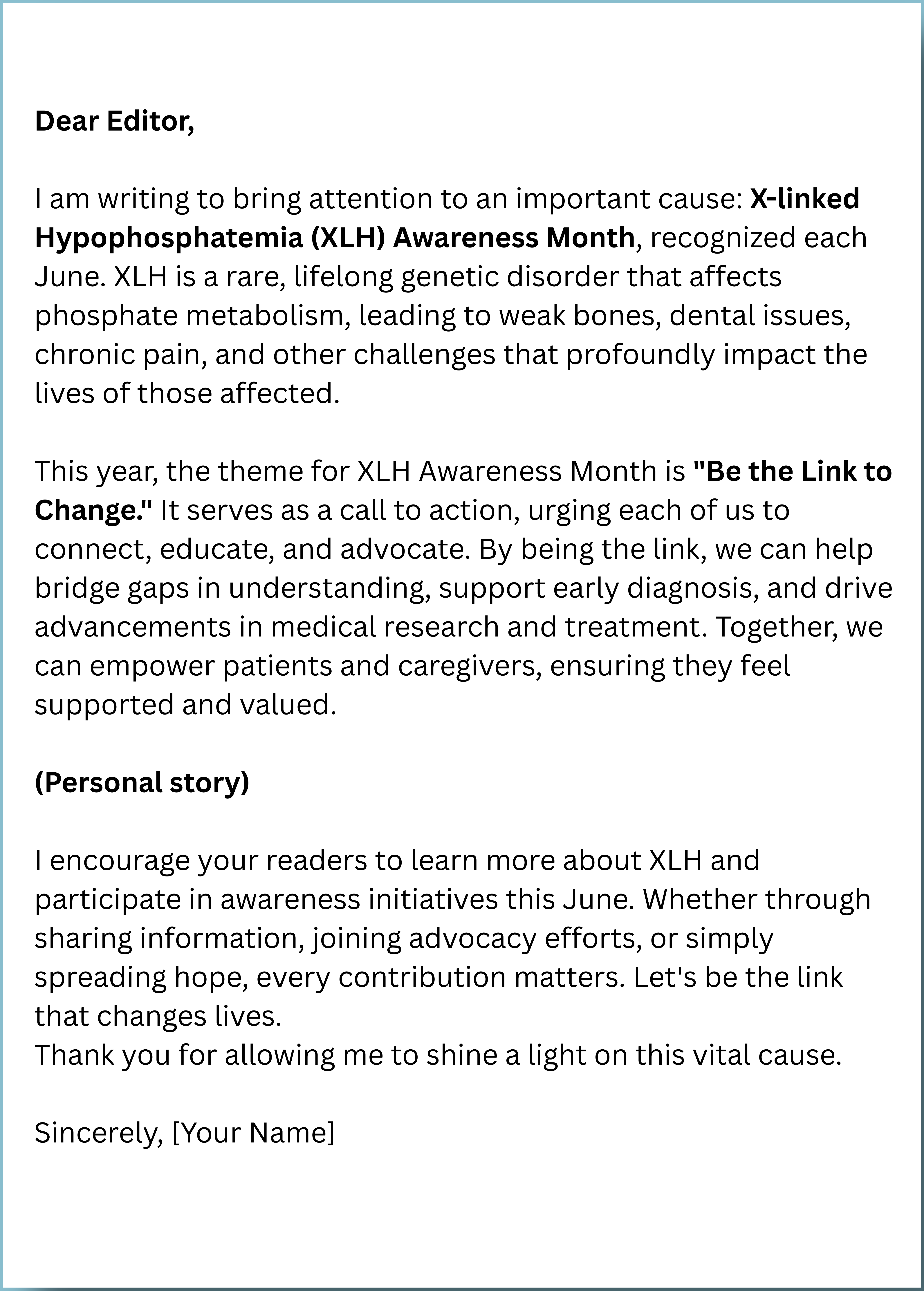
https://northpennnow.com/news/2025/feb/28/upper-gwynedd-mother-daughter-duo-takes-on-xlh-a-legacy-of-resilience/

