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Collaborating to Address Data Gaps and Care Barriers through Lived Experiences:

The XLH Community Impact Survey

Chief Patient Officer Summit

Lisa Savitt

Vice President
SmithSolve

Susan Thiele

Senior Director, Brand & Therapeutic Comms
Kyowa Kirin North America

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XLH Community Impact Survey

"For generations, families living with XLH have struggled to explain the disease to many of the professionals involved in their care. Without the data to back them up, patients have often reported feeling dismissed, or that their concerns were not validated."

\- **Susan Faitos**, Executive Director, The XLH Network

Goal: To quantify and deepen understanding of the experience of adult and child XLHers in the U.S. and barriers to care

- Costs of living with XLH
- Access to expert, quality care
- Physical, mental health, and social impacts

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XLH Community Impact Survey

Case Study

Today, we will share our approach to:

- Secure buy-in from key stakeholders
- Design a survey that meets both need and budgets
- Engage a steering committee to guide strategy and outputs
- Communicate results clearly and consistently
- Action insights

> "XLH affects me every day by putting limitations on the things I can do with my child… and it affects my job, my every day, my real life, and everything I do."
>
> **– Layla F**

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Build a Collaborative Foundation to Ensure Alignment & Buy-in

Collaborate from the start

- The XLH Network
- Patient Advocacy
- Medical Affairs
- HEOR
- Omni-channel marketing
- Legal, Regulatory, Compliance

Gain alignment on objectives

- Inform communications strategies and education
- Expand HCP awareness, understanding and empathy for the lived experience of XLHers
- Support community policy activities and advocacy efforts

Identify target audience

- XLHers
- HCPs
- Policy makers
- Internal functions
- Others

Collaborative Foundation

XLH Community Impact Survey

Establish a Cross-functional Team to Power Survey Design & Outputs

Survey At-A-Glance

Core Project Team

XLH Network Leadership
Patient Advocacy & Comms
Medical Affairs & HEOR
Omni-channel Marketing

Consulted

Legal, Regulatory
Compliance, Data Privacy

Informed

Kyowa Kirin Leadership
XLH Network Board
XLH Commercial Team
Patient Services

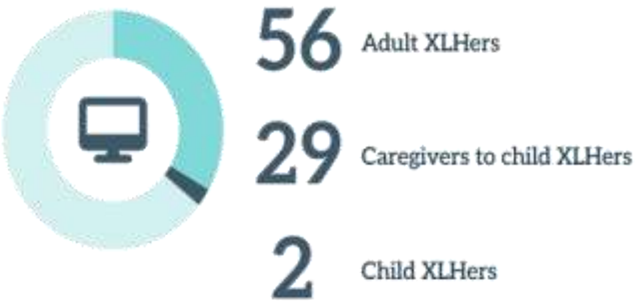
Data Outputs

Conference presentations,
peer-reviewed publication,
white paper, fact sheets,
microsite, social media content

Recruitment Channels

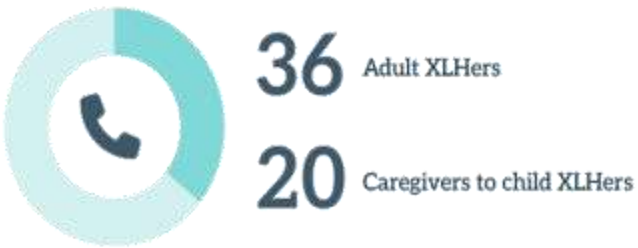
XLH NETWORK
KYOWA KIRIN cares
ACCESS · ASSISTANCE · UNDERSTANDING
XLH LINK

Online Survey



56 Adult XLHers (18+ years old), 29 caregivers to XLHers under 21 years old, and two child XLHers in the United States shared their experiences through an online survey.

Interviews



Of these 87 participants, 36 Adults XLHers and 20 caregivers completed a 60-minute phone interview.

