



The Even
Exchange
Spring
2019

2019 AXYS Family Conference

Visit our [conference website](#) to view the [conference agenda](#), find [fun things to do in Atlanta](#), [book your hotel room](#) and of course [register for the conference](#).



Support Group Leaders to meet at the conference

Those who currently lead regional and/or online support groups and those interested in doing so will meet during the conference on Saturday at 5 pm. [Contact Carol](#) for more information.

Road to Atlanta Rewards Program

Be rewarded with FREE registration to the 2019 AXYS Family conference, hotel accommodations or both when reaching the reward level you choose in our new [Road to Atlanta "rewards" program](#). If you are participating in the program and achieve your goal, AXYS will handle your registration and hotel room so you need not register or book your room beforehand. Sign up and start fundraising today. (The Road to Atlanta fundraiser deadline is May 31.)

Please support those in our community who are participating in the [Road to Atlanta "rewards" program](#). Choose any of the fundraisers and make a generous donation to help them meet their goals and attend the conference.



XXYY Family Gathering

The XXYY gathering will take place after the AXYS Conference from June 30th-July 2nd. We will be staying at the Embassy Suites in Downtown Atlanta. We are planning a meet and greet for Sunday evening. Monday is sightseeing which will include the Georgia Aquarium & the World of Coca Cola with some time for relaxing by the pool. Tuesday will be a half day of sightseeing as this will be a travel day for most. Nine families have signed up so far.

Research Opportunities

As a service to the X and Y variation community, AXYS shares studies that individuals, parents or families may want to consider joining. All listed studies have been approved by their respective Institutional Review Boards (IRB), and a copy of that approval is on file with AXYS. Check out the current opportunities on our [Research Opportunities](#) webpage.



AXYS Clinic and Research Consortium Spotlight:

Klinefelter and All XY Variations Program at the Children's Hospital of Philadelphia

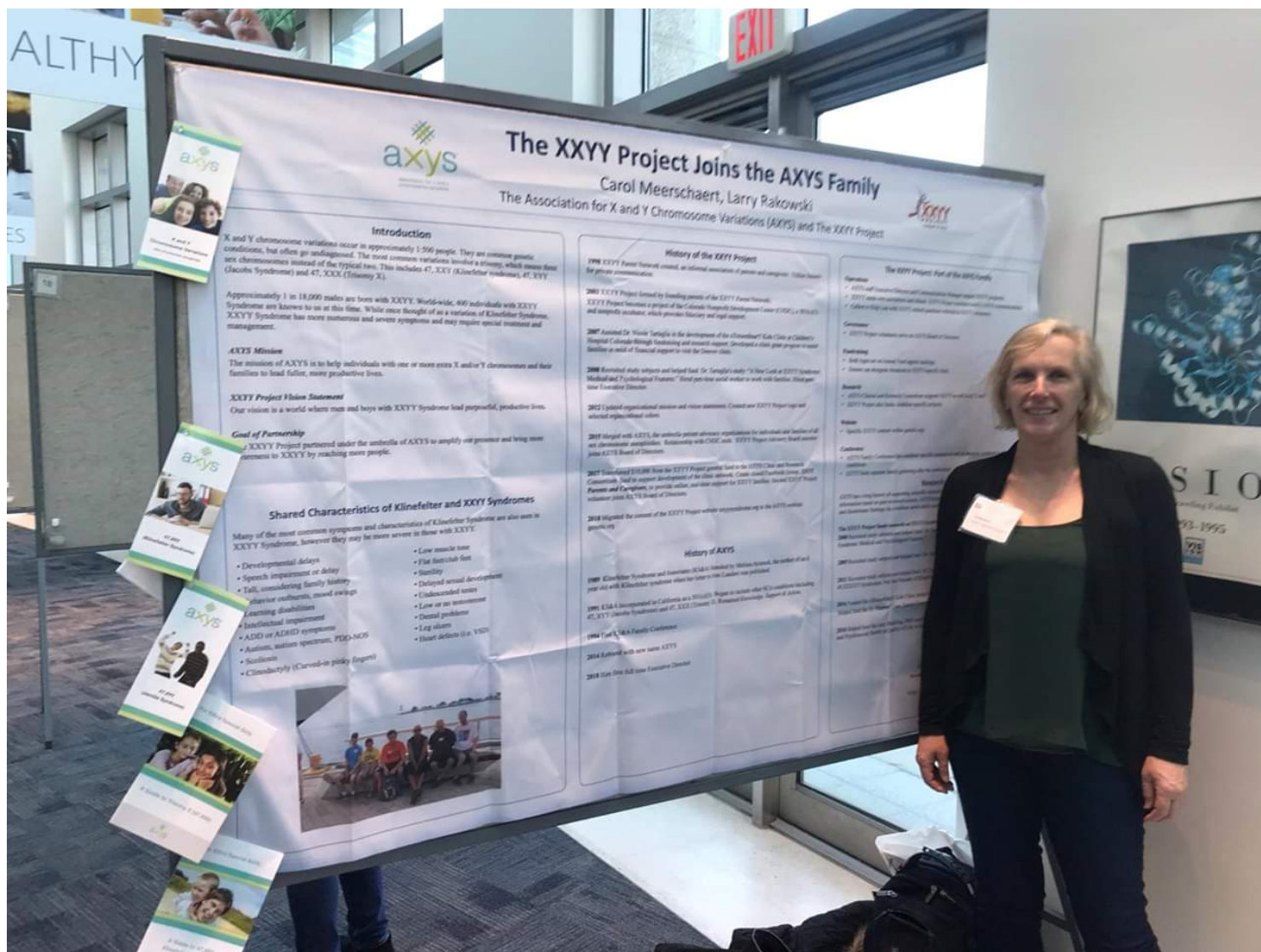
In 2015, the AXYS Board of Directors created the AXYS Clinic and Research Consortium (ACRC). This consortium operates as independent clinics which collaborate with one another, share informational resources, and explore opportunities to participate in joint research projects.