ox47.com/news/local/girl-with-rare-bone-disease-tries-new-fda-approved-drug-shows-miraculous-improvement?fbclid=IwY2xjawJIMzJleHRuA2FlbQIxMQABHZYh7jc-HHDqrTJK9ufM6hFw7_SC9WOW6tKGyG2vdx03Q5EqC-Pu9ttS7w_aem_GtRa8_zFpeNg6tdc_QBANg

https://eldoradospringsmo.com/front-page/the-fight-of-a-lifetime/

Letter to the Editor or Press Release

This is a great way to raise visibility and awareness for XLH. Include a patient story and educational information from an expert. Include a call-to-action that directs readers to the XLH Network website.



Dear Editor,

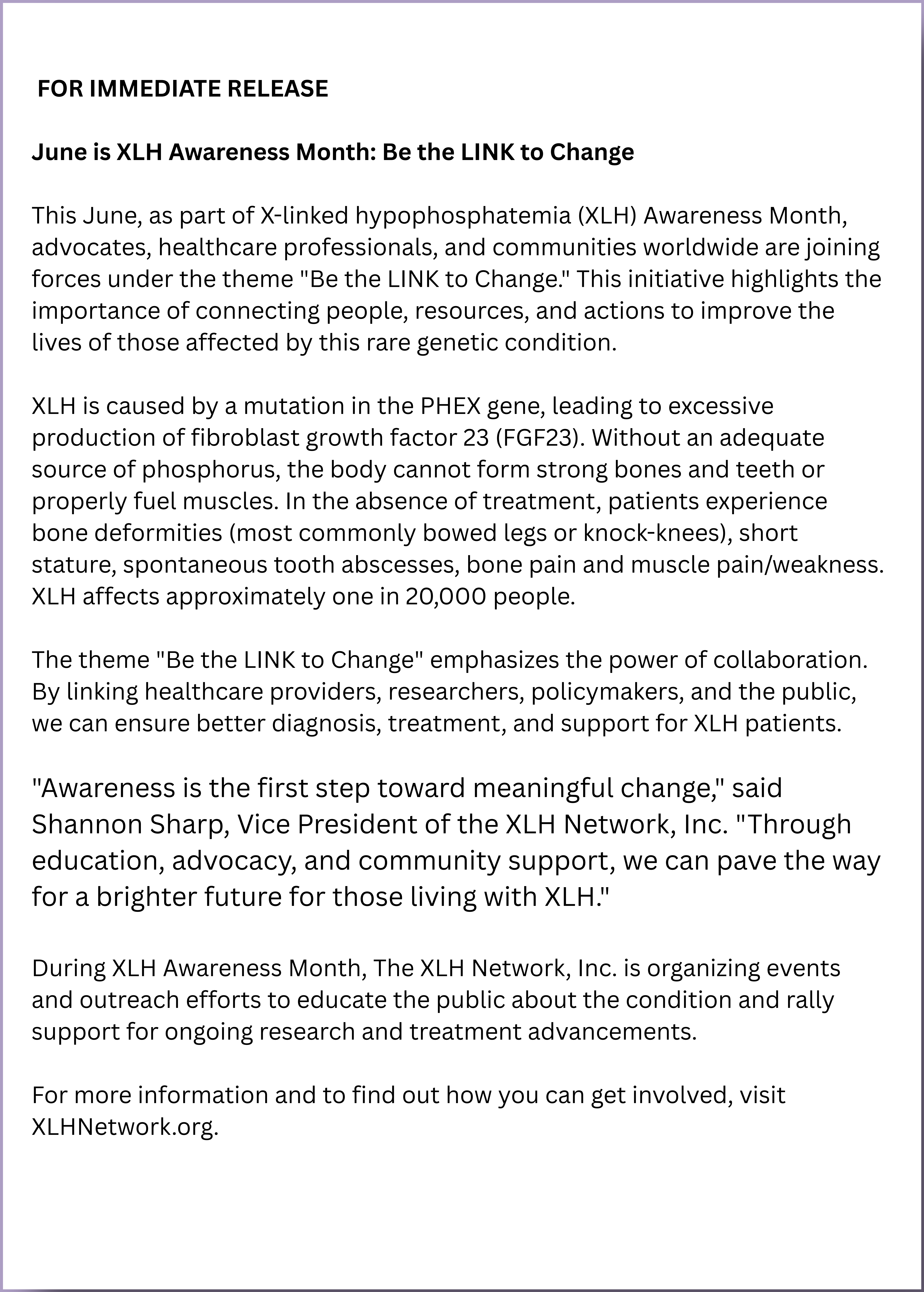
I am writing to bring attention to an important cause: **X-linked Hypophosphatemia (XLH) Awareness Month**, recognized each June. XLH is a rare, lifelong genetic disorder that affects phosphate metabolism, leading to weak bones, dental issues, chronic pain, and other challenges that profoundly impact the lives of those affected.

