



- Go to: <https://www.donorview.com/xlh-network>
- Text "623" to 518 990 7899
- Scan the QR code.

Nashville Notes

Our first post-pandemic XLH Day was a rousing success! Over 120 attendees made the trek to Nashville for a weekend of connecting, learning, socializing and much more. Drs. Kathryn Dahir and Jill Simmons from Vanderbilt shared new information and research about XLH. Pediatric dentist Dr. Margaret Maclin provided a refreshing new look at XLH and dental issues. Board members Elizabeth Olear and Marian Hart gave an insightful presentation about the effects of XLH across the life span. The Saturday night dinner/gala was quite the celebration with music and dancing set against the Nashville skyline at sunset. Thank you to all that attended, and stay tuned to learn about our plans for 2023.



ELSA

(Ensuring Lasting Smiles Act)

Families living with XLH often experience the challenge of paying for expensive dental work to maintain a healthy bite and smile. ELSA is a bill going through

Online Groups

Our online support groups are going strong! There is a group available for anyone but if we are missing a category please let us know. Groups are normally

Congress that can help alleviate this. This bipartisan legislation requires all private, group, and individual health plans to cover medically necessary services that are needed to repair congenital anomalies; stipulates that such coverage include services & procedures that functionally repair or restore any missing or abnormal body part that is medically necessary to achieve normal body functioning or appearance; and clarify the inclusion of adjunctive dental, orthodontic, or prosthodontic support.

We only have until the end of the year to get this passed, or we start all over again in 2023. **PLEASE** take a moment to click **HERE** to see how you can help this bill go through in 2022!

held Wednesday evenings from 8:00 - 9:30 PM ET Watch our social media pages for updates.

- **Men's Group:** open to all males living with XLH. Led by board members Geoff Edelson, Chris Younger and Jason Grant.
- **Spontaneous Parents:** open to parents with a child who has a spontaneous case of XLH. Led by board members JoBeth Souza and Shannon Sharp.
- **Aging with XLH:** open to all dealing with the effects of XLH after 45(ish). Led by executive director Susan Faitos and board member Kelly Rushing.
- **Transition Age Group:** open to teens and young adults. Led by board members Marian Hart and Sarah Das.

For more information on any of these groups, feel free to email executivedirector@xlhnetwork.org

There are two more online support groups in 2022! The Men's Group will meet 12/7 and the Aging with XLH Group will meet 12/14. Click on the picture below to register.



Men's Group
Wednesday, Dec. 7th
8:00 - 9:30pm Eastern Time

For men only, this group is a safe and confidential space to discuss issues related to XLH. It will be facilitated by XLH Network board members Chris Younger and Geoff Edelson.

Click [HERE](#) to register

XLH
NETWORK



Aging with XLH

An online support group focused on managing XLH over age 45(ish). Open to all, this confidential group is facilitated by member Kelly Rushing and Executive Director Susan Faitos

Wednesday, December 14th

8:00 pm - 9:00 pm ET

Register [HERE](#)

XLH
NETWORK

In Gratitude

We are fortunate to have dedicated and committed board members at the Network. Which makes it difficult to say goodbye when one or more steps off. This year we are saying "see you later" to **Sara Show and Geoff Edelson**.

Sara has been on the board since 2018, and has brought a strong voice for advocacy to the table, as well as her wealth of knowledge from her legal background. She was the original leader of the Spontaneous Parents group and will continue in her role as a member of the Community Congress for the EveryLife Foundation, representing the Network. We thank her for her service and time, and wish her well in all future endeavors.

Geoff is one of the original board members, having served for over 10 years. As treasurer for his last three terms, he has kept us on track with budgeting, fundraising, and more importantly, being responsible with how we use our donations. Geoff can always be counted on to help out at events, and carries with him a wealth of knowledge about the history of the Network. He will be missed for his guidance, his compassion, and his sharp wit. Thank you, Geoff - for all you have done for the Network and for the XLH community.

Meet Our New Board Members

Charles Pomeroy

Charles is one of the original members of the Network, having been involved in the creation of the very first XLH Day. He can be counted on to help out at any event, often playing many roles at once. We are looking forward to utilizing his expertise in technology. Charles resides in Connecticut with his wife, Ilona and his daughter, Grey.

Kelly Rushing

Kelly is a familiar face at Network events, and is our most dedicated volunteer. She was instrumental in developing our plans for Nashville, and she co-leads the Aging with XLH group. Kelly brings creativity, humor and a fierce compassion for the community with her. Kelly resides in Alabama with her husband Ricky.

What to watch for in 2023

- New & Improved Website
- New Dates for Cross Country Challenge:
 - July 4th - Labor Day
- Kid's Camp
- XLH Day in the Fall
- Regional Get-Togethers

Our work is made possible by donations from the community. Please consider contributing.

[Donate Now](#)



xlhnetwork.org

The XLH Network, Inc. | 911 Central Ave. #161, Albany, NY 12206 5183509541

[Unsubscribe susan.faitos@xlhnetwork.org](mailto:susan.faitos@xlhnetwork.org)

[Update Profile](#) | [Constant Contact Data Notice](#)

Sent by executivedirector@xlhnetwork.org in collaboration with



Try email marketing for free today!