



Welcome to The XLH Network's Spring and Summer Newsletter!

This season is shaping up to be one of our busiest ever at the Network...full of connection, learning, and community, and we are excited to share what's ahead.

In this issue, you'll find information about upcoming events, news from The XLH Network, important updates, and opportunities to stay involved.

Make sure to keep this newsletter handy for important dates in 2026!

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# XLH Day 2026



## Join Us in Indianapolis

People often talk about finding their "people" when they come to XLH Day for the first time. So our mascot this year is "Hope"...the rare disease zebra proudly sporting XLH Network colors. She'll be leading the way to Indy, where we will have amazing speakers, networking and social opportunities, a trip to the zoo, and so much more! Watch our social media pages and your email for information about the weekend's agenda, how to register, etc. Registration will open on June 23rd. Follow Hope to XLH Day 2026!

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[Donate to the Network](#)

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**SAVE THE DATE**  
**XLH CAMP**  
**JULY 21-25, 2026**

**Join us at our summer camp!**

Summer Fun Awaits for an unforgettable season of excitement, friendship, and adventure!

- ✓ Outdoor Exploration
- ✓ Sports & Games
- ✓ Creative Arts & Crafts
- ✓ Campfire Nights

More details—including registration information, —will be shared soon.

## XLH Summer Camp

We are excited to announce that XLH Camp is just around the corner! Taking place July 21–25, this special week brings together children and families affected by XLH for an unforgettable experience filled with connection, learning, and fun.

XLH Camp is more than just a summer camp; it's a place where kids can simply be kids, surrounded by others who understand their journey. Campers will enjoy a wide range of activities like outdoor adventures, arts and crafts, bowling, swimming, snorkeling, and classic campfire moments, all in a supportive and accessible environment tailored to their needs.

For families, camp offers a unique opportunity to build lasting friendships, share experiences, and connect with a community that truly “gets it.” Whether it’s a first-time camper or a returning family, everyone leaves with meaningful memories and a stronger sense of belonging.

We can’t wait to see new and familiar faces as we come together for another incredible year of XLH Camp.

## XLH Awareness Day – Raising Voices, Building Community



Each year on XLH Awareness Day, our community comes together to shine a light on XLH. While XLH is lifelong, awareness helps drive earlier diagnosis, better care, and stronger support for individuals and families navigating this journey.

This day is about more than awareness—it's about connection. It's an opportunity to share stories, educate others, and advocate for continued research and improved treatments. Whether you're living with XLH, caring for someone who is, or supporting the community, your voice matters.

This year, we're proud to share that 50 individuals stepped forward as XLH Awareness Ambassadors, helping expand our reach across the country. As part of this effort, ambassadors requested official proclamations from their state governors to recognize June 23 as XLH Awareness Day. In addition, press releases were distributed to local media outlets in each ambassador's community to encourage coverage, spark conversations, and raise public awareness through stories and features. If you would like a copy of the press release to share with media in your area, please email [shannon.sharp@xlhnetwork.org](mailto:shannon.sharp@xlhnetwork.org).

We also challenge you to tell at least one person about XLH on Awareness Day. A single conversation can lead to understanding, earlier diagnosis, and stronger support for those affected.

Finally, join us on the evening of June 23 as we host an educational presentation about XLH and come together to celebrate our community.

Together, we can amplify awareness, inspire action, and strengthen the XLH community.

Please consider making a donation to one of our many projects!

## Regional Meetups

We have several regional gatherings this year, hosted by our amazing volunteers. These are great opportunities to connect with others in your area, learn more about the Network, and just have fun! Good food, good people, good times!

- May 16th, 2026 Elysburg, PA
- May 31st, 2026 San Carlos, CA
- June 6th, 2026 St. Louis, MO

For more information, or if you are interested in hosting an event in your area, please email our Regional Meetup Coordinator, Becky Fields, at [rebecca.fields@xlhnetwork.org](mailto:rebecca.fields@xlhnetwork.org).



