



Summer 2023 Newsletter

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June is XLH Awareness Month and we have so much to share with you! It's going to be a full month of activities designed to raise awareness of XLH and also honor our communities and families living with XLH. Keep reading to find out how you can participate.



RAISE YOUR VOICE ON JUNE 23RD!

You are the key to changing legislative policy. XLH Awareness Day on Capitol Hill gives you an opportunity to meet members of Congress or staff and tell your



4TH ANNUAL CROSS COUNTRY CHALLENGE

Join us as we get our kicks on Route 66 this year. We will begin our 4th Annual Cross Country Challenge in Chicago and head west to Los Angeles.

rare disease story. Every voice matters and through raising our voices we can make a difference.

We will have a one-hour training the week before the event. One-on-one meetings will be available if wanted. Please plan to be available all day on **June 23rd** as meetings are scheduled around your member of Congress.

Register using the link below:

Register for Capitol Hill

Registration for the race begins on **June 23**. The race will officially begin July 4th and end on September 22 when we meet up in Los Angeles. Form a team of 10 members or join one of our teams of individuals who are looking for teammates! Registration fee is \$25. Add on an optional t-shirt for \$15

Registration opens June 23rd. Watch our web site and social media pages for the registration link.

XLH Day in Sunny California



This year's XLH Day promises to be one of our best ever! We'll start early on Friday 9/22 with a social event at an accessible beach house with a swimming pool. Lunch, activities and transportation from the hotel and back are provided.

On Saturday we'll have a rich educational program with customizable breakout sessions so you can attend the topics most important to you and your family. From the latest in XLH research to dental issues, school 504 plans, and pain management, we will have it all!

A sit-down dinner with music and a live D.J. will be on the agenda for Saturday night, and on Sunday morning we will bid you all a fond farewell over breakfast.

Cost is \$30 for adults, \$20 for ages 5 thru 17. Children 4 and under are free. Families of 4: \$80.

Registration will open on 6/15/23. Check our website for updates and registration link. Limited scholarships are available.

Did you know? The XLH Network has been in operation for 27 years, now serving over 2000 members. Help us continue to grow by donating today.

Donate to the XLH Network



XLH KIDS CAMP

It's almost, but not completely too late to sign up for XLH Kids Camp in July. There are still a few spots left. Volunteers are also welcome and needed. For more info, please email shannon.sharp@xlhnetwork.org.

Download for
Facebook

Download for
Instagram

Raise Awareness on Social Media!

Click the links on the left to download your own PDF copy of the XLH Awareness Banner. Available for Facebook and Instagram. Use it to raise awareness or set up a donation for the XLH Network. *(note: files will need to be converted to images once downloaded).*

New Website On the Way!

We have upgraded our website and we will be rolling it out during the month of June. New features include:

Member Portal: Think of it like a Facebook group, but for everyone.

Store: Grab your XLH Network Merch!

Event Calendar, Newsletter Archives, expanded research section and so much more!



Learn About XLH

X-Linked Hypophosphatemia (XLH) is a rare genetic disorder affecting about one in 20,000 people.

[READ MORE](#)



Find a Doctor

Since XLH is a rare genetic disease, it can be difficult to find doctors with relevant experience diagnosing and treating XLH.

[READ MORE](#)



Join Our Community

Become a member of the XLH Network today. The XLH Network is the main hub of connection and support for those living with XLH.

[READ MORE](#)

SNEAK PREVIEW

DATES TO REMEMBER

JUNE 1ST - 30TH is XLH Awareness Month

JUNE 9th - Last day to register for Virtual XLH Awareness Day on Capitol Hill

JUNE 15th - Registration for XLH Day opens

JUNE 23rd - XLH Awareness Day, Virtual Day on Capitol Hill, Cross Country Challenge Registration Opens

JULY 4th - Cross Country Challenge Begins

On-going Groups

Aging with XLH
An online support group focused on managing XLH over age 45(ish). Open to all this confidential group is facilitated by member Kelly Rushing and Executive Director Susan Fattos

AGING WITH XLH

An ongoing support group for XLHers 45 years and older. Meets on the third Tuesday of each month. Next meeting: June 20th.

[Register for Aging Group](#)

Men's Group
Wednesday, May 17th
8:00 - 9:30pm Eastern Time
For men only, this group is a safe and confidential space to discuss issues related to XLH. It will be facilitated by XLH Network board members Chris Younger and Geoff Edelson.
Click to register or follow link below

MENS GROUP

For males of all ages living with XLH. Meets quarterly. Next meeting: August 16th.

[Register for Men's Group](#)

Parent's Group
For parents of a child with spontaneous XLH
SPECIAL GUEST: John Duncombe PT, DPT
8:00 PM Eastern Time
7:00 PM Central Time
6:00 PM Mountain Time
5:00 PM Pacific Time
Parents of children with spontaneous XLH have a different path to go down than those with XLH already in their families. This ongoing, confidential group is designed to offer support to those parents, whether their children are newly-diagnosed or teens.

SPONTANEOUS PARENTS GROUP


For the parents of children with a spontaneous case of XLH. Meets quarterly. Next meeting: July 12th.

[Register for Spontaneous Group](#)

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