XLH Community Impact Survey

Engage Outside Experts to Inform Survey Development & Outputs

Multi-disciplinary Steering Committee

Susan Faitos, MA
Executive Director, XLHN
- Person living with XLH
- Background in social work

Bryan
Person living with XLH

Jill H. Simmons, MD
Vanderbilt University Medical Center
- Program for Metabolic Bone Disorders
- Prof. of Pediatric Endocrinology

Thomas O. Carpenter, MD
Yale School of Medicine
- Director, Yale Center for XLH
- Prof. of Pediatric Endocrinology, Orthopedics & Rehabilitation

Costs of living with XLH

- Direct medical costs
- Non-medical costs (e.g., home modifications, travel to doctor)
- Indirect costs (e.g., reduced productivity at work/school)

Access to expert, quality care

- Access to experienced healthcare providers
- Ability to transition from pediatric to adult care
- Insurance navigation

Physical, mental health, and social impacts

- Mental/emotional health
- Physical symptoms, sleep disturbances
- Relationships, social activities
- Caregiving

XLH Community
Impact Survey

Turn Insights into Impact via Multi-stakeholder Communications Plan


XLH Community Impact Survey
Brand Style Guide

Logos

XLH Community Impact Survey

XLH Community Impact Survey

Color Palette

Icons

March - **Data Analysis & Branding**


Dental Impact of XLH: Far-Reaching and Costly
Results from the XLH Community Impact Survey

97% of adults & 75% of children

61%

75%

Learn more today:

ENDO 2024

June – XLH Awareness Month - **Advocate for Change**

May - **Data Abstracts**

ASBMR®
The American Society for
Bone and Mineral Research


The costs of living with XLH

nearly
$7,000

The XLHer care experience

nearly
180 miles

The impact of XLH on mental health

83%
of adults

Coming Soon!

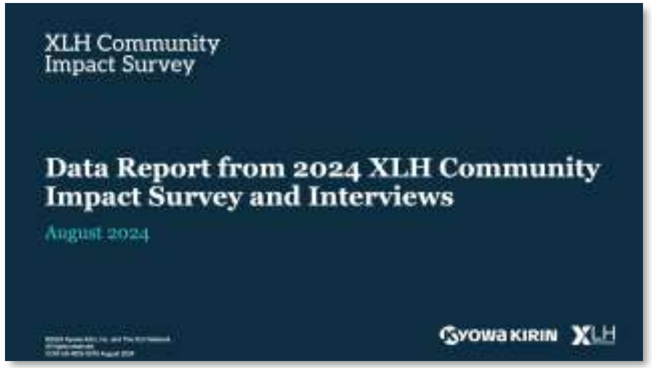

Results Coming Soon ...
XLH Community Impact Survey

Be the first to know!

XLH Community Impact Survey
Full Results Coming Fall 2024

XLHimpact.com

Turn Insights into Impact via Multi-stakeholder Communications Plan



XLH Community
Impact Survey

Data Report from 2024 XLH Community Impact Survey and Interviews

August 2024

August – **Comprehensive data report**

Save the Date for
XLH DAY 2024

October
12th

XLH Community
Impact Survey

The Results Are In!

85+ members of the XLH community shared their lived experiences through the XLH Community Impact Survey, and now you can read the findings.

Scan the QR code to read the white paper *Insights for Change: Findings from the XLH Community Impact Survey*, and visit XLHimpact.com for the full research findings, resources for action, and to sign-up for future updates!

Together, we can make an impact on XLH.

October 12 – **Patient Conference**

National Organization for Rare Disorders
39,057 followers

NORD Member The XLH Network, Inc and Kyowa Kirin, Inc.- U.S. will present findings from their #XLH Community Impact Survey at next week's #NORDSummit!