This year, the theme for XLH Awareness Month is **"Be the Link to Change."** It serves as a call to action, urging each of us to connect, educate, and advocate. By being the link, we can help bridge gaps in understanding, support early diagnosis, and drive advancements in medical research and treatment. Together, we can empower patients and caregivers, ensuring they feel supported and valued.

(Personal story)

I encourage your readers to learn more about XLH and participate in awareness initiatives this June. Whether through sharing information, joining advocacy efforts, or simply spreading hope, every contribution matters. Let's be the link that changes lives.
Thank you for allowing me to shine a light on this vital cause.

Sincerely, [Your Name]



FOR IMMEDIATE RELEASE

June is XLH Awareness Month: Be the LINK to Change

This June, as part of X-linked hypophosphatemia (XLH) Awareness Month, advocates, healthcare professionals, and communities worldwide are joining forces under the theme "Be the LINK to Change." This initiative highlights the importance of connecting people, resources, and actions to improve the lives of those affected by this rare genetic condition.

XLH is caused by a mutation in the PHEX gene, leading to excessive production of fibroblast growth factor 23 (FGF23). Without an adequate source of phosphorus, the body cannot form strong bones and teeth or properly fuel muscles. In the absence of treatment, patients experience bone deformities (most commonly bowed legs or knock-knees), short stature, spontaneous tooth abscesses, bone pain and muscle pain/weakness. XLH affects approximately one in 20,000 people.

The theme "Be the LINK to Change" emphasizes the power of collaboration. By linking healthcare providers, researchers, policymakers, and the public, we can ensure better diagnosis, treatment, and support for XLH patients.

"Awareness is the first step toward meaningful change," said Shannon Sharp, Vice President of the XLH Network, Inc. "Through education, advocacy, and community support, we can pave the way for a brighter future for those living with XLH."

During XLH Awareness Month, The XLH Network, Inc. is organizing events and outreach efforts to educate the public about the condition and rally support for ongoing research and treatment advancements.

For more information and to find out how you can get involved, visit XLHNetwork.org.

Legislative Advocacy

Contacting your Member of Congress

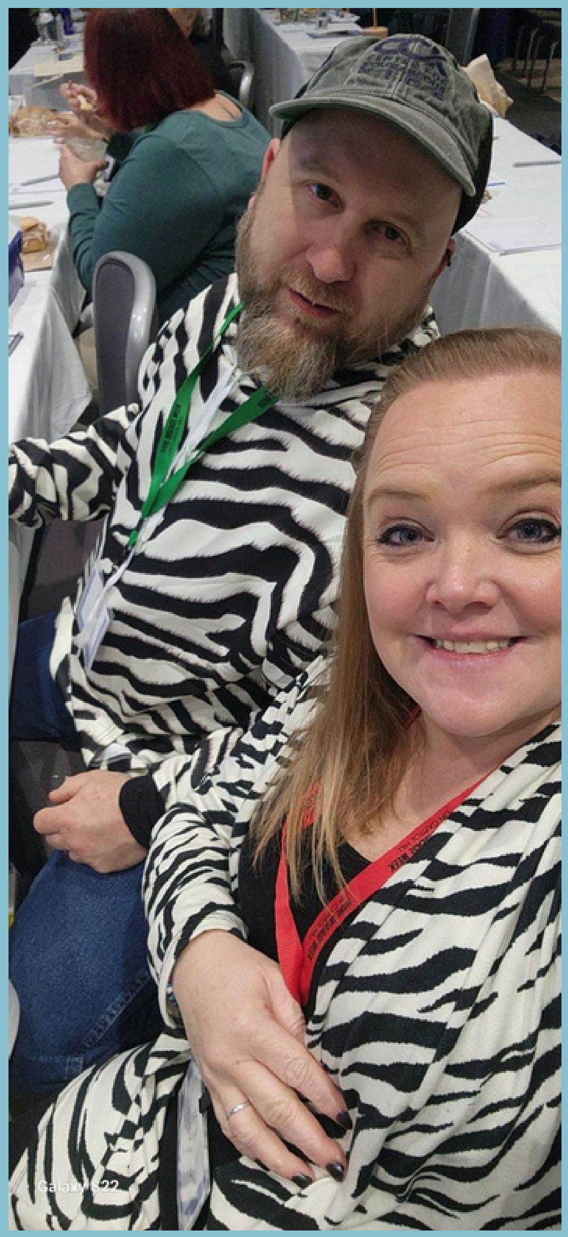
As an XLH advocate you are a very important part of the legislative process. You can make a difference by making your voice heard by your Senators and Representative.

