



Dedicated to providing information, connection and support to individuals with one or more extra X or Y chromosomes.

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AXYS at ACMG

AXYS had a booth, staffed by board member Myra Byrd, at the **Annual Clinical Medical Genetics Meeting** in Charlotte, North Carolina. It was a great way to spread awareness about X and

ACRC Gathers in Chicago

Members of the **AXYS Clinic & Research Consortium (ACRC)** met in April for an all-day meeting to discuss how to better serve the X and Y

Y variations to key professionals and Myra reported that many of them stopped by to chat, learn more about X and Y variations, and pick up one of our helpful booklets.



AXYS Seeking Personal Stories

Under the Variations section of the AXYS website, there is a section on personal stories submitted by families. AXYS is seeking additional stories for the genetic signatures: 47,XYY; 47,XXX; 48,XXYY; 48,XXXY in addition to 47,XXY. It isn't necessary to provide a photo or last name. A short story of 600-800 words is ideal, providing details about age and circumstances of diagnosis, finding appropriate educational strategies and treatment, and impact on the life of the individual and his or her family. We are looking for stories at all life stages from prenatal to adult. Visitors to the website are very interested in reading this material. Please submit your story to info@genetic.org.

Webinars, Webinars!

***Does AXYS record the webinars?
Yes, we do!***

Was there a presentation that you missed? Not to worry. We usually post all webinars within a day or two of their airing. On our dedicated AXYS

variation community and improve overall research. Topics included the development consensus-based treatment guidelines, how to better serve adults, and how to increase government funding of research.

[Learn More](#)



Research News

- all variations

New Articles

AXYS has made it easier to find the latest research news by adding an option in the "News" section of our website home page called "**Research & Treatment Articles.**" Recently we added the following:

- **Vocal and gestural productions of 24-month-old children with sex chromosome trisomies**
- **Klinefelter syndrome: more than hypogonadism**

Opportunities for Families to Participate

AXYS maintains a webpage called "Research Opportunities for Families." There are many ways your participation can make a difference. Not all opportunities involve travel. In fact, some simply require the completion of an online survey.

Here's one of the the latest opportunities we posted:

- **The eXtraordinary Babies Study: Researching the Natural History of**

YouTube channel, you'll find 20 recordings from the past two years.

[View the webinars](#)

Upcoming Webinars

- **May 1, 2018: Pete Wright of Wrightslaw – IEP and 504 Plans for Students with X and Y Variations [Register](#)**
- **May 16, 2018 Susan Howell, MA, CGC – [Disclosing the Diagnosis in X and Y Variations](#)**

Please be sure to visit the AXYS website home page calendar for news about other upcoming webinars.

[Learn More](#)

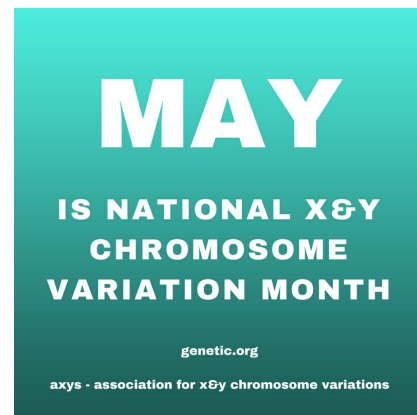
Health and Neurodevelopment in Infants and Young Children with Sex Chromosome Trisomy

This study is designed to research the natural history of neurodevelopment, health and early hormonal function in infants with XXY, XYY, XXX and other sex chromosome variations in an effort to identify early predictors of developmental and health outcomes. We will also evaluate different developmental screening tools in infants with sex chromosome variations so we can develop recommendations for pediatrician caring for infants and young children.

May is National X & Y Chromosome Variation Awareness Month

May 1st kicks off National X & Y Chromosome Variation Awareness Month. This is a great time to spread awareness by educating others about your or your child's condition. With greater awareness comes greater acceptance. You can start by sharing information with your doctors, nurses and dentists. But don't stop there - educate your pharmacist, school nurse, teachers, family and friends too. The more that people know, the more they will understand, and greater understanding will lead to more support for all of those with an X & Y variation.

Did you know that if we all do our part to increase awareness it will help to encourage better support from educators, educate more medical professionals, establish more specialized clinics dedicated to X & Y chromosome variations, and help to fund much needed research?



Throughout the month, AXYS will be giving you ideas on how you can get involved in spreading awareness. We hope you will pledge to become part of the change we all wish to see for the X & Y community.

[Get involved!](#)

Update: Bregante Family's



As reported in our last issue, the Bregante Family of San Diego, CA is matching, dollar for dollar, donations to AXYS up to 5,000. We're now halfway there. The Bregantes are particularly interested in improving knowledge about adults with an X or Y variation, and their contribution will be targeted to that part of our mission and goals. Please help us match their grant by clicking [here](#). Thank you!

XXYY Project

New content has been added to the AXYS website regarding 48,XXYY. You'll find a new **overview/summary of XXYY** [here](#) and an Letter to the Editor of the Asian Journal of Andrology titled "**Fertility achieved through in vitro fertilization in a male patient with 48,XXYY syndrome**" [here](#).

Changes coming to the XXYY Project website

Sometime in the months to come, visitors to the XXYY Project website at <http://xyysyndrome.org/main/> should expect to be redirected to <https://genetic.org/variations/about-xyyy/> where the XXYY Project will be fully integrated within the AXYS website. Don't worry, the XXYY Project is not going away! It's just taking its rightful place as one of the important X and Y variations under the AXYS umbrella.

What's New at Genetic.org

We've been working hard to make it easier to find the latest research and treatment articles. Clicking under the home page graphic/link beneath the word "News" will now show you the very latest and greatest in content.

The following links will take you to AXYS website pages that have new content added in the past few months. Take a look!

- [Library of Research & Treatment Articles](#)
- [Prior Webinars](#)
- [Ways to Give to AXYS](#)
- [Featured Research Papers](#)

Upcoming Events

Conferences

- May 4, 2018: Triple X conference - Garvin Institute for Genetic Research at Darlinghurst, Sydney, Australia. Learn more [here](#).

Support Groups (click [here](#) for details about support groups and the following meetings)

- May 26, 2018: 1pm- AXYS Los Angeles Support Group Potluck for KS/XXY. [831 N. Clybourn Ave. Burbank, CA.](#) Please RSVP.
- June 8-10, 2018: Western Europe XXYY Family Gathering, Reinhardshagen, Germany
- June 16, 2018: 10am-12pm- AXYS Chicagoland Connections Support Group for X&Y variations: Rush University Medical Ctr, [1653 W. Congress Pkwy, Chicago IL](#)
- July 21, 2018: 1pm- AXYS Los Angeles Support Group Potluck for ALL variations. [831 N. Clybourn Ave. Burbank, CA.](#) Please RSVP.
- October 27, 2018: 1-4pm: Massachusetts Area States Trisomy X Support Group. "Taking it to the MaXXX," Good Shepard Parish, [99 Main St. Wayland, MA.](#)

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