



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)

thecenterforchronicillness.org/programs

- Online support groups for individuals with rare chronic conditions

Global Genes

globalgenes.org/mental-health-and-well-being

- Resources to support managing pain strategies to rest and recharge

Mental Health America (MHA)

mhnational.org

- Online screening, worksheets, and tools

National Alliance on Mental Illness

nami.org/support-education/mental-health-education
nami.org/support-education/support-groups

- Information about how to access mental health care
- Support groups for adults with mental health conditions

Parents or Caregivers

Caregiver Action Network

caregiveraction.org/rarecaregivers
caregiveraction.org/caregiver-support-tips

- Resources and support tips for rare disease caregivers

Center for Chronic Illness (CCI)

thecenterforchronicillness.org/programs

- Web-based support groups for parents, partners, and friends of individuals with chronic illness

Global Genes

globalgenes.org/toolkit/rare-caregivers-guidebook

- Strategies to navigate the rare diagnostic odyssey and daily complexity of care and support services

National Alliance for Mental Illness

nami.org/your-journey/family-members-and-caregivers
nami.org/your-journey/kids-teens-and-young-adults

- 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)

thecenterforchronicillness.org/programs

- Web-based peer support groups for young-teens (12-14) or teens (15-17) with chronic conditions

National Alliance for Mental Health

nami.org/your-journey/kids-teens-and-young-adults

- Tips for talking with parents or friends, finding help, navigating accommodations in school

US Pain Foundation

uspainfoundation.org/resources

- Information about living well for youth with chronic pain

If you or a loved one are struggling with mental health you can,

- Reach out to others with XLH
- Talk to your doctor or a mental health professional
- Call the National Helpline **1-800-662-HELP (4357)**

*This is a curated list and is not meant to be an exhaustive list of all organizations, services, or online resources. These resources are created by and hosted on third-party websites that are not reviewed, controlled, or endorsed by Kyowa Kirin.