- Send an email, letter, or call – tell your story briefly, ask for their support with specific pieces of legislation or issues, and share how they can help the rare disease community.

Personal Meetings

The XLH Network offers yearly virtual meetings with your members of Congress. During these meetings you will have the opportunity to tell your XLH journey and ask your member of Congress for support regarding policies that could make an impact in the life of rare disease.

There are other opportunities throughout the year to meet with your member of Congress like Rare Disease Week on Capitol Hill sponsored by Everylife Foundation and Rare Across America by Rare Disease Legislative Advocates.



XLH
Awareness
Day
Resources

Logos

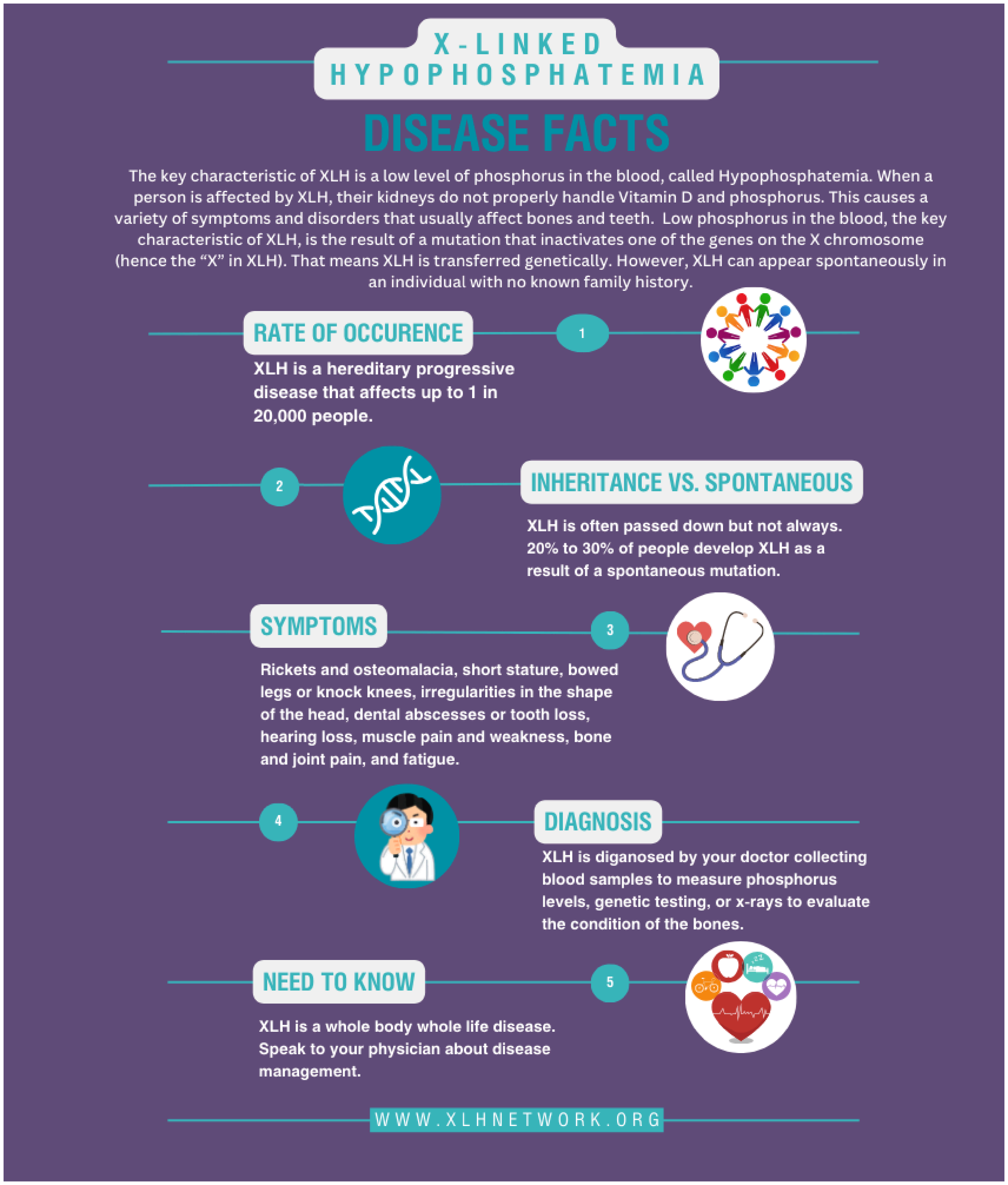
The XLH Awareness Day logo is the official logo of the XLH Awareness Day 2025 campaign and is designed to be used in awareness day outreach. We hope you use this on your social media, event materials, or press outreach.

