



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

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AXYS Family Conference Headed to Atlanta

The AXYS Board of Directors recently authorized the signing of a contract with the Emory Conference Center and Hotel in Atlanta, Georgia for June



2019. Specifically, the welcome reception will take place Friday evening, June 28 while the conference sessions will be held Saturday and Sunday, June 29-30. As always, sessions will be designed to address a wide variety of issues and most sessions will be of interest to those impacted by any of the X and Y variations, though some will be targeted to one or another specific variation. In addition to the sessions, meetings for self-advocates will be planned and activities/childcare will be available for children.

Though planning is still in the early stages, attendees can expect to hear many of the top experts in the X and Y variations field discussing medical and medication interventions, therapies, counseling and education. The great majority of sessions will be designated as family-friendly, however a small number of sessions will be more technical in nature especially those involving planned, ongoing or recently completed scientific research.

Much of the excitement and benefit from conference attendance comes from the social interaction between parents, siblings, self-advocates and treatment and research professionals that takes place outside of the structured sessions. Those who are new to the X and Y variation community tend to have an especially meaningful and powerful experience. Therefore, AXYS will schedule and organize a number of opportunities for conference attendees to get to know one another and to learn from one another.

AXYS understands that there is a growing need for more and better information for adults with an X or Y variation, to compliment the current information geared for children and adolescents. As a result, the speaker selection process will take that into close consideration when selecting topics and presenters.

Registration will become available early in 2019, including information about the cost of conference registration, though we are pleased to report that we have negotiated a lower hotel price than last year's conference with the nightly rate set at \$135 plus tax and fees.

We encourage everyone to mark their calendars now for this exciting and informative event!

Clinic at CHOP Joins the ACRC

The AXYS Clinic & Research Consortium (ACRC) has a new member! Children's Hospital of Philadelphia's (CHOP) Klinefelter and All XY Variations Program includes family visits combined with genetics and a dedicated team. In terms of fertility counseling, the clinic works closely with a reproductive urologist at the University of Pennsylvania who sees both adolescents and adults. The clinic also collaborates with the neurodevelopmental and psychology team affiliated with the Autism Research Center at CHOP for families who need developmental or psychology evaluation. Learn more at <https://genetic.org/im-parent-affected-child/clinics/>.



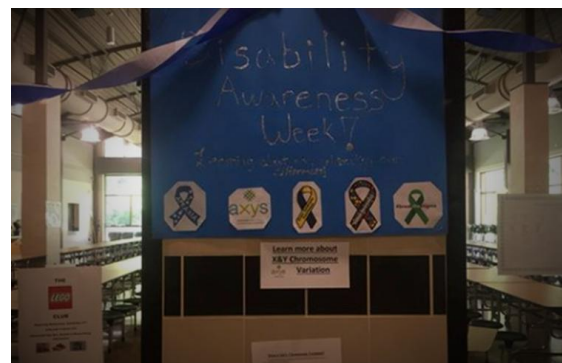
Matthew's Story

Matthew is a 26 year old man who has 47,XXY. Learn about his journey, his challenges, and his accomplishments from multiple perspectives.

Read Matthew's story and others at <https://genetic.org/more-personal-stories/>.

Do you have your own personal story to share? Please share it with us! Send your story to info@genetic.org and it

Middle School Teacher Spreads X&Y Chromosome Variation Awareness



Brittney Caracciolo writes:

"I am the Life Skills Support teacher at Phoenixville Area Middle School in Pennsylvania where I teach students with special needs in grades 6-8. My 19-year-old brother has Klinefelter's Syndrome and I have always gone with my parents to AXYS meetings whenever possible for as long as I can remember. At the last meeting I attended at DuPont Hospital, they mentioned designating the month of May as X & Y Chromosome Variation Awareness Month. The idea occurred to me that, as a teacher, I have a perfect audience to inform people about these chromosome variations. Not to mention, there are probably students in my school that may have a chromosome variation but don't even know it."

[Read more](#)

could be featured on the AXYS website.

AXYS Chicagoland Support Group Has First Meeting

AXYS Chicagoland Connections, a Support Group for X & Y variations, is underway!

