



THE EVEN EXCHANGE AXYS Newsletter - Fall 2016

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[For more news, upcoming events and information visit the AXYS website](#)

Upcoming Events

October 21: Los Angeles Area Support Group workshop for teachers and parents re: IEPs for kids with X & Y variations. 11am, Jocelyn Ctr., Burbank, CA. For details contact Lorena Quiroga 818-640-5393 or lorena.quiroga3@gmail.com. Also monthly mtgs. last Wed. every month.

October 29: SE Support Group meeting 1-4pm at Emory Univ. in Atlanta, Nell Hodgson Woodruff School of Nursing, Rm 276. Speakers: Brandi Kern, Parent to Parent of GA, on accessing resources + an update on the Emory clinic from Drs. Sharron Close & Amy Talboy.

October 30: New York Tri-State SCA Support Group mtg. 1-4pm. Hillwood Commons, Long Island University, 720 Northern Blvd., Brookville, NY. (accessible by bus from Hicksville train station) RSVP Anita at akychambers@gmail.com. \$5 family fee for refreshments.

November 5: Massachusetts Area States Trisomy X Support Group mtg. 1-4pm, Good Shepard Parish, 99 Main St., Wayland, MA. Girls/Ladies with Trisomy X and their families are

welcome. RSVP by 11/1/16 to Joanne Burke Jomamaburke@comcast.net

December 11: Midwest Support Group mtg: 1-3pm, Lawrence Memorial Hospital, 330 Arkansas, Lawrence, KS. Please bring your favorite holiday treat to share. RSVP Julie Urban at 785-766-4801 or jurbanslp@yahoo.com

XXYY Project Events: The XXYY Project tracks and promotes XXYY-related events throughout the world. Please visit <http://xyysyndrome.org/main/events/> for a complete listing.

[Please visit the AXYS Support Groups page for more details about these events.](#)

ALL CONDITIONS

The AXYS Family Conference is coming in 2017!

Mark your calendars for **Saturday & Sunday, June 24-25, 2017** for the AXYS Family Conference at Children's Hospital Colorado in Aurora. (Near Denver.) This event will bring together those from all the X and Y variations, of all ages, along with most of the leading clinicians, therapists and educators.

Here's what AXYS board member Carrie Riby shared about her prior conference attendance:

"I remember going to my first AXYS (at the time KS&A) conference over 10 years ago. My son at the age of 16 had just been diagnosed with XXY and while he was doing fine, I was in shock. I had never heard of Klinefelter Syndrome, let alone knew anything about it. It was great to meet other young men like my son and speak to the parents. Sharing our challenges and confirming why we were so lucky to have such amazing kids was transformative for me. The industry experts at the event gave me back some control that I thought I had lost in the initial diagnosis. It was such a relief to hear that we were not alone and that there was help and support available."

Details, including pricing, hotel information and speakers will be published in January.

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Report from the National Society of Genetic Counselors Meeting

by Myra Byrd, Chair, AXYS Board of Directors

I wanted to give everyone a brief update on the National Society of Genetic Counselors conference I attended last week in Seattle. AXYS had a booth to distribute information and AXYS board member Kimberly Daly came up from Portland to help with that effort. I was part of a panel on the effect that cell-free DNA screening (also known as NIPT or NIPS) is having on Patient Advocacy groups. Note: there is a push by the Genetic Counselors to refer to Non-invasive Prenatal Testing or Screening as cell-free DNA screening. Testing implies a diagnosis and the fact that cfDNA is not diagnostic is one of the biggest misconceptions. Many genetic counselors see the cfDNA screening as a public health crisis because of the burden it is putting on advocacy groups and they encouraged AXYS to help tackle the issue.

Genetic Counselors who visited our booth were excited to learn about the AXYS Clinic & Research Consortium (ACRC) as many feel strongly about the need for clinics especially for newly diagnosed patients. Many counselors mentioned that knowing there is support from AXYS, and available clinical care, makes a patient more likely to continue the pregnancy and to feel hopeful.

A huge thank you to Virginia Cover for all she has done to produce the materials we use: her book, the pamphlets and the booklets. So many counselors came by the booth to pick up pamphlets and to tell us how fantastic our materials are and how often they use and refer patients to our website. They would walk up and say "I love AXYS!"



I wish all of you could have been there because it really is so gratifying to hear how important the work we do is for Genetic Counselors. It was like a 4-day love fest of appreciation!

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Research Opportunities for Families

AXYS provides a dedicated webpage for researchers from around the world who are wanting to recruit individuals or families for a research project they are conducting. These projects can range from the very simple, for example, a request to go online and complete a survey, to the more complex, including requirements for travel to a research institution and a multi-day stay.

All requests for AXYS to post a research opportunity are reviewed by the appropriate member or members of our professional advisory board and AXYS always requires a copy of the approval or certification document from the researchers Institutional Review Board (IRB).