Please note:

- Logos cannot be altered in any way.
- It should not be used for commercial purposes.
- The logo should only be used for education and advocacy purposes for this campaign as outlined in this document.

Infographics

The infographics below and on the following page lay out the burden of XLH. Some information is based on results from a recent XLH Community Impact Survey performed by Kyowa Kirin and the XLH Network. The attached infographics can be downloaded and used in campaign outreach.



X-LINKED HYPOPHOSPHATEMIA

DISEASE FACTS

The key characteristic of XLH is a low level of phosphorus in the blood, called Hypophosphatemia. When a person is affected by XLH, their kidneys do not properly handle Vitamin D and phosphorus. This causes a variety of symptoms and disorders that usually affect bones and teeth. Low phosphorus in the blood, the key characteristic of XLH, is the result of a mutation that inactivates one of the genes on the X chromosome (hence the “X” in XLH). That means XLH is transferred genetically. However, XLH can appear spontaneously in an individual with no known family history.

RATE OF OCCURENCE

1

XLH is a hereditary progressive disease that affects up to 1 in 20,000 people.

2

INHERITANCE VS. SPONTANEOUS

XLH is often passed down but not always. 20% to 30% of people develop XLH as a result of a spontaneous mutation.

SYMPTOMS

3

Rickets and osteomalacia, short stature, bowed legs or knock knees, irregularities in the shape of the head, dental abscesses or tooth loss, hearing loss, muscle pain and weakness, bone and joint pain, and fatigue.

4

DIAGNOSIS

XLH is diganosed by your doctor collecting blood samples to measure phosphorus levels, genetic testing, or x-rays to evaluate the condition of the bones.

NEED TO KNOW

5

XLH is a whole body whole life disease. Speak to your physician about disease management.

WWW.XLHNETWORK.ORG

Dental Impact of XLH: Far-Reaching and Costly

Results from the XLH Community Impact Survey

Teeth can define a smile and be part of one's identity. Dental health is also an important aspect of physical health and can be an indicator of other serious health conditions.[1] People with X-linked hypophosphatemia (XLH), a rare metabolic bone disorder, have lower than normal phosphorus levels, which affects the strength of their bones – including their teeth. Despite most people living with XLH (also known as XLHers) having dental insurance, dental issues can cost them dearly – physically and financially.
The XLH Community Impact Survey is a collaborative initiative between Kyowa Kirin, Inc. and The XLH Network to characterize the broader impact and lived experiences of people with XLH in the U.S.

