

The latest information about conferences, education, research opportunities, clinics and more.



THE EVEN EXCHANGE

AXYS Newsletter - Spring 2017

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

Upcoming Events

FAMILY CONFERENCE



June 24-25, 2017 in Aurora, Colorado

Click [here](#) to visit the support group page where you will find more detail about each of the following U.S. events.

International XXYY events can be found [here](#).

April 28: Triple X Conference, Genetic Alliance Australia, Darlinghurst in Sydney, Australia. [Contact](#)

April 29: New York AXYS Support Group Gathering, Rochester, NY

April 30: Mid Atlantic Region (DE, DC, MD, NJ, NY, PA, VA & WV) Support Group Meeting in Wilmington, DE

May 6-7: Staten Island, NY Event for XXYY

May 13: NEXXYS Meeting, Braintree, MA

May 20: LA Support Group Annual Family Potluck & Picnic, Los Angeles, CA

June 9-11: XXYY family gathering in Bad Grund, Germany

June 19: Hundred Hole Hike at Ballyneal Golf Club, in Holyoke, CO. An AXYS fundraiser!

June 24-25: AXYS Family Conference: Aurora, CO

August 18-21: 48 XXYY UK Support Group Family Meet-up, Derbyshire, England

Why attend the AXYS Family Conference?

Colorado beckons!

While we at AXYS understand that not everyone can attend the family conference, if you are on the fence about coming, here are some things to consider:

- **The majority of the country's leading researchers and clinicians will be speaking and interacting with families**
- **Sessions will address most of the high-interest topics of interest to parents or those with an X or Y variation**
- **You will meet great people including those who have been on the X and Y variation "journey" for some time!**
- **You will forge friendships that will last a lifetime!**

[Remember, early registration and discounted hotel rooms end on May 23. Details here.](#)

Independence

Working with students with executive function challenges

By Myra Byrd

Recently, I was fortunate to hear from Dr. Michele Ramsay from College Internship Program in Brevard, FL. Dr. Ramsay spoke at my son's school's Parent Education Dinner and shared her experience working with students with executive function challenges. She offered many ideas to help our kids minimize frustration and build organizational and planning skills. As someone who works with post high school individuals with social and learning differences, she has advice to offer all of our families.

Dr. Ramsay shared with us the two critical skills that she thinks parents need to work on with students. She has observed how these skills affect outcomes for our children as they transition to young adulthood. She believes that these skills should start being taught in middle school...slowly and in small chunks. They are mastered over time!

1. **GETTING UP INDEPENDENTLY:** If you wake your kid up for school everyday, Dr. Ramsay says STOP! Getting up independently is a key predictor of success for students pursuing college and vocational objectives after high school. The students that did not master this skill were not successful in college or career pursuits after high school. They had to learn this skill gradually, once they came to Dr. Ramsay's program. Until they could get up independently it was difficult to get traction on any other objectives. We can help our kids to be prepared for an adult schedule and responsibilities, starting now. If your student has trouble Dr. Ramsay advocates establishing a consistent structure and sleep pattern, removing

technology/electronics from the bedroom, enlisting specialty alarm clocks, using apps (if a cell phone is not a problem for the child) and when all else fails, natural consequences (in conjunction with the school) to help our kids develop this skill. With all things, she recommends "chunking it"...taking one small step at a time...starting with getting up independently one day per week.

2. MEDICATION INDEPENDENCE: Since meds are critical to the functioning of many of our students, it is important that they know how to manage them independently in young adulthood. Dr. Ramsay thinks that beginning in middle school, students should learn the names and dosages of their meds, and how often they are taken. She recommends that parents have kids help place meds in pill sorters and supervise the taking of the meds. She recommends walking through the routine so that the child learns it by doing. The process is slow and takes time. Dr. Ramsay says that parents must bear in mind that colleges and even specialized post high school programs do not offer medication management. This is a critical skill for adult independence.

Apps and Other Technology

Welcome to Center on Technology!

Assistive and instructional technology (AT/IT) allows children across the ability spectrum to participate fully at home, in school, and in the community. The Center on Technology and Disability provides a wealth of free resources - personal and professional development (PPD) webinars, articles, guides, training materials and more. Whether you're brand new to assistive technology or an experienced user wanting to remain on the leading edge, CTD has high-quality, research-based materials and events for you!

Visit the CTC [here](#)

Participate in Research

AXYS maintains a webpage called "Research Opportunities for Families." There are many ways your participation can make a difference. Not all opportunities involve travel. In fact, some simply require the completion of an online survey. Take a look [here](#).

Research at the AXYS Family Conference in June

The eXtraordinary Kids Clinic in Colorado is recruiting boys 12-17 years old with XXY to participate in study of the body's energy system. Contact Dr. Davis to see if your son could qualify and schedule your study visit to coordinate with your conference travel! 720-777-6073 or Shanlee.davis@childrenscolorado.org

A New Study

"Imagine ID - Intellectual Disability and Mental Health: Assessing the genomic impact on neurodevelopment."