AXYS Chicagoland Connections had its first face-to-face meeting on Saturday, June 16, 2018 in Chicago. Twenty-five individuals were able to attend this meeting. Medical Director of the Rush University Medical Center Multidisciplinary X and Y variations Clinic Elizabeth Berry-Kravis, MD, PhD attended and provided an overview of the clinic. Angel Wang, the Clinic Coordinator was also there. It was a great opportunity for open discussion and collaboration for meeting the needs of individuals with X & Y variations in the Chicagoland area. Read more at <https://genetic.org/im-parent-affected-child/support-groups/> under "AXYS Chicagoland Support Group."



Officials Make Birthday Dreams Come True

"When a Dickson County, Tennessee boy invited law enforcement to his birthday party, they didn't let him down! Dayton was ready to celebrate his 10th birthday, and his mother, Tabitha Walp, decided to put out a post on Facebook inviting any and all law enforcement to stop by for some food and fun. Walp told NewsChannel 5 Dayton has a rare genetic disorder called 48,XXXY syndrome and added he has also been diagnosed with autism. She said she's constantly encouraged him to shake hands with law enforcement officials and thank them for their service."

[Read more](#)

XXYY News

Emory University Focuses on XXYY

Currently at Emory University, an eXtraordinary Team is working clinically and scientifically to improve understanding, identify needs and to create patient-centered solutions for all sex chromosome variations with recent projects focused on XXYY. A research team led by Dr. Sharron Close is partnering with patients and families to create new research pathways to bring greater understanding and awareness about the XXYY life experience. [Read more](#)

XXYY Project Website is Now Part of genetic.org

The XXYY Project website has officially moved! Visit genetic.org/xyy to check out newly updated information, reorganized to help make the information you need easier to find. We are happy to welcome and integrate the XXYY Project's information as a valuable contribution to the X and Y variation community.



What's New at Genetic.org

The following links will take you to AXYS website pages that have new content added in the past few months. Take a look!

- [Library of Research & Treatment Articles](#)
 - [Prior Webinars](#)
 - [Featured Research Papers](#)
 - [The New Home of the XXYY Project](#)
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Fundraising Tidbits

In 2016 and 2017, AXYS board member Gail Decker, Mary Ann Lisa and the parent support group on Staten Island, organized Bowl-a-thon's for the AXYS XXYY Project raising approximately \$5,500. For personal reasons, Gail could not organize the event this year so, instead, an appeal letter was mailed to those who normally attend the bowl-a-thon and that appeal has raised \$2095 which will be donated to the Ryan Scovell Research Fund.

This is the type of creative fundraising that makes the work of AXYS possible!

Evite Donations is a free tool that turns every Evite event -- birthdays, wedding, pet parties, professional events, holiday parties, fundraisers and more -- into an opportunity to raise funds for AXYS. Hosts use Evite to organize party logistics, and select AXYS, a member of the Pledgeling network, as their chosen charity. Guests donate without leaving [Evite.com](https://www.evite.com), and Evite never charges a fee to make donations. The backend integration for donation processing is powered by Pledgeling, which includes instant tax receipts to donors for their donations.

For more information on how to host an Evite Donations-powered event and help AXYS meet our mission objectives, please visit:

<https://www.evite.com/c/evite-donations/>.

Upcoming Events

Support Groups (click [here](#) for details about support groups and the following meetings)

- August 11, 2018, 12-5pm: Mid Atlantic Support Group X & Y Summer Social, Chadds Ford, PA
- August 25, 2018, 12-5pm: Southeastern Support Group - Annual Pool Party Social Event, 4688 River Court, Peachtree Corners, GA
- September 1, 2018: 12:30-4:30pm: AXYS Florida Support Group, 2190 Springs Landing Blvd., Longwood, FL
- September 8, 2018: AXYS Chicagoland Support Group, Details to be announced
- September 22, 2018: 1-4pm: Upstate New York Support Group, Butler/Till Building, 1565 Jefferson Rd., Building 200 Suite 280, Rochester, NY
- October 7, 2018: 1-4pm: AXYS Rocky Mountain Support Group, Children's Hospital Colorado, Anschutz Medical Campus, 13123 East 16th Ave., Aurora, CO
- October 27, 2018: 1-4pm: Massachusetts Area States Trisomy X Support Group. "Taking it to the MaXXX," Good Shepard Parish, 99 Main St., Wayland, MA
- November 10, 2018: Australian X & Y Spectrum Support Conference, Melbourne, Australia

Upcoming Webinars

Please be sure to visit the AXYS website home page calendar for news about other upcoming webinars. Expect to see new webinars soon!

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