



THE EVEN EXCHANGE

AXYS Newsletter - Summer 2016

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

Upcoming Events

July 30, 2016: Los Angeles Area Support Group Picnic, 1:00 - 4:00pm, 831 Clybourn Ave., Burbank, CA 91505. Learn more [here](#).

July 31, 2016: Teen & Family Bowling and Fun! Hosted by the extraordinary Kids Clinic.

1:00pm to 3:00pm, Celebrity Lanes, 15755 E Arapahoe Rd, Centennial, CO 80016. Free bowling (shoes included) and food! RSVP by 7/27, 720-777-8361 or

susan.howell@childrencolorado.org

August 6, 2016: AXYS Upstate NY Support Group Meeting, 12:00 - 4:00pm, 230 Cobbs Hill Drive, Rochester, NY 14610. Learn more [here](#).

August 6, 2016: New England Support Group (NEXYS), 2:00 - 5:00pm, Braintree Library in the Auditorium <http://www.thayerpubliclibrary.org/>. Tom and Marie Tobin will be talking about establishing an XXY clinic at Mass General Hospital. Contact Lori Earl, Lori.earl@gmail.com

or 857-526-1339 with any questions.

August 14, 2016: AXYS Southeastern Support Group Meeting, 1:00 - 5:00pm at the [Emory Conference Center](#) in Atlanta, GA. All X and Y variations.

August 20, 2016: Informal get together and planning meeting for the New York TriState KS/SCA Support Group in Brooklyn. Visit the group's [Facebook page](#) for time, address, and other details to be posted soon. Contact momofkandt4@yahoo.com for more information.

October 13, 2016: Guest bartender night at [BBC Tavern and Grill](#) located at 4019 Kennett Pike, Greenville, DE 19807 from 6:00 - 9:00pm to benefit the Nemours extraordinary Kids Clinic.

October 23, 2016: Mid Atlantic Support Group meeting 1:00 - 4:00pm at [Nemours Alfred I. duPont Hospital for Children](#), 1600 Rockland Road, Wilmington, DE 19803 in Classroom 1.

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.

SHOP FOR A CAUSE - THROUGH JULY 31!



Bravelets™ bracelets are more than just something to wear on your wrist. They are a symbol of hope, strength and courage and are designed to help you be brave in the toughest of times. Through the end of July - only - every item purchased from Bravelets, using our link, results in a **\$10 donation to AXYS**. The link is <https://www.bravelets.com/bravepa.../x-y-chromosome-variations>. Wear something beautiful and meaningful, and support the AXYS mission at the same time!

THE NEW AXYS WEBSITE - COMING THIS FALL!

The AXYS team is hard at work on a new genetic.org that will provide you with the latest consensus and evidence-based information on an easy to navigate site. And, of course, we'll also continue to provide meaningful support and insightful stories and reports from families and professionals. We'll keep you posted as we get close to launch time.

ADHD/EXECUTIVE FUNCTIONING CAMP

by Myra Byrd, Chair, AXYS Board of Directors



For many years, AXYS parents have discussed a need for camps that could give our kids experiences and strategies to deal with the issues they face in daily life. As the parent of a son with XYY, I feared my son would not be able to keep up at a wilderness camp. Our family had experience with a more intense wilderness program for another of our children that was extremely positive. Last spring, we began searching for something that would give Andrew the benefits of wilderness therapy in an environment adaptable to his limitations. A great resource is <http://www.additudemag.com/adhd-guide/adhd-camps-schools.html>. We found a few that seemed to meet the qualifications, but the one that seemed to offer the most and fit our schedule was S.O.A.R., a 40-plus year old program based in North Carolina that offers a variety of programs in many locations for youth and young adults who have ADHD, learning disabilities (LD) and executive functioning delays.

You can see all that they offer on their website at www.soamc.org, but I will tell you about our experience with the 18 day Wyoming Academic Adventure.

[Read the complete story here](#)



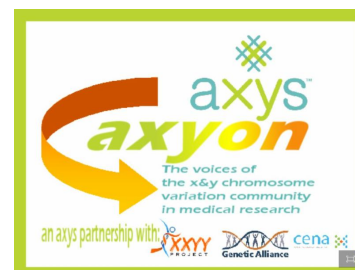
The AXYS Clinic & Research Consortium (ACRC)

by Robert Miller, AXYS Interim Executive Director

The ACRC is making steady progress towards providing quality and comprehensive evaluations and treatment, or treatment recommendations, at a variety of locations throughout the U.S. Thanks to the AXYS Board of Directors and the generous support of our donors, the ACRC members will be meeting in August to plan the next steps for this important AXYS initiative.

[Read more about the clinics](#)

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 are excited to announce that we are up to 229 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!

