Reach for the Stars!

THE XLH NETWORK, INC.

VIRTUAL XLH WEEK 2020

OCTOBER 3-10TH, 2020
Thank you for joining us for our very first Virtual XLH Week. Things are different for all of us this year and it was a tough decision to give up our plans to have a live event in Phoenix. We miss having the chance to see you all in person and to welcome our new members, but we felt that this was the right thing to do, for the health and safety of us all.

We are hopeful that by bringing you this extended program, with more options than ever, we will still be able to provide the informative and inspiring event you are used to. Take time to review the agenda and pick out the sessions that feel most relevant to you. Reach out to us if you have questions or are unsure about attending a session. Make a note in your calendar so you are sure to be available to listen to our fabulous guest speakers. And, take time to read the section in this program about accessing the live stream prior to the event, so you’re not scrambling at the last minute.

For some of you, this may be your first experience attending an XLH Network event. We welcome you and encourage you to use some of the networking options in the app to meet your peers.

We hope that all of you leave this week feeling like you have learned something new and that you have been encouraged by others around you.

Thank you again for joining us!

Susan Faitos, Executive Director
The XLH Network, Inc.
**VIRTUAL XLH WEEK 2020**

**DAY 1**

*Saturday, October 3rd. All times = Eastern Time*

**11:00 - 11:45 SPECIAL PRE-CONFERENCE SESSION: XLH 101**

*Elizabeth Olear, Marian Hart*

If you’re new to the world of XLH, or just need a refresher course before the week starts, plan on attending this session that covers the basics of XLH from birth to adulthood. Lead by two experts in XLH who are also experts in explaining the complexities of this condition, this session is geared toward the newly diagnosed patient, but useful for everyone. We will discuss XLH as part of a whole body, whole life and whole family diagnosis.

**12:00 - 12:10 WELCOME: The Week Ahead**

*The XLH Network, Inc.*

**12:10 - 1:10 RARE: IT’S WHAT UNITES US**

*Nicole Boice, Founder of Global Genes and Rare-X*, talks about her inspiring journey in the rare disease world and the role of patients as partners and drivers in healthcare and research.

**1:30 - 2:30 XLH Today: How the Landscape has Changed**

An insightful look at XLH through the life span, moderated by pediatric endocrinologist *Dr. Thomas Carpenter* and featuring *Dr. Erik Imel* with the pediatric and adolescent perspective and adult expert *Dr. Karl Insogna*. This session will highlight the changes in the understanding and treatment of XLH especially in the last two years and will answer specific questions and considerations for all those with XLH. We’ll see how far we have come and where we are going with these physicians who are the leading experts in XLH.

- Break with guided yoga stretch -

**2:45-3:45 XLH & DENTAL CARE PANEL DISCUSSION**

*Raghibir Kaur, DDS, Jason Grant, Shannon Sharp*

Dr. Kaur will discuss the latest research in XLH and dental issues. Jason Grant tells his story about obtaining insurance coverage for XLH-related dental treatment. Shannon Sharp talks about the Enduring Lasting Smiles Act.

Day One Continues Next Page
One of the best parts of XLH Day is just being able to hang out with your friends and relax.

We can't duplicate that online, but we can try for the next best thing. There are "social hours" each Saturday evening during XLH Week. These will be on a separate Zoom call so we can all see each other and chat. The Live Stream icon on your app will get your there!

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### VIRTUAL XLH WEEK 2020

**DIII DAY, CONTINUED**

**Saturday, October 3rd. All times = Eastern Time**

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<tr>
<th>3:45-4:30</th>
<th>PETE’S DIARY</th>
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| **Pete & Dede Dankelson**  
With his guitar in hand, Pete talks about embracing what makes you different. A great way to end the day with music and positive messages. |  |

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<th>4:30-4:40</th>
<th>FIRST DAY CLOSING REMARKS/UPDATES</th>
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**Break**

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<th>5:30-6:30</th>
<th>KID’S TALENT SHOWCASE/SOCIAL HOUR</th>
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| Take a break, move around and come back at 5:30 to kick back with your community and watch some very talented children perform.  
**Kids of all ages**: Here's your chance to STAR in our very own kid’s talent show. If you can sing, dance, play a musical instrument, recite a poem, tell a joke or have any other talent or just want to watch, please join the fun.  
**Note that for this session, you will need to sign out of the Livestream and then re-sign in at 5:30.** |  |
VIRTUAL XLH WEEK 2020

TUESDAY, OCTOBER 6TH
MEN AND XLH
In this interactive discussion hosted by Sean Baumstark & Kyle Bryant of the "Two Disabled Dudes" podcast, men of all ages will have an opportunity to discuss some of the specific issues that relate to them in regards to XLH.

