



AXYS Spring 2020 Newsletter: AXYS comes to you

Online Support Groups

In this time of social distancing we still want to connect with each other. With that in mind, AXYS has moved to Zoom. We held an online support group in the DC-VA-MD area. Thanks to Stefan Schwarz and Ginnie Cover for organizing the DC meeting and to Jonathan Blumenthal, MA and Erin Torres, MSN, CRNP from NIH for giving a great presentation.

Our next online support group will be for NEXXYS on Saturday, June 6. [We invite all who live in New England to join the conversation.](#)



Online chats by variation

We are also gathering families and individuals representing various conditions. We thank Andrea Millett for hosting groups for the Trisomy X community as well as Stefan Schwarz and Matt McKeon for hosting the Adults with XXY chat.

We have more chats on the way:

- June 27, 7pm ET - [AXYS Chat en Español: Una reunión de la comunidad hispanohablante de variación X&Y \(A gathering of the Spanish speaking X&Y variation community\)](#), led by Hannah Acevedo (AXYS Board Member and mom of a daughter with Trisomy

Continuing Medical Education

Due to the generous funding by the Kosoloski Family Foundation, and the efforts of the Torchia Family, AXYS is nearly ready to launch our first CME effort, Klinefelter Syndrome in Adults. Watch your email for the announcement. We thank Hooman Sadri, MD, PhD and Stuart Howards, MD our treasurer and for leading this project and connecting us with the Wake Forest School of Medicine CME Department.

To learn more about CME preferences we are holding Parents who are Physicians Focus Group: a discussion on CME preferences to help AXYS plan to educate healthcare professionals on X&Y

X, Silvia Mann (mom of a son with XYY) and Lorena Quiroga (LA Support Group Leader and mom of a son with XXY).

Complete this survey to let us know who is coming and what topics you want to cover: <https://www.surveymonkey.com/r/Espanolchat>

• **Coming soon - XXY Parents chat.** [Contact Gail Decker for more info.](#)

Have an idea for an online group? Send an email to Carol carolm@genetic.org.

Upcoming webinar

June 13 at 2pm Matt McKeon, MS, CCC-SLP will present **Understanding Communication Disorders**. Matt is a speech pathologist and an individual with XXY. He earned a Masters in Health Science in Speech Language Pathology in 2004 from Duquesne University, Pittsburgh, PA. Moved to Northern VA in 2007 where he currently resides in with his wife and 2 daughters.

Note that past webinars are on [our YouTube channel](#).

And if you missed our fantastic webinar, "School's Out! Now What?" or want to check out the distance learning and educational resources visit this page: <https://genetic.org/education/schools-out-now-what-distance-learning-resources/>

variations. [We ask parents who are doctors to join this focus group to help AXYS guide our CME efforts.](#)

June 23, 7pm. Led by Carrie Riby and Carol Meerschaert.

Families of Color

During the 2019 AXYS Family Conference, a group met to discuss how AXYS can strengthen our outreach to families of color. We know that X&Y variations are not linked to any ethnicity and we value diversity and inclusion. [Please join this effort by attending an online kickoff meeting on Tuesday, June 16 at 7PM.](#)

If you are interested, but cannot attend this planning meeting write to Carol to volunteer: carolm@genetic.org.



ACRC Moves Online too

We had to cancel our in-person [ACRC](#) meeting in March due to COVID 19. Robby Miller deftly transformed the meeting into a series of webinars, the first held May 29. The ACRC is working on creating clinics for adults with X&Y variations, a patient registry, CME projects, expanding the ACRC and finalizing the consensus documents. Watch for news on all of these exciting topics!

Thanks to [Clarus Therapeutics](#) for sponsoring this meeting.

AXYS CafePress Store

Support AXYS while stylishly raising awareness with an item from our [Cafe Press shop!](#)

Amazon Smile

Do you shop on Amazon? Remember to use [Amazon Smile](#) (be sure to set your charity to AXYS using [this guide](#)) and Amazon will donate a portion of your purchase to AXYS!

Facebook Fundraisers

Looking to honor someone for their or graduation? You can support AXYS [Facebook fundraiser!](#)

AXYS
PO Box 659
Paoli, PA 19301-0659
888-999-9428 | [Email](#) | [Website](#)
Email not displaying correctly?
[View it in your browser](#)
[Unsubscribe](#)

Stay Connected



[Donate Now](#)