In 2018 the [Klinefelter and All XY Variations Program at the Children's Hospital of Philadelphia](#) (CHOP) joined the ACRC.

[Read the CHOP ACRC Spotlight on the AXYS website.](#)

Update on the Development of Adult Specialty Clinics

A team consisting of AXYS staff and board members met with representatives from the AXYS Clinic & Research Consortium members at Children's Hospital Colorado and Emory University Medical Center to begin our work to establish adult specialty clinics. They are developing protocols for piloting these clinics. Watch for a survey regarding this soon.



AXYS and XXYY Project Poster at Rare Disease Day at NIH

Nearly 700 researchers, advocates, parents, individuals with a condition, and non-profit association professionals gathered for [Rare Disease Day at NIH](#).

Carol Meerschaert, our Executive Director, presented a poster titled, "[The XXYY Project Joins the AXYS Family](#)." Presenting a poster shines a light on AXYS and the conditions we represent.

When considered in aggregate, [X and Y chromosome variations](#) are not rare, but our community has a great deal in common with the rare disorder community: the struggle to be diagnosed, a lack of healthcare providers that are well-informed about our conditions, a desire for more research, and a mission to enhance the lives of those living with our conditions.

Volunteer

Do you want to get more involved? Visit our [committee webpage](#) to learn about the committees and let us know if you'd like to be involved. We have opportunities of all sizes from a one-time task to ongoing planning. Send an email to our [Executive Director Carol Meerschaert](#) and let her know how you can help. She will connect you with the committee leader that best matches your talents and the time that you can offer.



AXYS Webinars

[Register now](#) for our next webinar, "Engaging the X & Y Chromosome Variation Community in Research from Birth to Adulthood" to be held on April 18. In this webinar, Drs. Nicole Tartaglia and Shanlee Davis will discuss why clinical research matters and the importance of research studies in promoting better care for infants and young adults with X & Y chromosome variations. They will address how you can best evaluate research opportunities (terminology, examples of research, questions to ask, how you can contribute) and share current research opportunities across the US.

Did you know past webinars are available on demand on the [AXYS YouTube channel](#)? Take some time to view:

[Susan Howell MS, CGC, MBA - Disclosing the Diagnosis in X and Y Variations](#)

[Tracy Prout, PhD - How to Keep Your Cool Around Disruptive Behaviors](#)

And over 100 more videos. Do you have a suggestion for a topic or speaker? [Write to Carol](#) with your suggestions.

Library on AXYS website

When you seek information on X and Y conditions, please visit the [Library](#) tab on our website. The [Research Articles List](#) page makes it easy to search for a specific article in our library. You can search by name, author names, or date of publication.

Support Groups

AXYS Support Groups are facilitated by volunteers who schedule the programs and often arrange for speakers on topics of interest to individuals and families affected by X and Y variations. These groups offer the opportunity to share experiences and resources that they have found valuable. Some of our groups are affiliated with AXYS Clinic and Research Consortium hospitals, and they meet in those facilities. Other groups meet in libraries, medical centers, or churches. Here are some upcoming meetings. See our [Support Group page](#) for a full listing of all groups.

Upcoming Support Group Meetings:

[April 13, 2019: NEXXYS Support Group Meeting, Nashua, New Hampshire](#)

[May 4, 2019: Upstate NY Support Group Meeting, East Rochester, New York](#)

[May 18, 2019: Twin Cities Support Group Meeting, Chanhassen, Minnesota](#)

September 29, 2019: [San Francisco Bay Area Support Group](#) Family Picnic (time and location TBD)



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