While the list of opportunities is always changing, at the the time of publication of this newsletter these were the titles of the current projects:

- **National Institutes of Health (NIH) Behavioral, Cognitive, and Brain Imaging Study for Boys and Young Men with XYY**
- **Cardiometabolic Profiles of Boys with Klinefelter Syndrome (47,XXY)**
- **Body Composition in Infants with Klinefelter Syndrome and Effects of Testosterone Treatment**
- **Psychological and Motor Effects of Testosterone Therapy in Young Adolescents with Klinefelter Syndrome (47,XXY)**
- **The OXYGEN Study: The impact of genetic diagnosis of XYY, XXX, and XXY on life course quality of life**
- **Chromosome Abnormalities Involving the Sex Chromosomes: Clinical Study of Patients with Sex Chromosome Variants**
- **Understanding the extent to which family background influences learning and behavioral symptoms in individuals with Turner syndrome, Klinefelter syndrome, and Trisomy X.**

[More details about the above research projects including how to enroll](#)

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Meeting of the AXYS Clinic & Research Consortium (ACRC)



by Robert Miller, AXYS Interim Executive Director

With the financial support of AXYS, on August 14 all members of the ACRC met in Atlanta to share information and plan for the future. While the four-hour meeting delved into many topics, two important points emerged: All services should be evidenced-based or, at minimum, consensus-based, and the goal of services should always start from: how things can be made better and easier for families.

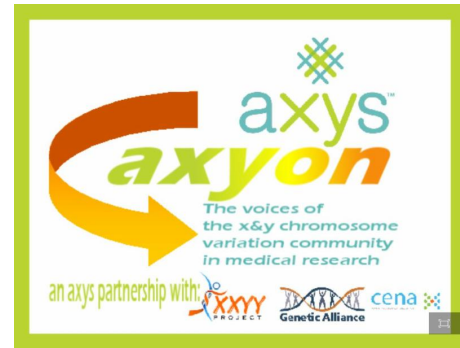
AXYS will continue to support regular meetings of the ACRC as it continues to discuss topics such as minimum standards for membership as well as services that are encouraged, though optional.

Families that are interested in seeing a X and Y variations clinic in their area are encouraged to contact AXYS.

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Advance research by participating in the **AXYON Registry**

by Susan Howell, MS, CGC, MBA and member of the AXYS Board of Directors



We are making progress but we need your participation in the AXYON Registry!

We have now reached 235 people in the AXYON registry. This is great, but we need more! The more people who enter information into the registry, the more powerful and useful the information is to researchers, and the more likely they will use our data and publish scientific papers about our variations. Help advance our cause for:

More awareness! Better education to professionals!

More funding to help promote further research and development of treatments for our families!

[Click here to access the AXYON registry and enter your information today.](#)

XXX

Expanding the Phenotype of Triple X Syndrome: A Comparison of Prenatal Versus Postnatal Diagnosis

AXYS is excited to see a newly published article about Trisomy X. While fairly technical in nature, this new peer-reviewed article in the American Journal of Medical Genetics is one of the few to delve deeply into Trisomy X syndrome. Therefore, AXYS is sharing it with our readers along with the suggestion that you share it with your medical providers including doctors and genetic counselors. We also would like to direct you to page 10 of the report where you will find a helpful summary of evaluation and treatment recommendations.

Thank you to all families who participate in such research!

[Read the full article here](#)

XXY

Advances in the Interdisciplinary Care of Children with Klinefelter Syndrome

In case you missed it when we first added this to our important news section, or didn't see the Facebook post, take a look at this important document and share it with your child's doctors, therapists and educators.

[Read the full article here](#)

The New AXYS Website is Almost Ready!

by Robert Miller, AXYS Interim Executive Director

We heard you and we've been hard at work on a brand new site that utilizes state-of-the-art website design and is much easier to navigate than our current site. Much of the site will be better divided into condition-specific sections and drop-down menus will ease your search for the specific information that is important to you. Our team is also working to make some of the more technical language more understandable for us non-scientists!

So hold tight. Our goal is to launch the new site in November.



AXYS Says Goodbye to Two Long-time Board Members

by Myra Byrd, Chair, AXYS Board of Directors

Shiela Clark has served on the AXYS (formerly KS&A) Board of Directors since 1993. She became involved with the organization when her son, Jim, was a teenager and has served as the Secretary-Treasurer and Secretary. Shiela and Jim have attended most of the AXYS conferences and she has been an invaluable asset to AXYS as a volunteer. Her 23 years on the Board also made her our unofficial historian! Shiela is a schoolteacher in California and recently decided that she would "retire" from the Board. We are tremendously grateful for her decades of service and will dearly miss her.

Roberta Rappaport recently decided it was time for her to leave the Board of Directors. Roberta founded the American Association for Klinefelter Syndrome Information & Support (AAKSIS) in 1999 to focus on the needs of adult men with Klinefelter Syndrome. Later, AAKSIS began holding its annual conference with what was then called KS&A. In 2013 the AAKSIS Board of Directors voted to cease operation and merge with KS&A and Roberta joined the Board of Directors of what became AXYS. Recently, Roberta saw to it that the development of the new AXYS website received the significant financial support that was necessary for it to move forward. Roberta has worked tirelessly on behalf of those affected by Klinefelter Syndrome and we thank her for all her contributions to the Klinefelter community and to AXYS!

How to Support AXYS During This Important Time

AXYS depends primarily on the support of people like you; individuals, parents and extended family members. As we move forward with many initiatives, our need for your help is ever greater. Won't you please consider a [donation](#) - of any amount - and support our work on the following projects:

New Website

- making your access to the latest and greatest information easier!

Clinics

- bringing evidence-based treatment to all parts of the country!

Support Groups

- making sure that no family or individual is alone with the diagnosis of an X or Y variation!

Research Registry

- helping the professional community succeed in better understanding X and Y variations!

Family Conference

- bringing the X and Y community of individuals, families and professionals together!

[DONATE HERE](#)

*Considering donating but want to talk about AXYS and our plans going forward?
We'd love to talk with you! Send an email to director@genetic.org and we'll make
sure you get connected to the right person.*

AXYS | (888) 999-9428 | Email | Website

STAY CONNECTED:

