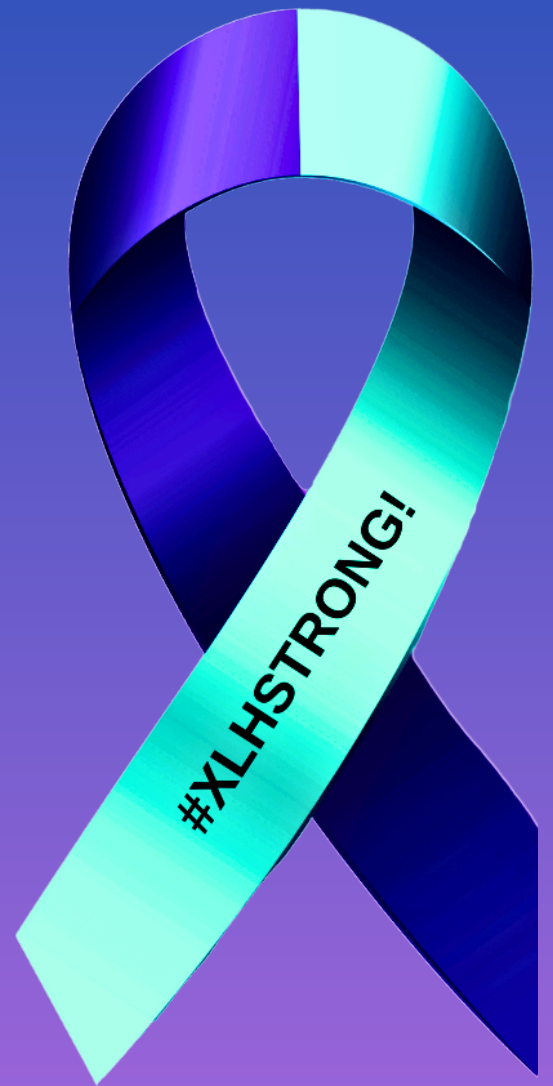


ANNUAL REPORT 2024

**MAKING AN
IMPACT**



FROM OUR EXECUTIVE DIRECTOR

Dear Members,

As we reflect on this past year, I am filled with immense gratitude and pride for all we have achieved together. This annual report is a testament to the combined efforts, dedication, and passion of our extraordinary community of supporters, volunteers, staff, and partners.

This year was transformative for our organization. We expanded our programs, reached significant milestones, and impacted the lives of numerous individuals and families. From assisting a family new to XLH to participating in research that enhances understanding of the impact of living with XLH, we are always aware that none of these accomplishments would have been possible without your steadfast support.

Thank you for being an integral part of our journey. We invite you to explore this annual report and celebrate the achievements we have accomplished together. As we look ahead, our mission to support families living with XLH and to reach underserved populations has never been more critical, and our commitment to increasing resources for the XLH community has never been stronger. Please feel free to contact us if you have any questions or are interested in volunteering.

Susan Faltos

Susan Faltos

Executive Director, The XLH Network, Inc.



MISSION & VISION

Our Mission

The mission of the XLH Network is to promote XLH awareness and education for affected families, medical professionals, and the community at-large; to support physicians and other providers of medical care for better diagnosis and treatment; to create resources and a community for affected individuals and their families so they can understand and cope with the complications of the disease; and to foster the search for a cure.

Our Vision

The vision of the XLH Network is to promote and foster early, accurate diagnosis; readily available and well-managed treatment; and a healthy quality of life for those afflicted with XLH and related disorders.



What is XLH?

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

OUR IMPACT IN 2024

2,566

Members

2,322

Unique visits to
website

177

Annual
conference
attendees

86

Members went
to XLH summer
camp

60

Pup Squad
members

51

Cross Country
Challenge
participants

30

State
proclamations

17

Members
advocated to
Congress

5

Support groups
available

4

Research
projects or
articles

2

Regional
Meetups

OUR TEAM



Board Members

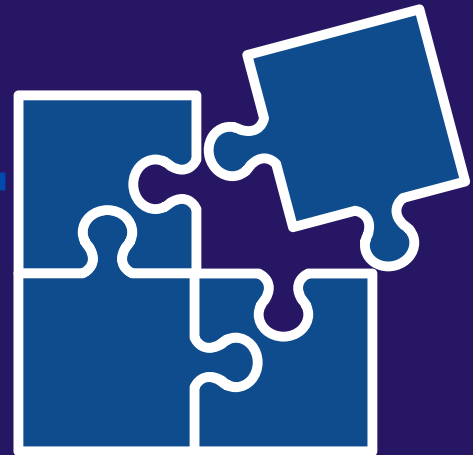


**Executive Director
& Assistant**



Volunteers

The XLH Network is a team effort, historically rooted in the invaluable contributions of our dedicated board members and volunteers. Team members bring their unique perspective and expertise, creating an environment where ideas flourish and initiatives thrive. Together, we collaborate to address the diverse needs of those affected by XLH.



