



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

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## Letter from your new Executive Director

It is my distinct pleasure to serve as your new Executive Director. I'm touched by the warm welcome I've received from everyone in this amazing organization.

I'd like to share a bit more about me so you can get to know me better. Your first question probably is, "How do you pronounce Meerschaert?" Easy: /myrrh-sh-heart/. My grandfather came to the US from Belgium and as far as I know everyone named Meerschaert is my relative. I come from a large family, as did my Dad, so my son is the 100<sup>th</sup> descendant of my Grandma and Grandpa Meerschaert.



I do not have anyone in my large family with a SCA, *that I know of*. However, since so many people with an SCA are not diagnosed, who knows? I can relate to many of the issues that people with an SCA encounter as two of my children are on the Autism spectrum. The world of misdiagnoses, IEPs, neuropsych appointments, as well as a bundle of future hopes and concerns

are all very familiar.

You may have read a bit about me and my professional experience in a [letter from our board chair Gary](#). I grew up in Michigan, moved to Houston where I earned my BS in Nutrition from UT Houston, and then spent many years in central Massachusetts where I had a private practice as a Registered Dietitian. I moved to Maine where I earned an MBA with an emphasis on small business and marketing. Then on to the Philadelphia area to work for several non-profit associations to help them grow, get better known, and further their mission. You can find all of the [details on LinkedIn](#); feel free to link with me there.

When I am not working, I enjoy gardening, hiking, kayaking and skiing. I love being outdoors.

I am so impressed with our wonderful board of directors, clinic directors, support group leaders and caring volunteers. Your passion, skills, and dedication inspire me.

I will work diligently to further AXYS and all of our goals. And I look forward to meeting as many of you as I can via email, Facebook groups, webinars, support group meetings and at our 2019 Family Conference next June in Atlanta.

## AXYS Awarded Grant to Develop Adult Specialty Clinics



Many adults with X and Y chromosome variations experience difficulty in finding adult specialists familiar with the range of medical issues that affect them into adulthood. For many adults, there are a range of endocrinology disorders, neurological complications, and autoimmune disorders that affect their health. Many have continuing problems with psychiatric complications, autism spectrum disorders, and learning disabilities. Of approximately 500 annual calls and e-mails to the AXYS help line, 20 percent request assistance in finding medical professionals who can provide specialty consultation and treatment recommendations for adults for their primary care physicians.

In addition, many families have difficulty in obtaining medical documentation required to access disability services or receive appropriate workplace accommodations. While pediatric programs have experience with providing multi-disciplinary care, adult clinics find more difficulty in coordinating multi-disciplinary care.

[Continue the story at genetic.org](#)

## Mid-Atlantic Support Group Social Brings Families Together

On August 11th, the Mid-Atlantic Support Group held a summer social get together in Chadds Ford, PA. The gathering consisted of 22 families, 21 individuals with a variation, and over 50 attendees total. Families came from Massachusetts, New York, New Jersey, Pennsylvania, Maryland, Delaware and California. Children and adults representing XXY, XYY, XXYY and Trisomy X enjoyed a cook-out and various indoor and outdoor games. For some, it was the first time ever meeting someone else with their condition. For others, it was an opportunity to catch up with friends.



[Continue the story at genetic.org](#)

## Thank You, Mrs. Mary Ann Hyde

On behalf of everyone at AXYS I am very grateful and honored to announce that Mrs. Mary Ann Hyde has recently made a very generous gift on behalf of her son, Art. The gift was intended to help support and advance the development of adult-focused specialty clinics as well as supporting research into Klinefelter Syndrome.

Many of you may know Art from his long-time involvement with the organization formally known as KS&A (that has now evolved into AXYS). Art lives in Colorado and has known Dr. Tartaglia and her team in Denver for many years. He has been a contributor to the different KS list-serves and now social media sites and maintains a very active and independent lifestyle, including semi-annual cross-country road trips to spend time with his mother, Mary Ann, in Tennessee.

It has been my pleasure to get to know Art through email communications and from the many articles he diligently sends me on a wide range of topics associated with KS. I also had the pleasure of getting to know his mother, Mary Ann, via email messages and telephone and can tell you I only hope to be as active on my computer when I am in my 90's as she has been with me! She actively follows AXYS developments and activities and has expressed her thanks many times for everything we are trying to do to improve awareness, support and resources for the entire KS community. Her recent gift just emphasized how grateful she is to the organization for being there for her and her son.

Thanks, Mrs. Hyde and you, too, Art, for your continued involvement and support for AXYS. It is people like you that help us continue to grow and provide even more services to the entire SCA community. We really appreciate your kindness and help.

With gratitude,



Gary Glissman  
AXYS Board Chair

## New Research Opportunities for Families

The following studies are looking for volunteers.