WEDNESDAY, OCTOBER 7TH
TRANSITIONAL TOOLKIT TAKEAWAYS
Designed for young adults and those that love them, the Transitional Toolkit was recently developed via a collaboration with The XLH Network, Quinnipiac University and Ultragenyx. The Toolkit is a comprehensive guide for transitioning health care from pediatrics to adult services. In this session, Maya Doyle, LCSW will highlight the most significant pieces of the toolkit and discuss ways to use and adapt it to your family’s needs.

THURSDAY, OCTOBER 8TH
CARING FOR THE CAREGIVERS
Cristol O’Loughlin founded Angel Aid Cares with the purpose to source research, relief and inspiration for mothers of children with rare diseases. In this session she emphasizes the importance of self-care for any caregivers, and walks through some techniques and strategies for men and women who are caring for someone with rare disease to make sure they have their own support system intact.

Speaker Bios can be found in the XLH Week App
11:00 - 11:45
**SPECIAL: CHILDREN'S ACTIVITY: NAME A STAR**
Learn more about stars and constellations, travel through galaxies virtually, give a name to a real star, do a craft.

12:00 - 12:30
**WELCOME BACK/ABOUT THE XLH NETWORK**
*The XLH Network, Inc.*

12:30 - 1:30
**EVIDENCE-BASED PHYSICAL THERAPY INTERVENTION: A TARGETED STRATEGY**
*Dr. Carolyn M. Macica, Dr. Keith Steigbigel*
This session will present information related to the physical and functional limitations of adult XLH. Recent adult studies have been translated into an evidence-based physical therapy (PT) intervention to address the major physical and functional comorbidities of adult XLH. Highlights of the adult study, what we’ve learned from clinical and basic research, and a targeted PT programming strategy will be presented by the investigators and one of the patients enrolled in both studies.

- Break with guided yoga stretch -

1:45-2:45
**XLH & MENTAL HEALTH PANEL DISCUSSION**
*Maya Doyle, LCSW, Jennifer Gentile, PH.D., Amber Hamilton*
In this interactive discussion, patients and professionals discuss some of the mental health challenges of living with XLH, as well as coping and management strategies.
3:00 - 4:00 TWO DISABLED DUDES

Sean Baumstark and Kyle Bryant from the popular podcast "Two Disabled Dudes" lead this interactive discussion about living your best life with XLH. You’ll laugh, you’ll cry, you’ll get all the "feels". Rachael Jones, Jason Grant, JoBeth Souza and Susan Faitos round out this lively panel.

4:00 - 4:15 WRAP-UP/CLOSING REMARKS

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5:00 - 6:00 SOCIAL HOUR/AWARDS

Take a break and come back for a casual social hour. The Network will announce the Cross Country Challenge awards and XLH Week Games winners.

Activities for Kids of All Ages

Saturday 10/3: Kids of all ages are invited to participate in our Kids Talent Showcase Starting at 5:30 pm. See Agenda for details. If your child wants to be a STAR, email us at executivedirector@xlhnetwork.org so we’re sure to put him/her in the program.

On Saturday 10/10, at 11:00 a.m., there is a Star-Themed kid’s activity. If your child wants to participate in the craft making portion of this session, they will need the following easy to find materials:

- Cardboard Tube (center of paper towels)
- 1 piece of cardstock
- scissors
- tape
- 2 rubber bands
- markers
- stickers (to decorate telescope)
Virtual XLH Week 2020

How to Access the App & Event

Access to the app for #XLHWeek2020 is easy! You can use the app from your phone or other mobile device, view it through your computer’s browser, or download the app to your computer (recommended). You will need the App to view the live stream of the event.

- To download for your iOS/Apple device, go to the App Store and search for XLH Network.
- For your Android device, go to Google Play and search for XLH Network.
- To download the app for your desktop computer, go to: https://download.socio.events/event/NzA3OQ%3D%3D

Using the App

The first time you use the app, it will ask you for your email address, and to set up a password. Make sure you use the email address you registered with.

Once you are in the app, look around! Check out the agenda and speaker bios. Say hello to your friends on the Networking wall. If you are new, introduce yourself.

Desktop App

Mobile App
On the opening day of #XLHweek2020, go to your app and click on the Live Stream icon. If you are on a mobile device, you are ready to go!

If you are using your desktop computer, clicking on the Live Stream icon will open another browser window for Zoom. If you don’t have Zoom already installed, you can install it at that time, or just use Zoom on your browser. Keep the app window open, so you can switch back and forth from the app to the live stream on Zoom.