Their report highlights the profound effects of X-linked #hypophosphatemia on patients' finances, daily activities, and mental health. Read more here: https://bit.ly/4haZ3k4

October 22 – **Conference Poster**

September – **Conference Poster**

October 15 – **Campaign Launch**

XLH Community Impact Survey

Achieve Goals and Uncover Insights to Guide Future Efforts

- ☑ **Quantified lived experiences**
- ☑ **Enhanced corporate visibility and reputation**
- ☑ **Gained insights to inform future programming**
- ☑ **Established framework for cross-functional planning and execution**

Community/Patients

165+ reached at XLH day conference
30+ white paper downloads

165+

HCP

2 scientific posters
Assets shared at ASBMR, ENDO

2

Policy

30+ Congressional briefings using campaign assets

30+

Comms Launch (1 month)

2400+ XLHimpact.com visits
2000+ release views
400+ white paper downloads
3.3K+ social engagements

2.4k+
site visits

XLH Community
Impact Survey

Close Knowledge Gaps and Address Barriers to Care

CheckRare
rare disease insights

Rare Disease Mental Health Resource Guide

X-linked hypophosphatemia (XLH) can present unique emotional, mental, and social wellness challenges for those living with the condition and their loved ones. Despite this, the XLH Community Impact Survey reported that few adults and children living with XLH access professional help.

Though XLH may be rare, you're not alone. The organizations listed below provide mental health resources, support services, and opportunities to connect that may be right for you.

Resources to Support Mental Wellness

Adults	
Center for Chronic Illness (CCI)	• Online support groups for individuals with rare chronic conditions
Global Genes	• Resources to support managing pain strategies to rest and recharge
Mental Health America (MHA)	• Online screening, worksheets, and tools
National Alliance on Mental Illness	• Information about how to access mental health care • Support groups for adults with mental health conditions
Parents or Caregivers	
Caregiver Action Network	• Resources and support tips for rare disease caregivers
Center for Chronic Illness (CCI)	• Web-based support groups for parents, partners, and friends of individuals with chronic illness
Global Genes	• Strategies to navigate the rare diagnostic odyssey and daily complexity of care and support services
National Alliance for Mental Illness	• Resources for supporting family members with mental health challenges and to help caregivers take care of themselves
Teens and Kids	
Center for Chronic Illness (CCI)	• Web-based peer support groups for young teens (12-14) or teens (15-17) with chronic conditions
National Alliance for Mental Health	• Tips for talking with parents or friends, finding help, navigating accommodations in school
US Pain Foundation	

If you or a loved

• Reach out to

XLH Teeth Talk:
Advice from a Dentist

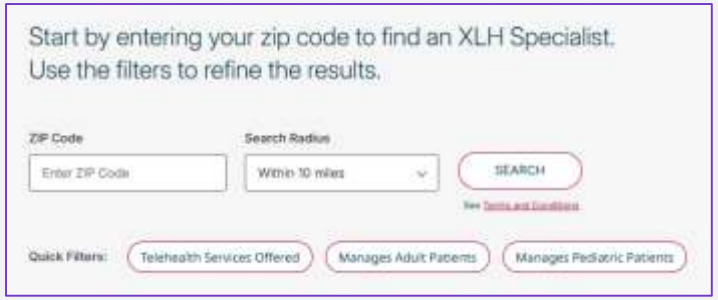
Raghbir Kaur, DMD

Positively XLH:
Speaking Out About Mental Health

Logan

Person with X-linked hypophosphatemia (XLH)

Cross-functional Activities


Start by entering your zip code to find an XLH Specialist.
Use the filters to refine the results.

Manuscript in Development


Findings from the XLH Community Impact Survey

Understanding XLH

"Research projects like this, which focus on the actual lived experience of someone with XLH, will lead to a greater understanding of XLH and facilitate meaningful discussions between XLHers and all those involved in their care.

The XLH Network is proud to be a part of this project."

- **Susan Faitos**, Executive Director, The XLH Network

Closing Data Gaps Together

Listen First

- Understand the gaps
- Identify shared needs

Be the Bridge

- Build cross-functional teams
- Define roles

Plan Ahead

- Start with the end in mind
- Align and secure cross-functional resources

Experience Matters

- Secure the right partners
- Capture cross-functional metrics and share success

XLH Community Impact Survey

Thank you!

Susan Thiele

Susan.Thiele.38@kyowakrin.com

Lisa Savitt

Lisa.Savitt@smithsolve.com

XLH Community Impact Survey

SmithSolve