[Learn how you can be a part of this valuable research.](#)


- NIH Behavioral, Cognitive, and Brain Imaging Study for Boys and Young Men with XXY
- Learning and Brain Development in Boys with 47,XYY Syndrome, Idiopathic Autism, & Typically Developing Control Boys
- The Relationship of Physical Function and Psychosocial Health on Quality of Life in Men with 48,XXYY
- Family Experiences and Attitudes on Support When Receiving the Diagnosis of an X & Y Chromosome Variation



**NIH Research Study**  
seeking participants with  
**XXY Chromosome Variation**

**Currently enrolling**  
**males ages 5-25.**

No cost.  
Compensation, flights, hotels included.

 **NIH** National Institutes of Health  
Bethesda, MD (Washington, DC)

[www.nimh.nih.gov/JoinAStudy](http://www.nimh.nih.gov/JoinAStudy)

## What's New at Genetic.org

The following links will take you to AXYS website pages that have new content added recently. Take a look!

- [Featured Research Papers](#)
- [Searchable Research Articles List](#)
- [The XXYY Project](#)
- [AXYS on Facebook](#)
- [Support Groups](#)

## Fundraising Tidbits

**Now Open:**  
**The AXYS Cafe Press Shop!**

Need an eXtraordinary gift for someone? Want to help spread awareness? We have you covered!

Shop [AXYS on Cafe Press](#). We have tees, hats, bags and more. 100% of the net proceeds will go directly to AXYS!

We thank Dave Mechler for his wonderful design work.

Show  
your  
support  
and  
help  
spread  
awareness!



## #GivingTuesday

There's #BlackFriday and #CyberMonday... and then there's #GivingTuesday, the international day of giving. We are gearing up to make the most of this year's #GivingTuesday, so stay tuned to find out how you can help.



## Support Group News

### AXYS Rocky Mountain Support Group

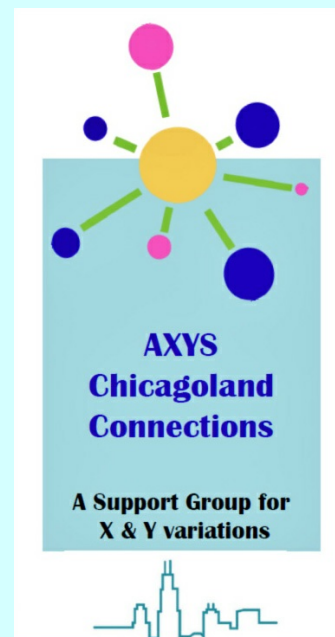
Thanks to all who attended the October 7th education event for the Rocky Mountain Support Group of AXYS. It was great to learn so much from Dr. Shanlee Davis about the risk of cardiometabolic health conditions on individuals with X & Y variations.



We were also lucky enough to have a meet and greet on October 22nd with Ryan Bregante. It was a great chance for many guys to hang out in a relaxed environment. Please save the date to the upcoming bowling event **February 10th, 2019**. More information will be coming out soon.

### AXYS Chicagoland Connections

The AXYS Chicagoland Connections support group had its second face-to-face support group meeting on September 8, 2018. A sincere THANK YOU to Dr. Carla Z. Minutti, MD, Pediatric Endocrinologist at Rush University Medical Center who was our Guest Speaker for sharing her in-depth subject matter expertise. Dr. Minutti was very engaging and willing to answer the myriad of questions from the group.



This support group is still relatively new and is growing. New members are reaching out on an on-going basis. As the group grows, the diversity of the members are increasing.

If you are interested in joining in any capacity, please send an email to [connectionsxy@gmail.com](mailto:connectionsxy@gmail.com). In your email please note if you would like to be added to email distribution lists for the support group materials and/or if you would like to join the private Facebook Support Group Page. Please note your email information will NOT be shared with anyone without your permission.

The next face-to-face meeting will be in February 2019!

## Upcoming Events

### Support Group Meetings

- [October 27, 2018, 1-4PM: Massachusetts Area States Trisomy X Support Group Meeting, Wayland, Massachusetts](#)
- [November 3, 2018, 6PM: Annual XXYY Sydney "Mums Only" Dinner,](#)

[North Parramatta, New South Wales, Australia](#)

- [November 10, 2018: Australian X & Y Spectrum Support \(AXYS Australia\) Conference, Melbourne, Victoria, Australia](#)
- [November 10, 2018, 1-3PM: AXYS Twin Cities Support Group Meeting, Chanhassen, Minnesota \(First Meeting!\)](#)
- [November 14, 2018: 7PM EST: AXYS Trisomy X Global Support Group Conference Call](#)
- [December 1, 2018: AXYS Florida Support Group Meeting, Tampa, Florida](#)

[See a full list of AXYS Support Groups](#) that meet both in-person and on Facebook.

**Save the date! June 28-30, 2019**  
**The AXYS Family Conference in Atlanta, Georgia**

## Upcoming Webinar

October 30, 2018: David Hong, MD - Navigating the Mental Health System: A Guide to Treatment Options

[Register now!](#)

All webinars are scheduled for 8:30PM EST, 7:30PM CST, 6:30PM MST, 5:30PM PST



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