**XLH Network Regional Meetup**  
Bay Area, East Bay,  
South Bay & Sacramento Valley

**May 31** 12:00 - 3:00 PM  
San Carlos, CA

Join us for a relaxed, casual, get-together with XLH Network members in your area. Networking, resources, socializing, and some fun activities! For more details, or to sign up, send an email to: [susan.faitos@xlhnetwork.org](mailto:susan.faitos@xlhnetwork.org)

**ST. LOUIS REGIONAL MEET-UP**

**JUNE 6, 2026**  
NOON - 4:00PM

OLDE TOWNE PARK  
PAVILION C  
1 PARK STREET  
SAINT PETERS, MO 63376

Lunch meat and chips will be provided. Bring a side or dessert.  
RSVP to Becky Fields (317)440-3860 or [rebecca.fields@xlhnetwork.org](mailto:rebecca.fields@xlhnetwork.org).

## New! Peer Support Groups

Our NEW Peer Support Groups will be starting next week. Sessions will be guided by members of The XLH Network who have been specially trained in peer support, along with the help of Dr. Al Freedman, PhD., a psychologist who specializes in helping rare disease families. Please find all of the info below for

our 3 groups and head over to <https://xlhnetwork.org/peer-support/> to register!

### **CAREGIVERS GROUP**

*Third Monday of  
each month.  
7:00pm – 8:30pm  
ET*

Our caregiver group is for adults who care for or support someone living with XLH.

Whether you are a parent, partner, family member, or other caregiver, this is a welcoming and confidential space to connect with others who understand the caregiver experience.

Come share what's working, ask questions, exchange resources, or simply listen and feel less alone.

### **LIVING WITH XLH**

*Third Tuesday of  
the month, 7:00pm  
– 8:30pm ET*

This group is designed to support adults 18 and over who are living with XLH themselves. It offers a confidential, friendly space to connect with others who understand the day-to-day realities of living with XLH — from managing symptoms and appointments to navigating work, relationships, family life, emotional stress, and self-advocacy.

### **NEWLY- DIAGNOSED**

*Meets quarterly.  
First meeting is  
Thursday, May  
21st, 5:30 –  
7:00pm ET*

For families navigating a new XLH diagnosis within the last two years. Whether you are newly diagnosed yourself, supporting a child, or helping a loved one understand what comes next, this group offers a welcoming place to ask questions, share concerns, learn from others, and find connection during the early stages of the XLH journey.

*Did you know you can designate your donation to a specific program within the Network? Email our executive director for more details:  
[Susan.Faitos@xlhnetwork.org](mailto:Susan.Faitos@xlhnetwork.org).*

# Coming Soon:

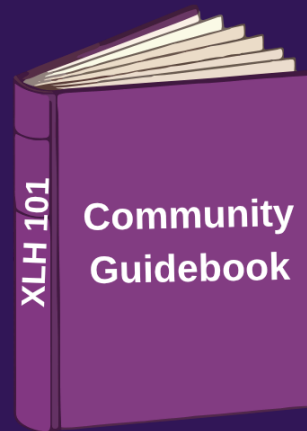


We are thrilled to announce the upcoming launch of our new Patient Registry — an important step forward in building a deeper understanding of XLH and the real-life experiences of those affected.

This registry will give individuals and families in the XLH community an opportunity to share their experiences through surveys and ongoing participation. Over time, this information can help identify patterns, highlight unmet needs, support advocacy, and guide future research focused on improving care and quality of life for people living with XLH.

The registry will help strengthen the voice of the XLH community and provide valuable insight into what it truly means to live with this rare condition.

We look forward to sharing more details soon!



The new XLH Community Guidebook will be a practical, living resource created for (and by) individuals and families affected by XLH.

Developed in partnership with Kyowa Kirin, this guidebook is designed to be more than a one-time publication. Think of it as a growing manual for navigating life with XLH. It will include information, resources, lived-experience insights, and practical guidance to help community members better understand XLH, advocate for care, and find support at different stages of life.

Because knowledge changes, care evolves, and our community continues to learn from one another, the guidebook will be a dynamic resource that is reviewed and updated over time. Our goal is to create something that stays useful, relevant, and responsive to the real experiences and needs of people living with XLH.