If you are not familiar with Zoom, check out this article on getting started: https://support.zoom.us/hc/en-us/articles/201362033-Getting-Started-on-Windows-and-Mac

For those of you who have attended an XLH Day before, you know that one of the best parts is just being able to hang out with your friends and relax.

We can’t duplicate that experience online, but we sure can try for the next best thing! There are "social hours" each Saturday evening during XLH Week. These will be on a separate Zoom call so we can all see each other and chat.

You will still click on "Live Stream" in the app to get to the Social Hour events. Children’s Activities will also be on a Zoom call.

We encourage everyone to try out the app and make sure they can log in **PRIOR** to 10/3. If you have any problems, contact us at executivedirector@xlhnetwork.org. Once the event starts, our ability to help with technical issues may be limited.
We know that attending a virtual event can be an adjustment for participants. We have compiled a list of tips to help you get the most out of your week.

• **Test Your Tech:** Before the event, make sure that your chosen device is working properly, fully charged, and has wifi access. We will do everything on our end to ensure a great experience and we don’t want you to miss a thing.

• **Connect with Others:** On the event platform there are tools for chatting by text, audio or video with other participants. We encourage you to take advantage of these networking tools to see who is participating and connect with them.

  If you are active on social media, follow the event hashtag – #XLHweek2020. We’d love to have you join the conversation as we post about key takeaways, event highlights and more. And, don’t let the networking stop when the event stops. We encourage you to trade contact information and connect with fellow participants on other platforms such as LinkedIn or Facebook, or simply by email.

• **Ask Questions:** #XLHweek2020 offers many opportunities to engage with the content and get your questions answered by the presenting experts. Don’t be shy about taking advantage of this time to learn everything you can!

• **Minimize Distractions:** When attending a virtual event, it can be easy to start multi-tasking and become distracted. To get the most out of the sessions, close your email and block off your calendar so you can focus on the presenters and engage in the Q&A opportunities.

• **Stay Muted:** Background noise, however slight, can interfere with everyone’s ability to hear the speakers. Please stay on "Mute" unless you are actively engaged in the conversation, or asking a question.

• **Take Breaks:** It’s a long day, so feel free to get up and move during this event!
Autosomal: refers to a genetic trait that is determined by a mutation on a chromosome other than the sex-determining X and Y chromosomes.

Burosumab: a newly FDA-approved antibody that binds to FGF23 thereby blocking the ability of Fibroblast Growth Factor 23 to cause phosphate-wasting.

Calcitriol: an active form of vitamin D that increases phosphate absorption. Some patients with hypophosphatemia have a decreased ability to produce this hormone, so it may be used in treatment.

Chiari Malformation: malformation of the base of the skull that may be associated with genetic forms of hypophosphatemia.

Eight plate surgery: orthopedic surgical procedure that involves the insertion of a plate on one side of a growth plate to guide the bone into a straighter, more anatomically correct orientation.

Endocrine system: the collection of hormones (and the sources of the hormones) that regulate metabolism and other bodily functions.

Enthesopathy: calcification of tendons or ligaments.

Fibroblast Growth Factor 23 (FGF23): a hormone that may be secreted by bone cells or a tumor; excessive secretion leads to hypophosphatemia.

Hyperparathyroidism: overproduction of parathyroid hormone, may be caused by phosphorus supplements, especially if not sufficiently balanced with calcitriol.

Hypophosphatemia: disorder characterized by low levels of phosphorus in the blood. It may be caused by a genetic mutation or a tumor.

Nephrocalcinosis: calcification of the kidney, a potential adverse effect of treatment with calcitriol or other active vitamin D analogues.

Osteomalacia: soft, poorly mineralized bones in adults.

Osteotomy: orthopedic surgical procedure that cuts a bone to realign it with the joint.

Phosphorus supplements: sometimes referred to as K-phos or Neutra-phos, may be used to treat hypophosphatemia.

Spinal stenosis: narrowing of the spinal canal due to calcifications.

Tumor-Induced Osteomalacia (TIO): disorder characterized by a tumor that produces excessive levels of Fibroblast Growth Factor 23.

X-Linked: when a genetic trait is determined by a mutation on the sex-determining X chromosome.
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.

Community, Knowledge, Compassion

The XLH Network Inc., is a non-profit 501(c)3 organization. Please consider making a tax-deductible donation so that we can continue to provide you with quality information, networking and advocacy opportunities: https://xlhnetwork.networkforgood.com/projects/29168-every-day-giving

Text-to-Donate to the Network:
Text "Give" to 518-941-8512