



THE EVEN EXCHANGE

AXYS Newsletter - Summer 2017

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

Upcoming Events

Click [here](#) to visit the support group page where you will find more detail about each of the following U.S. events. International XXYY events can be found [here](#).

August 18-21: 48 XXYY UK Support Group Family Meet-Up, Derbyshire, England

September 16: 2-4pm in Room 276 at Emory University's Nell Hodgson Woodruff School of Nursing, 1520 Clifton Road, Atlanta, GA. The speakers, attorneys Heather Nadler and Mark Biernath of Nader Biernath, LLC, will share from their expertise in estate and special needs planning.

October 1: 10am, Sydney, Australia XXYY Meet Up. CENTENNIAL PARK NSW. Bring picnic rugs or chairs, your own food & drinks, sunscreen, hats. Contact Carol Vigo 0401 170 060.

AXYS Receives Two Grants to Promote Education Through Webinars

AXYS is pleased to announce that Endo Pharmaceuticals has awarded AXYS a \$15,000 Community Partnership grant to fund online and in-person health promotion programs for adults with XXY. In addition, Roche Diagnostics Corporation awarded AXYS \$10,000 for patient education and health promotion programs for all X and Y variations. The funding allows AXYS to provide a series of webinars featuring professionals with expertise in Klinefelter syndrome and other X and Y variations. Webinars can be accessed through viewers' home computers in real time or later as stored broadcasts on the website. AXYS expects to cover topics such as hormone replacement, minimizing complications such as DVT and osteoporosis, prenatal screening, assisted reproduction, and enhancing emotional health. The grant also provides seed money for local support group meetings. Watch the website for the webinar schedule, coming in early Fall.

AXYS to Launch Professional Directory

The most common questions to the AXYS Help Line request health care provider recommendations by geographical region. AXYS has promoted development of the Clinic and Research Consortium but also recognizes the need to maintain a listing of local providers for the X/Y Variation community. This directory will be built by members who can submit the name and contact information for providers who have shown interest and competence in gaining clinical expertise in X and Y variations. Providers submitted to the Professional Directory must be licensed in their state in their particular area of practice. AXYS cannot vet providers, and the directory contains a disclaimer that the organization itself does not specifically recommend these professionals. Thanks to Stefan Schwarz and to the Trisomy X community for their contributions of provider lists that they have maintained privately over the years. AXYS invites additions to the directory now using the form available on the website at: <https://genetic.org/professional-directory/>

The directory will be available for viewing in September.

The AXYS 2017 Family Conference

Videos and Slides now available

Not everyone was able to make it to Children's Hospital of Colorado for the AXYS Family Conference. That's why AXYS made sure to tape numerous sessions and to request slides from all presenters. These presentations provide in-depth contents; some specific to one variation or another, some to all variations. Here's where to find them:

[VIDEOS](#)

[SLIDES](#)

Coming Soon! New research opportunities are on the horizon

The eXtraordinaryY Kids Clinic is excited to announce several upcoming research opportunities for children (birth to 5) with XXY, XXX, and XYY starting Fall/Winter 2017! Led by Dr. Nicole Tartaglia, Dr. Sophie van Rijn, Dr. Judy Ross, and Dr. Shanlee Davis. Study sites in Denver and Philadelphia. For more information, contact: extraordinarykidsclinic@childrenscolorado.org

Participate in Research

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. Take a look [here](#).

Hundred Hole Hike: 16 hours, 181 holes and 101,841 steps in Support of AXYS

Brandon Urban, as noted in our Spring newsletter, cares about AXYS and the work it does. [Read more](#) about Brandon's recent exhausting, but ultimately rewarding, Hundred Hole Hike.

We Made It!

Phase 1 of our Matching Funds Campaign Reaches Goal

Myra & Michael Byrd generously said that if AXYS supporters donated \$10,000 they would match it with a personal donation of their own.

Thanks to you, we made it! This will help us to continue to build and manage the AXYS Clinic & Research Consortium, develop a Professional Directory, continue to enhance our website, and many, more things. Now get ready for phase 2 where another generous donor has stepped forward and offered to provide a \$5000 matching grant! We'll be reaching out to you soon with information as to how you can help us reach that goal. In the meantime, we appreciate your understanding that an organization such as AXYS, which receives no government funding, must always be looking to the community for help.



Exciting News from the AXYS Clinic & Research Consortium (ACRC)



"Consensus Documents" being planned

By Robert Miller, AXYS Executive Director

The afternoon prior to the recent AXYS Family Conference saw a meeting of the ACRC. All but one of the nine clinics were represented. The discussions were deep. While many plans for going forward were considered, one in particular will have profound implications for the X and Y variation community; That is the development of consensus documents summarizing what the experts believe to be state-of-the-art interventions for X and Y variations.

Consensus documents go by many other names including "Care Considerations" and "Treatment Recommendations." Regardless of what they are called, they will be written for professionals but in such a way that they are understandable and useful to families.

Consensus develops over time, as enough people work with enough individuals for an agreement to develop about what works and what doesn't. In many ways, consensus can be equated to "professional opinion." It is based on the notion that if a significant number of professionals, particularly from a variety of relevant disciplines, agree about a particular topic, it may indicate that there is some validity to the matter on which they agree. Coming to consensus can be a time-consuming process, involving much discussion and a critical review of any literature that already exists regarding the intervention, however, in the absence of scientific evidence, consensus-based intervention is the next best thing.

AXYS will keep you updated on the development of these documents which will, sometime in 2018, be posted on our website.