The survey was fielded between Nov. 2023 and Feb. 2024, and included an online survey (56 adult XLHers, 29 caregivers of child XLHers, and 2 child XLHers) and interviews (36 adults and 20 caregivers), and reflected the experiences of XLHers 2 - 69 years of age. Respondents answered questions about types and impact of dental issues, dental care providers, dental insurance coverage and deductibles, and out-of-pocket expenses for dental care.

Dental issues in people with XLH are common and appear early

97% & **75%**
of adults of children
reported at least 1 dental issue:

- Cavities
- Poor enamel
- Abscesses
- Early tooth loss
- Delayed tooth growth

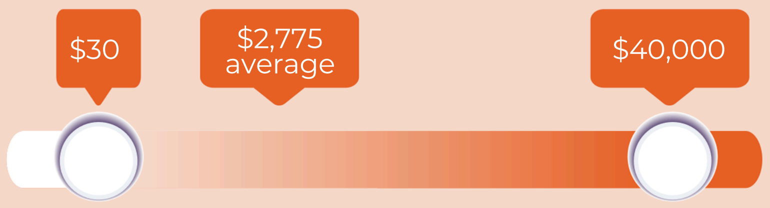
On average, dental issues first appeared at age **4**

Required dental procedures are expensive

XLHers underwent extractions, crowns, and root canals

61% of XLHers paid out-of-pocket for dental expenses last year:

Reported cost range:



Finding knowledgeable dental providers is essential

75% said their dentist is receptive to learning about XLH,

yet rated the XLH knowledge of their dental provider at only a 5 on a scale of 1-10
1 = extremely poor
10 = excellent

Learn more today:

Find resources at XLHlink.com or XLHnetwork.org

Connect with The XLH Network on social media

Contact publicaffairs.na@kyowakirin.com for more info about the XLH Community Impact Survey

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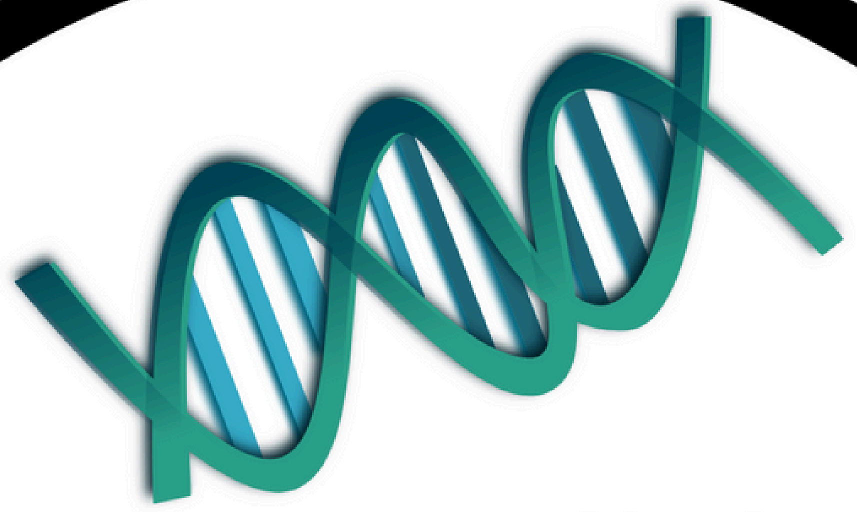
1. DDS, Matthew J. Messina. *"Health Issues a Dentist Can Identify by Looking in Your Mouth."* Ohio State Health and Discovery, The Ohio State University, 15 May 2023, health.osu.edu/health/dental-health/health-issues-a-dentist-can-identify.

COR-US-RDS-0076 June 2024

Selfie Sign

We encourage you to engage on XLH Awareness Day by taking a selfie and sharing your story on social media. The *'I Became a Link'* Selfie Sign is an easy way to show your support.



I became a link for change and advocated for XLH Awareness Day 2025.

XLH NETWORK

June 23, 2025