Watch our social media pages for announcements about the release of the guidebook!

## Why YOUR Donation Matters

Throughout this newsletter, you've seen donation buttons connected to many of our programs, resources, and upcoming projects. Those buttons are there because The XLH Network depends on donations, grants, and sponsorships to keep this work moving forward.

Your support helps us provide education, peer connection, advocacy, community resources, research initiatives, and events that bring people with XLH together. Every gift, no matter the size, helps us continue building programs that support individuals and families at every stage of their XLH journey.

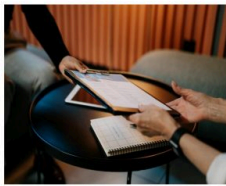
When you donate to The XLH Network, you are helping strengthen the only national organization dedicated specifically to the XLH community.

[Donate Here](#) or use the QR code below. Either way, we appreciate you!!



*Note change in donor platforms:*

*When you donate to the Network now, you may notice that we have switched donor platforms from DonorView to Zeffy. Nothing needs to change on your end...we just wanted to let you know in advance. Thank you!*



## Are you interested in taking part in an interview to help us develop new XLH-specific physical function questions?

We are looking to talk to adults with XLH to get their opinions on two new XLH-specific questions that are being developed for use in clinical trials and in clinical settings. These new questions will help capture the impact of XLH on physical function.

The interviews will be conducted by Spire Outcomes and are expected to last about 20 minutes. If you take part, you will be compensated for your time. Thank you for your consideration.

Your insights are vital to this research!

### Eligibility requirements:

- ✓ Must be an adult, aged 18 years or older.
- ✓ Must have a confirmed diagnosis of XLH and be able to provide documentation of this diagnosis.
- ✓ Must reside in the United States and be fluent in English.

Please follow the link to the eligibility screener survey below to get started today!

[Eligibility Screener Survey](#)

### Have questions?

Contact Spire Outcomes at [XLH@spireoutcomes.com](mailto:XLH@spireoutcomes.com) or the Spire Outcomes study investigator:

**Annabel Bowden**  
Email: [annabel.bowden@spireoutcomes.com](mailto:annabel.bowden@spireoutcomes.com)  
Phone: +1 (325) 399 9094



MED-US-CRV-2620004 Mar2025

## Save the date - Upcoming Online Event

### The Critical Role of Dental Care in XLH

Register to learn more about the role dental care plays in XLH



Jason and Alice, living with XLH  
Jason (f), Alice (m), Lisa (f)

### Dental Care and XLH

XLH can have significant effects on dental health, requiring specialized care and preventive strategies. This session will highlight the importance of dental monitoring and ways to manage oral health challenges.

### The Critical Role of Dental Care in XLH

#### DAY AND TIMES

Tuesday, April 28  
7:30pm ET / 4:30pm PT and  
9:30pm ET / 6:30pm PT

#### LOCATION

Zoom

#### PRESENTER(S)

- Lisa, mother of Alice and wife of Jason, who live with XLH
- Dr. Juan Yepes, DDS, MD

This presentation is brought to you by Kyowa Kirin. The presenters have received compensation for this engagement.



Scan to save your spot or visit [xlhlink.com/patient-events](http://xlhlink.com/patient-events)



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Above: Joely standing with then-president Bill Coogan, receiving her founders award. Baltimore, 2018.

## In Memoriam

In the history of The XLH Network, the story begins with this simple but powerful moment:

*“In 1996, a college student in Minnesota connected online with a man in England and a man in Canada, both of whom were living with XLH.” That college student was Joely Valentine, who recently passed away.*

What began as a few people finding one another across distance and isolation became the beginning of a movement — one that grew into what is now a nearly 30-year-old organization serving individuals and families affected by XLH. We are grateful for those who helped start this movement and laid the foundation for the XLH Network we know today.

We are especially glad we had the opportunity to honor Joely in 2018 at XLH Day in Baltimore and to recognize the role she played in the earliest days of our community.

Judging from the amount of comments on our social media posts, Joely had an impact on many members of our XLH community.

**Our thoughts are with her family and loved ones at this time.**

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