

NETWORK NEWS

Spring -Summer 2021

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Just in the nick of time, we're getting our Spring/Summer newsletter out! Read about our main summer event, The Cross-Country Challenge. Learn how you can join us in celebrating XLH Awareness Day on June 23rd. Catch up on the latest XLH Research, and check out our Coming Events section to save the dates for the second half of 2021 as we continue to celebrate our 25th Anniversary. Happy Reading! -Susan

COMING EVENTS

MONDAY, JUNE 14TH:

REGISTRATION FOR THE CROSS
COUNTRY CHALLENGE BEGINS.

SCROLL DOWN FOR MORE
INFO.

TUESDAY JUNE 22ND:

GROUP FOR PARENTS OF
CHILDREN WITH SPONTANEOUS
XLH.

WEDNESDAY JUNE 23RD:

XLH AWARENESS DAY AND
CROSS COUNTRY CHALLENGE
KICK-OFF ON ZOOM.

FROM OUR PRESIDENT BILL COOGAN

Hello everyone. My name is Bill Coogan and I am currently the President of The XLH Network Inc.

I joined the organization in February of 2011. Three members of my immediate family have XLH and I joined in their honor. I wanted to be of any help that I could and at the same time learn all that I could about the disorder.

During my tenure, I have had the honor and privilege to be Treasurer, then Vice President and finally President. It has been a very interesting time of service and I have had the privilege of working beside very talented, devoted Board members, Medical Doctors, and Clinical researchers. We have all had the same goal in mind and that is to be of assistance to our members and their families in any way possible.

During those ten years I have seen our membership grow, seen us conduct many educational/social events for our members throughout the USA, personally meet many of you over the years, and see a medication become available to those with XLH and learn of how it has had a positive impact on your lives. All of this has made me very proud to be a member of the Network. It is something that I can look back at over time and feel that I have made some small contribution to this worthy organization and it's members.

I am certain that the future of the Network will be a very promising one since I know that my fellow Directors and our Executive Director have the talent to make the organization bigger and better with each year.

I would like to wish you all an enjoyable Spring and Summer. Be well. Thank you for the opportunity to represent and serve you.

Bill

Our 25th Anniversary



In honor of the 25th anniversary of The XLH Network, Inc., we are launching a special fundraising campaign! Our goal is to raise \$250,000 to take us into the next quarter century! Given how far we've come and how much we've accomplished over the past 25 years, we know we can do more if we have the capacity!

Where are we now, after 25 years?

- We are 2,500 members strong;
- We have two part-time staff including an Executive Director;
- We have started and grown from XLH Days to Weekends to Weeks;
- We have virtual programming, like yoga, Coffee Chats, and Bingo nights;
- We have brought in specialists to address member's concerns such as hearing loss and disability insurance; and
- We have started affinity groups, for men, and for caregivers of Spontaneous XLHers!

Where can we be, with more capacity?

- We can reach more people affected by XLH in remote areas;
- We can start regional chapters and hold regional events;
- We can increase the frequency and type of programming and affinity groups;
- We can more effectively advocate for legislation like the Ensuring Lasting Smiles Act, and for early diagnosis and new treatment;
- We can fund research; and
- We can engage more members as volunteers!

To do this, we need your help! How can you help?

- Donate!
- Become an XLH Ambassador! Do you have a fundraising idea?
Are you active on Social Media? Help us engage members in the campaign!

· For more information or to get involved, contact Sunindiya.Bhalla@xlhnetwork.org

2nd
Annual



XLH Cross-Country Challenge 2021



2nd Annual Cross-Country Challenge

On your mark! Get set! Go!!! It's time for the Second Annual Cross Country Challenge, XLHCCC.

Are you ready to join us? Have you started thinking about who will be on your team and what your team name will be? The Cross Country Challenge registration will open Monday June 14th! The event begins June 23rd and will run for 6 weeks. This year's theme is "Go the X-tra mile for XLH!"

Here is what you need to know:

- Register as an individual or a team, but it is a team activity. We will put those who register individually on a team which is a great way to meet others!
- Registration fee is \$25/person or \$225 if you register a team of 10. Remember this is not only a challenge but a fundraiser for the XLH Network
- Official XLHCCC t-shirts are available to purchase at the time of registration.
- Points will be awarded for physical activities, fundraising, and non-physical activities.
- Personal fitness devices connect directly to platform this year.
- Prizes, friendship, and fun are guaranteed! We want you to join us this year! Since this is the Network's 25th anniversary year, we have set our fundraising goal at \$25,000. Will you help us do that?

Registration opens Monday, June 14th at noon Eastern Time, Click here to register: [REGISTER XLHCCC](#)

[Click Here to Donate Now to our 25th Anniversary Campaign](#)

Recommended by our Scientific Advisory Board:

[A breakdown of the differentiating clinical features between XLH and TIO](#)

[A Recent Compilation of Adult Complications and their Frequency](#)

[Patient-Reported Outcomes in Children with XLH \(from a randomized trial of burosumab vs. conventional therapy\)](#)



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