



## Fall 2020 Newsletter



### Game Night

We invite you to come play with us! AXYS is having our first game night to raise awareness, raise funds and have fun. You only need one ticket per household. Generous AXYS Supporters have donated \$600 in door prizes so come play and have a chance to win up a \$25, \$50 or even a \$100 gift card. **Register now:** <https://axysgenetic.networkforgood.com/events/23767-axys-game-night>

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## Telethon

On Giving Tuesday, December 1, AXYS will hold our first 90-minute Telethon and we need your help. This will be a sharing event where our community can share talents like joke telling, singing, poetry reading, or any other form of family-friendly entertainment. We also want to celebrate your accomplishments. Send an email to [Carol](#) with your idea. She will send you the details of how you can participate in this fun event.

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## zoom

Since we've been COVID social distancing we've been holding Zoom chats for groups like Positive Social Expression for XXY Adults, XYYY Dads, XXXY Chat, as well as groups based on the region where you live. Please watch your emails for the announcements and you can see them all listed on [our Facebook page](#). Events are also listed at the bottom of the homepage of [genetic.org](#).

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## Targeted Support and a Request

## Clinic Spotlights



### AXYS Welcomes our First Canadian Clinic to the ACRC

The [Flannigan Fertility clinic](#) specializing in Reproductive Medicine has joined the ACRC. Led by urologist [Dr. Ryan Flannigan, MD, FRCSC](#), this clinic specializes in male infertility and sexual medicine in individuals with genetic disorders leading to male infertility such as Klinefelter Syndrome, and mixed gonadal dysgenesis (45X, 46XY). Dr. Flannigan performs sperm retrievals, and fertility management.

Dr. Flannigan contributed to the AXYS Consensus Document on Fertility. He trained at Weill Cornell. Dr. Flannigan also researches what contributes to a lack of sperm production, and trains future doctors and researchers.

Besides his busy work schedule Dr. Flannigan has a toddler at home. He enjoys the outdoors in beautiful British Columbia, riding his bike, running, and hiking.

AXYS often invites targeted groups to join an area support group meeting, or a condition specific support group meeting. Don't miss out—share your information with us to help you get what you need. Simply fill out and submit the form on [this page](#) to share the condition you are most interested in and to name the person with the condition. Make sure your mailing address is correct.

We are also asking for ethnicity, language spoken and profession. This information is optional and all information you share with AXYS is 100% confidential. We have recently renewed interest in a Spanish language support group, and a families of color support group. We want to be able to let you know about groups that may be of interest to you. Feel free to let us know if you would like to create another targeted group.



### Serve as a Helpline resource

Every month dedicated volunteers answer the calls and emails that come to our Helpline ([helpline@genetic.org](mailto:helpline@genetic.org) and call 888-999-9428). We want to match people with someone who has successfully navigated their situation; be that a prenatal diagnosis of an X&Y variation, raising a child with a particular variation, or someone who lives in their area. We also seek volunteers from different racial and ethnic backgrounds so we can offer a cultural match. Do you speak another language in addition to English? We'd love to have you.

For clinic appointments call: Judy Chiu, 604-875-5003  
More information by email: [info@flanniganfertility.ca](mailto:info@flanniganfertility.ca)

### Families of Color

AXYS is planning programs for Families of Color in 2021. We encourage you to join us. Please email [Carol](#) or [Erin](#) if you want to be part of this group.

### 2021 AXYS Family Virtual Conference

As you may have heard our conference will be virtual next year. While we do not know what the status of the COVID 19 pandemic will be a year from now, we feel that in the interest of health it is best to plan a virtual event.

While we are sad to not get together in person, we are excited to offer our amazing educational sessions to you in your home. It is our hope that this will allow the maximum number of individuals with an X&Y variation and their and families to participate.



### Conference Suggestions

If you are willing to accept call those who seek our help and have a one on one conversation with them please fill out [this survey](#) to be added to the Helpline Resource list.



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## Webinars

Thanks to the support of [Clarus Therapeutics](#) we are offering monthly webinars featuring doctors from our ACRC sharing their research. Many are sharing scientific research papers written for a special edition of the journal Medical Genetics Part C. Thank you to Dr. Tartaglia and all of the doctors, scientists and researchers who help us understand X&Y variations and share this knowledge with other doctors and scientists so that they can offer better care to our community.

We will be having at least one webinar each month so watch your email to register.



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## Upcoming events

- [October 20, 2020, 7PM EDT, Webinar: Testosterone Replacement Therapy in Adult Males | Zoom](#)
- [October 22, 2020, 6:30PM EDT, AXYS Game Night | Zoom](#)

The Conference Planning Committee is taking under consideration past conference attendee surveys, the surveys we have done prior to other conferences, and emails and conversations from our community. We are using this feedback and your suggestions to plan our 2021 AXYS Family Virtual Conference. We have a few suggestions from this survey we posted in February but you can still add your ideas:

[www.surveymonkey.com/r/2021ConferenceSuggestions](http://www.surveymonkey.com/r/2021ConferenceSuggestions)

Should we hold the event in May or June? How do you want the sessions to be structured? Let us know!

<https://www.surveymonkey.com/r/Virtualconference>.

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## Board of Directors

We're thrilled to announce our newest [board members](#):

Erin Frith is now our Chair and Gary Glissman has moved to the role of Past Chair. Carrie Curtis is now the secretary.

John Sloss joins us from Canada. Erin Torres, who you know if you participated in an NIH study has joined the board as well as Dalene Basden, who you know from many conferences and NEXXYS meetings. We also welcome Silvia Mann.

Welcome new board members!!

- [October 24, 2020, 2PM EDT, NEXXYS \(New England XXY Support\) Group Meeting | Zoom](#)
- [October 24, 2020, 11AM EDT, AXYS XXXY Chat | Zoom](#)
- [October 27, 2020, 7PM EDT, AXYS XYY Chat | Zoom](#)



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## Support AXYS

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### 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!

### Employer Matching Gifts

Some employers will double or even triple your gift to AXYS.

### Facebook Fundraisers

They are easy to set up and allow your friends to help support AXYS. Please consider holding a [Facebook Fundraiser](#) for AXYS for a birthday, anniversary or other occasion.

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