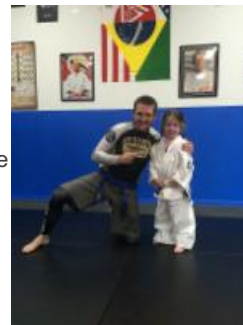
[Click here to access the AXYON registry and enter your information today.](#)

XXX

Martial Arts and the Road to Becoming Bully-Proof!

by Erin Frith, AXYS Board of Directors

Violet, age 5, recently earned her first stripe in jiu-jitsu. She studies at a local academy that has a program developed especially for teaching children on how to be "bully-proof." Violet struggled socially at the start of her first year in school. She is quiet and agreeable in loud social situations, and some children chose to take advantage of her timidness. Practicing jiu-jitsu has proven to be a fantastic opportunity to help her alleviate some of her social weaknesses, as well as compensate for some of her physical challenges. Jiu-jitsu, along with other martial arts, helps to develop muscle strength (addressing hypotonia), especially core strength. Classes also expose students to volume changes, and other physical sensory experiences, helping children learn to deal with uncomfortable sensations. Violet will even go upside down now! Jiu-jitsu has also been fantastic for Violet in her social development. She chooses to interact with peers, has become more assertive, and is not afraid to tell people to stop. Martial arts has been a fantastic experience and her father and I are excited about her continued growth in the program!



If you'd like to learn more about how we decided to enroll our daughter in a martial arts class, please feel free to contact me at erinfrith@gmail.com.

XXYY

The XXYY Sibling Project: A Voice to be Shared

by Mika and Jenna Nagamoto, Nicole Tartaglia, MD and Susan Howell, MS, CGC, MBA

The eXtraordinary Kids Clinic is excited to announce the XXYY Sibling Project! Led by the clinic's summer interns, Mika Nagamoto and Jenna Nagamoto, with dedicated support from Dr. Nicole Tartaglia, Rebecca Wilson, PsyD and Susan Howell, MS, this project aims to highlight a sibling's perspective of having a brother with XXYY, giving siblings a voice that can be heard and shared. By highlighting the positives while addressing the hardships, siblings learn and understand that they are not alone. The XXYY community consists of passionate, incredible people with many different perspectives, all of which have the potential to make a difference.

Mika and Jenna are undergraduate pre-health students currently hard at work interviewing families attending XYY gatherings in Colorado, Boston, and Los Angeles for this project. They will compile interviews and accounts of daily interactions within families of the XYY community into a short video documentary. Inspired and touched by XYY families, Mika and Jenna will continue to share their new knowledge, promoting awareness and understanding of XYY as they pursue their professional careers.

The video documentary created from this project aims to capture unique moments of sibling interaction, and relatable accounts of boys with XYY through the eyes of their siblings and parents. Individual experiences and perspectives offer advice and guidance from various members of the community. The project opens the doors into several families of XYY, further connecting everyone through their shared stories and experiences.

This video documentary will serve as a tool to advance awareness, improve education, build community and demonstrate support for XYY syndrome through audiences at conferences, symposiums, and sibling workshops. The XYY Project can promote the video to increase awareness and education for providers, families, schools and community groups. Most importantly, the video will serve as a tool to create discussion that assists in giving support and guidance to the many siblings of boys with XYY.

We are hoping to have the video completed by the end of 2016. We are grateful and offer a sincere thank you to the XYY Project and dedicated families who were willing to participate and contribute in support of this project.

XYY

Updates

by Gary Glissman, Vice-Chair, AXYS Board of Directors

One of the biggest challenges involved with XXY is the fact that it is such a variable condition relative to the neuropsychological impact it may have on different individuals. And there is no way to test for this until problems become more visible and there's no way to know how significant the challenges may become. In many ways, this issue is more of a concern to many of us than the medical challenges that are typically associated with XXY.

Fortunately there is quite a bit of research interest in this area and we're seeing more and more research papers on brain functions, brain anatomy and brain mapping. This research, combined with more studies of XXY brains and related quality of life associations, will eventually begin to produce more specific recommendations on what can be done to assist individuals with specific problems.

The important takeaway on all this for me is that despite the subtle nature of some of the challenges we see related to behavior or decisions or actions, the problems are often not voluntary or purposeful. There are things we do not yet fully understand about how brains operate that may be causing things to happen that we want to assume are choices or deliberate efforts to create problems. I would argue that we simply don't know what may be influencing certain behaviors and therefore our usual assumptions about how to correct problems may not be valid or effective.

Here are three different papers that may help explain some of this new research and how it may relate to XXY. Caution: some of these articles can be very difficult to read but can be useful when you are trying to work with other health professionals to help them understand what may be happening and encouraging them to learn more about XXY research.

* Updated Brain Map Identifies Nearly 100 New Regions

http://www.nytimes.com/2016/07/21/science/human-connectome-brain-map.html?_r=0

* Neuroanatomical correlates of Klinefelter syndrome studied in relation to

the neuropsychological profile

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3830066/pdf/main.pdf>

* A comparison of neural correlates underlying social cognition in Klinefelter syndrome

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4249469/pdf/nst190.pdf>

On another very positive note, the 2nd International Workshop on Klinefelter Syndrome was conducted this past March in Germany. It involved an amazing collection of top scientists and experts involved with XXY research and will give you a good idea of the types of things being studied and published. There is some excellent material in these papers and I would urge everyone to read through all of them.

<http://www.unitask.it/attachments/article/24/XXY%20Programmbuch-1.pdf>

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STAY CONNECTED:



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