



Letter from the Executive Director

Last century, many futurist articles started with “by the Year 2020...” and then a prediction was made. So it seems like a good time to reflect on where we are and craft a vision for AXYS for this year and beyond.

Growth and visibility are key parts of our vision. AXYS now serves just under 7,000 families. But we know that X&Y variations are as common as red hair so we want to become more visible so we can serve the entire X&Y variation community, and grow AXYS. Our 2020 Brand Refresh project will help us do that. Thank you Carrie Riby for leading this effort.

We start the year in a good financial state thanks to the generosity of our community. Our [online silent auction](#) was a smashing success because so many of you bid on items and our community was lovingly donated items to auction from beautiful hand crafted items to a classic car.



Graphic created by Dave Mechler

[The Annual Fund Appeal](#) was also very successful. Thanks to Gregg and Camille Simons, Gary Glissman and Andrea Millett for sharing their stories. Thanks to everyone who donated. Community members donated from \$10 to \$10,000, each a heartfelt

gift supporting the work of AXYS.

We have grand plans for AXYS in 2020 and beyond. On March 27 the [ACRC](#) will meet in San Francisco. [Clarus Therapeutics](#) has pledged to support this meeting. We've supported Clarus with testimony before the FDA and now are celebrating with them as they bring an [oral testosterone](#) to market. This advocacy work on behalf of those with 47, XXY will continue in 2020 and beyond. We will end the day with a social gathering at the [Dogpatch Wineworks](#). Watch your email for details soon!

Our CME (continuing medical education) article on KS in adults, funded by the grant from the Kosloski Family Foundation, is nearly complete and then will be submitted for CME credit. We are working with Wake Forest School of Medicine to administer the credits. ACRC member Dr. Hooman Sadri has been our guiding light in this process and we cannot thank him enough. It is great to have an MD on our board, Dr. Stuart Howards, to also guide us in the world of CME. Stuart serves as the AXYS board representative on this project. We look forward to offering several CME programs to educate physicians and other health professionals on X&Y conditions.

Planning for the [2021 AXYS Family Conference](#) has begun. We expect to announce the location soon. Visit the [webpage](#) to share your ideas for the conference and to sign up to volunteer.

We will hold our first [webinar](#) in 2020 on February 20 with the topic of College for Students with Learning Differences. You can [submit questions](#) to us directly that our experts will answer during the webinar.

Board members Hannah Acevedo and Bill Mulkern, along with past board member Carrie Riby are leading the Support Group Leaders Committee. We are working hard to create a strong, supportive structure for both our [in-person and online groups](#).

AXYS Welcomes New Board Member



AXYS Welcomes New Board Member Justin Dausch

AXYS is thrilled to announce that Justin Dausch has joined our board. Justin served as a volunteer for AXYS in the area of finance in 2019. An attorney licensed to practice in Pennsylvania and New Jersey, Justin can be called upon to guide AXYS on legal matters. His main role on the board will use his expertise on finance and compliance. "I looking forward to utilizing my professional experience to give back to the community," said Justin.

Two board members move into new roles with AXYS

Ginnie Cover, MSW, who wrote the book [Living with Klinefelter Syndrome \(47,XXY\) Trisomy X \(47, XXX\) and 47, XYY: A Guide for Families and Individuals Affected by Extra X and Y Chromosome Variations](#) and has supported AXYS in numerous ways is rolling off the board. But fear not, she is still with us as she will continue to lead our Grants Committee and use her excellent writing to obtain support for AXYS.

Carrie Riby is also changing roles. She is moving from a board role to the lead role in our Brand Refresh project and advising AXYS on branding and marketing. She continues to lead her Rochester Support Group and is serving on the in person support group team.

We cannot thank these two amazing women enough. AXYS offers our deepest appreciation and gratitude for all they have done and all they will do in the future.

New ACRC Clinic in New York City

AXYS is thrilled to announce that the Weill Cornell Medicine Klinefelter Syndrome Clinic, Weill Cornell Medical College in New York City has joined the ACRC. They see all X&Y variations; they see children and adults. Learn more on their website: <https://urology.weillcornell.org/klinefelter-syndrome>.

Welcome Dr. Lilian Cohen, MD MPH!

Clarus Launches New Oral Treatment for Testosterone Deficiency

AXYS congratulates Clarus Therapeutics on the launch of Jatenzo, "the first oral testosterone medicine approved by the U.S. FDA in more than 60 years." [Read the full press release.](#)

JATENZO[®] 
(testosterone undecanoate)
Capsules



Privacy and confidentiality

All who volunteer for AXYS sign a statement of confidentiality. AXYS never rents, shares or sells our mailing list to anyone or for any reason. We want to reiterate this so you can feel confident that we respect and protect your privacy.

AXYS Helpline

The AXYS Helpline is one of the most popular services we offer. Dedicated, trained volunteers answer emails and phone messages. Due to the volume of questions we have created a new email address for these queries: Helpline@genetic.org. Rick will now monitor and answer administrative and business questions sent to info@genetic.org. The toll free phone line 888-999-9428 remains the same

Volunteer today for a committee

AXYS thrives because dedicated volunteers offer their time, treasure and talent. [Check out our committees](#) and if you want to help, just [send Carol an email](#). We appreciate all you do for AXYS!

Support Groups

AXYS Support Groups are facilitated by volunteers who schedule the programs and often arrange for speakers on topics of interest to individuals and families affected by X & Y variations. These groups offer the opportunity to share experiences and resources that they have found valuable. Some of our groups are affiliated with ACRC hospitals, and they meet in those facilities. Other groups meet in libraries, medical centers, or churches. Here are some upcoming meetings. See our [Support Group page](#) for a full listing of all groups.

Upcoming Support Group Meetings:

[March 1, 2020: NY Tristate Support Group Meeting, New York, New York](#)

[March 7, 2020: Florida Support Group Meeting, Melbourne, Florida](#)

[April 18, 2020: DC-MD-VA Support Group Meeting, Rockville, MD](#)

[April 19, 2020: Twin Cities Support Group Meeting, Edina, MN](#)



Upcoming Webinar:

College for those with learning differences in the X & Y variation community

February 20, 2020 | 7PM Eastern (6PM Central, 5PM Mountain, 4PM Pacific)

[Register today!](#)

AXYS CafePress Store

Support AXYS while stylishly raising awareness with an item from our [Cafe Press shop!](#)

Amazon Smile

Do you shop on Amazon? Remember to use [Amazon Smile](#) (be sure to set your charity to AXYS using [this guide](#)) and Amazon will donate a portion of your purchase to AXYS!

Facebook Fundraisers

Looking to honor someone for their birthday or graduation? You can support AXYS with a [Facebook fundraiser!](#)

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