Cambridge University Hospitals NHS Foundation Trust and the University of Cambridge.

X and Y variations being studied: Sex Chromosome Aneuploidies. Learn more [here](#).

Hundred Hole Hike

By Brandon Urban



It has been nearly sixteen years since our son Ben was born, and almost four years since we learned of his diagnosis of Klinefelter Syndrome...I am participating in the Hundred Hole Hike at Ballyneal Golf Club, in Holyoke, CO, on June 19th to help support AXYS. The Hundred Hole Hike (HHH) is a national-network of golf marathons where participants plan to walk 100 or more holes of golf in one day in order to raise money for various worthwhile charitable causes. Read more [here](#)...

[Support my efforts. Make a pledge!](#)

[May is National X and Y Chromosome Variation Awareness Month!](#)

The AXYS southeastern support group helped raise awareness in the State of Georgia by requesting and participating, along with a contingent from Emory University, in an X and Y Chromosome Variations Awareness Day at the Georgia Capitol on February 28. Members were also involved in educating Georgia legislators with an exhibit in the Georgia Capitol on March 3. As a result, Georgia Governor Nathan Deal signed the proclamation making May X and Y Chromosome Variations Awareness Month and the proclamation will be formally presented to the group on May 17! A session at the AXYS family conference in June will share what has been learned through these advocacy efforts and how other support groups and individuals can become involved in a similar way.

How to achieve a similar proclamation in your state:

- **What can you do to help?** Write a letter or email your Governor and ask that he or she declare May as National X & Y Chromosome Variation Month. Most states will only issue a proclamation to people who actually live in that state. So if you have family or friends who are willing to help, ask them to send letters. Governors tend to respond when there are multiple requests.
- **When can you do this?** Now! Get those requests in today, so that your Governor has time to review your request and get it signed for May.
- **What do you need to do?** Google "Governor of (state)" and get your Governor's full name and address or if your Governor prefers email requests, the information on what to do will be listed on their website. Below is the sample letter to be used along with the sample proclamation text and list of AXYS clinics. You might want to personalize your letter or leave it just the way it is. Either way is fine.
- **Why is this so important?** Because it helps our efforts in getting much needed medical and educational support for all of you. Aren't you tired of trying to explain your child's condition to medical professionals? How about explaining your child's educational needs to his or her teachers? Raising awareness is fundamental to ensuring those things happen.

For further guidance, a sample letter and a sample proclamation, please contact Sandy Schindler <sandyschindler21@gmail.com>

The AXYS Clinic & Research Consortium (ACRC)



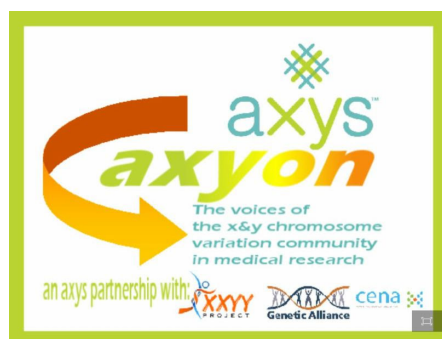
by Robert Miller, AXYS Interim Executive Director

In 2015, the AXYS Board of Directors voted to approve the development of a consortium of

clinics, organized, coordinated and funded, in part, by AXYS. Though each clinic operates independently, as members of a consortium they collaborate with one another, share informational resources, and have the opportunity to participate in joint research projects. In addition, AXYS organizes annual meetings of the consortium at which members meet to discuss topics important to the SCA community. The goal of AXYS is to ensure that all families impacted by any of the chromosomal variations have access to the best available evaluation and treatment or treatment recommendations. The AXYS Clinic & Research Consortium is one of the important ways we are achieving that goal.

[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

In December of 2015, AXYS was proud to launch the AXYON Registry, a grant-funded, web-based, self-reported registry specific to X and Y chromosome variations. This registry allows people like you to contribute information specific to your experience with an X and Y chromosome variation. Your contribution to the registry is CRITICAL to helping advance research in X and Y chromosome variations!

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

XXY, XYY, XXX

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

[Now available for free from AXYS!](#)

Thanks to the generosity of the book's author, Virginia Isaac's Cover, MSW, AXYS is pleased to make this book available to the X and Y variation community, in its entirety, at no cost. Please feel free to download and/or print it for your personal use.

XXYY

The XXYY Project

The XXYY Project is a project of AXYS. In addition to the XXYY content found on the AXYS website, the project maintains its own website at <http://xyysyndrome.org/main/>. In addition, representatives of the XXYY Project serve on the AXYS Board of Directors and an XXYY Committee advises the AXYS Board on how to best represent the needs of the XXYY community.

All Conditions

Recommended Reading

- [Does ADHD raise the risk of other mental health issues?](#)

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STAY CONNECTED