[Read more about the clinics](#)

Cognitive Performance and Quality of Life Issues

by Gary Glissman

In case you have not had a chance to visit the AXYS website lately, several new research papers (see below) have been added in the library that you may want to review and also share with your health care providers and others. Two of these articles involve research by Dr. Claus Gravholt and his team at the Department of Endocrinology and Internal Medicine at Aarhus University Hospital in Denmark. This multidisciplinary clinic specializes in treating XXY individuals over the age of 15 and is one of the few clinics in the world that has that distinction. They see more than 400 adult patients with KS and have published a number of excellent research papers in the past based on their experiences. [Read all of Gary's article...](#)

- [Quality of Life in Men with Klinefelter Syndrome: the Impact of Genotype, Health, Socioeconomics, and Sexual Function](#)
 - [The Role of Genes, Intelligence, Personality, and Social Engagement in Cognitive Performance in Klinefelter Syndrome](#)
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Building Community

by Myra Byrd

Now that I have handed over the board chair role to Gary Glissman (see article at end of this newsletter), I am able to focus more of my attention on issues related to XYY. I'm interested in ideas for building our community, including having online support group meetings, regular support calls and regional support group meetings with a speaker.

If you aren't a member of our Facebook group, but are on Facebook, please join our AXYS XYY page. If you are on the XYY Chromosome Disorder page, please encourage people to join our page as well. Both groups are "Closed" Facebook groups. In a Closed group, people not in the group can see who the members of the group are, but not their posts. No one except members can post.

I've been involved with AXYS (formerly KS&A) since 2005, on the Board since 2006 and I chaired the Board of Directors for 7 years. In that time, I've seen the XXYY, Trisomy X and XXY communities grow while our 47,XYY community remained very small. With your help, I'm hoping to change that! If you have ideas or questions, are interested in helping to moderate the Facebook page or helping to coordinate any of these activities, please email me at myrabyrd@aol.com.

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

If you've never read the April 2016 article by Kristen Wigby, Cheryl D'Epagnier, Susan Howell, Amy Reicks, Rebecca Wilson, Lisa Cordeiro, and Nicole Tartaglia, you'll now find it on our website [here...](#)

The XXYY Project: Post-Conference Gathering

Sibling video project shared by Dr. Nicole Tartaglia

By Gail Decker

The post-conference gathering was held at The Great Wolf Lodge in Colorado Springs, CO. We had 14 xxyy guys and their families meet up and we all had a blast! It was nice to have social time with all. The guys were able to enjoy the resort which had mini golf, a water park, and of course an arcade!! It was great to catch up with old friends and meet some new families and welcome them into the mix. We even had a visit from Dr. Tartaglia, who did a brief presentation on research and shared a video that her interns worked on last year. The video showed how the siblings of xxyy guys are affected by this genetic condition. It was interesting to see that whether the siblings were younger or older than their xxyy sibling, they were affected in some way. I'm not saying that they were affected in a bad way but it did touch their lives more than we thought. They had to learn coping skills to deal with their brother. They weren't mad, but didn't know what to do to help. It was eye opening to the parents that watched the video for the first time, as we often forget that our other children are part of the equation when dealing with xxyy!

All Variations

Recommended Reading

Sex Chromosome Variations

This is an article written by AXYS board member Ginnie Isaacs Cover, MSW, MBA for the July 2017 issue of Exceptional Parent magazine. It provides some general information on sex chromosome variations and highlights certain challenges parents can face in getting the appropriate care and assistance for their child. [Read here...](#)

Changes at AXYS

by Myra Byrd

In the spring of 2005, I was part of the planning committee for the first ever Family Conference on Trisomy X and 47,XYY. We gathered at UC-Davis in Sacramento and that's where I met some of you for the first time, including Dr. Nicole Tartaglia! My son, Andrew was 5 years old at that conference. We had known his diagnosis of 47,XYY since I was 12 weeks pregnant, but we'd never met anyone else with the condition, nor anyone who knew much about it. In May of 2005, I was asked to join the Board of Directors of what was then called KS&A and is now AXYS. I became Vice-Chairman in 2009 and seven years ago, I became Chairman of your Board of Directors. No other position I've held has brought me more pride, joy, satisfaction and challenges. It has been my honor and privilege to serve this organization and those affected by X and Y chromosome variations. To say it has been life-changing would be a vast understatement!

As much as I love serving in this role, it's time for me to put on another hat within AXYS. I feel a bit of nostalgia about the change, but I'm excited for the new challenges and goals ahead. I will still be involved with the Board of Directors and committed to cultivating our network of clinics in the AXYS Clinic and Research Consortium. I'm also determined to grow the 47,XYY community within AXYS and will devote more time to the Facebook pages we maintain.

I am leaving the Chairman's position in the very capable hands of Gary Glissman. Most of you know him from our conferences and the AXYS Facebook pages. Gary has an adult son with 47,XXY and a background as a registered nurse and healthcare administrator, all of which have been wonderful experiences and viewpoints to bring to the Board. Gary has been serving as Vice-Chairman for many years and often stepped into the Chairman's position in my absence. He has worked especially hard to broaden our library of articles on X and Y chromosome variations and has been the driving force behind our Criminal Justice initiative. I know that Gary will be a fantastic Chairman of the AXYS Board of Directors!

I can't end my time as Chairman without thanking everyone who served on the Board of Directors during my tenure and the three Executive Directors who made everything work

smoothly in our day to day operations. I am also especially grateful to all of YOU, because without your donations, AXYS and the services we provide would not exist. I will "see" all of you on social media and of course at future conferences. Thank you for allowing me to serve alongside you.

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STAY CONNECTED:



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