Our Team

Our volunteer-driven model highlights inclusivity and shared vision. Board members, the Executive Director, and volunteers work together to advance our mission and enhance the well-being of the XLH community.



Finding the Network changed my life. I'm so grateful for the support I've received, and can't thank you enough for all that you do. I hope that more people can benefit from the amazing impact you make on so many people's lives. Thank you!



- MONICA

Member



From the day that my family discovered the XLH Network I knew that I had to be a part of the organization that made us feel much less alone in this journey. We have always been welcomed and embraced with endless love and support. Since then, I have been constantly finding ways to fundraise, advocate, support, and bring fun activities to our young members! It is truly an honor to be able to give back to the organization that has given so much to my family!



-JAYLA

Volunteer/Board Member



PROGRAM HIGHLIGHTS

Research Project / White Paper

- Partnered with Kyowa Kirin to produce the XLH Community Impact Survey.
- Participated in publishing the associated White Paper.
- Co-authored abstracts to present at ASBMR and NORD.



Annual Conference (XLH Day)

- Had record attendance (177) at our annual conference.
- Offered 25 unique sessions / groups.
- Over 35% of budget for conference spent on financial assistance for attendees.



XLH Awareness Month

- 30 state proclamations received
- 34 congressional meetings
- 17 Network members participated
- 15 states represented



PROGRAM HIGHLIGHTS

Advocacy Training Series

- Quarterly training calls for members
- Topics included
 - Legislation 101
 - Sharing Your Rare Disease Story
 - Advocacy 101



XLH Kid's Camp

- 86 campers attended.
- Travel scholarships offered.
- Activities included canoeing, fishing, horseback riding, swimming, Stage Night, and Parent Education Night.

Pup Squad

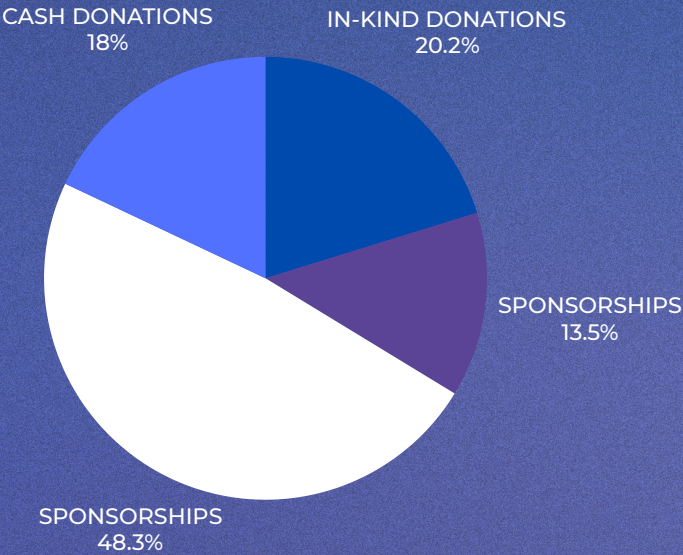
- Quarterly Zoom meetings for children
- 60 members
- Mascot is "Link" (see picture to right)



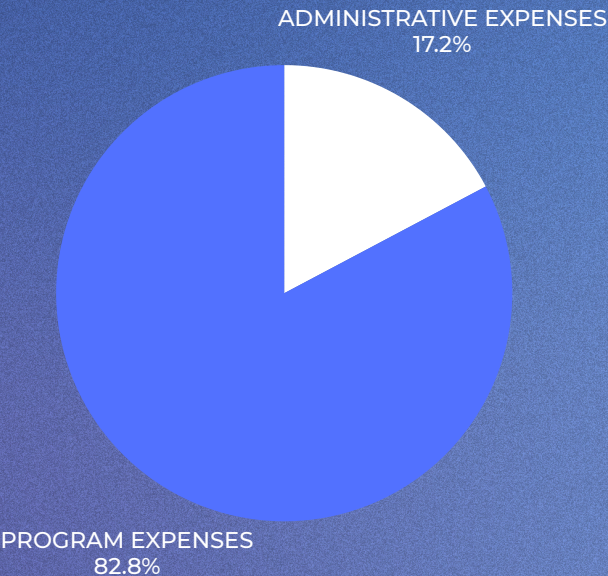
2024 FINANCIALS

2024 SUMMARY

Revenue



Expenses



HOW WE SPEND YOUR CONTRIBUTIONS

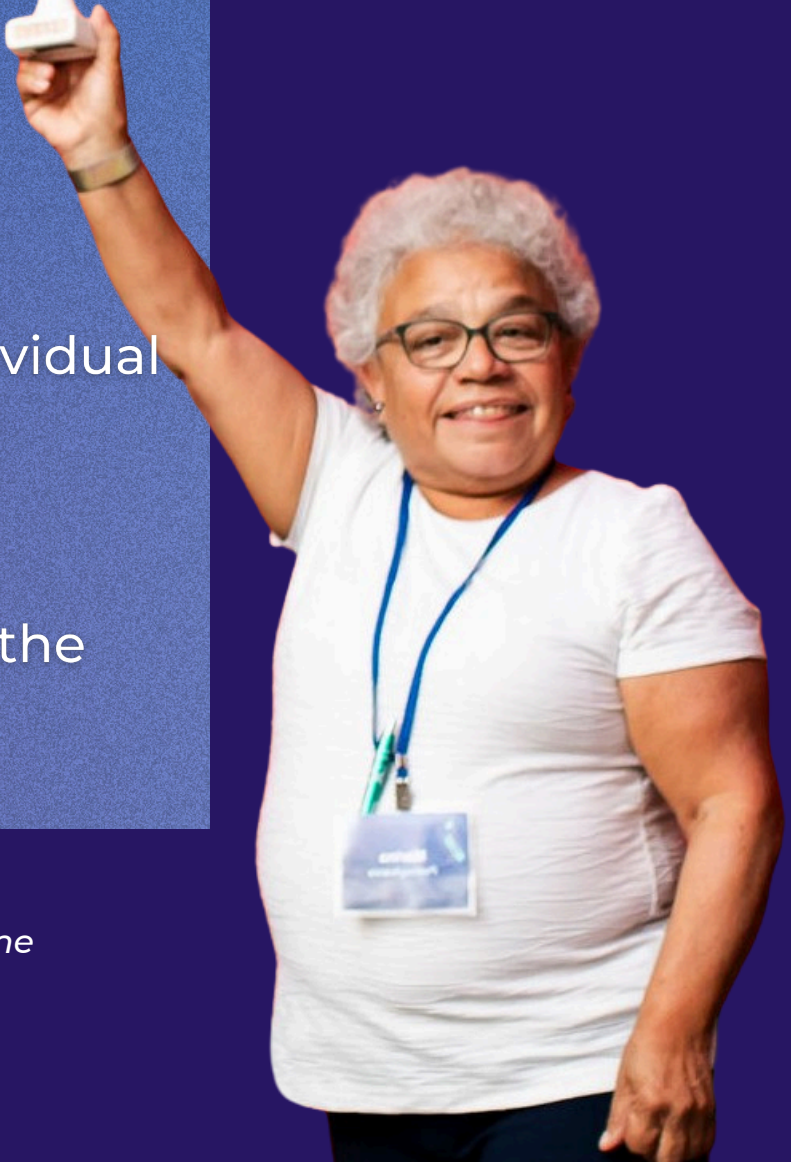
EXPENDITURE CATEGORIES	01/01/2024 - 12/31/2024
MEMBER EVENTS AND SCHOLARSHPS	\$191800.9
SALARIES	\$77615.47
OFFICE & OVERHEAD EXPENSES	\$35827.8
PROFESSIONAL SERVICES	\$19315
OUTREACH/FUNDRAISING	\$17716.47
ADVOCACY	\$14196
BOARD DEVELOPMENT	\$7179.54
Total	\$364722

Additional information, including data from previous years, can be found on our Candid GuideStar profile: <https://www.guidestar.org/profile/20-2441942>

WITH GRATITUDE

**Thank you to all who sponsored or
donated in 2024!**

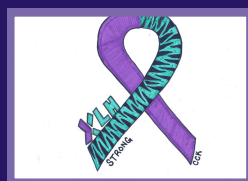
- Kyowa Kirin North America
- Center for Courageous Kids
- Spectrum, Inc.
- Plybon Company
- Prosperity Law Firm
- Our many generous individual donors*
- Our members who held personal fundraisers for the Network



**For privacy reasons we do not name
individual donors unless
agreed to in advance.*

USEFUL LINKS

- [Learn more about us at XLHNetwork.org](#)
 - XLH Resources
 - Physician Database
 - Event Calendar
 - How to Get Involved
- [Read about the Community Impact Survey](#)
 - Download the White Paper
 - Download the report
 - View the poster
- Donate
 - [Donate online](#)
 - Donate via Venmo @xlhnetwork.
 - See our website for additional ways to donate.



GET IN TOUCH!

Thank you for your interest and support of The XLH Network. If you'd like to learn more about what we do or set up a meeting to discuss further support, please use the information below to contact us.



Susan Faitos

Executive Director

✉ executivedirector@xlhnetwork.org

JoBeth Souza

President, Board of Directors

✉ JoBeth.Souza@xlhnetwork.org



Gold
Transparency
2024

Candid.