



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

Hello. We hope you find this issue of the AXYS newsletter helpful. As you may have already begun to notice, we'll be sending out more frequent news updates such as the Research Article of the Month and other items that we think you'd like to know about before the next quarterly issue of the Even Exchange.

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## **Legal Resources**

We've created a new section on our website call "Legal." You'll find it under the "Resources" section. We created it

because individuals with an X or Y variation may, on occasion, find themselves involved with government institutions, care providers, law enforcement and/or a legal system that is unfamiliar with X and Y variations.

[Learn More](#)



## New Oral Testosterone Drug

A group of people representing AXYS and the Klinefelter Syndrome community traveled to Washington, DC in early January to provide public comments at an FDA hearing related to the approval of a new oral testosterone drug called Jatenzo.

The Clarus drug company has developed this oral pill as an alternative for men that require testosterone replacement therapy (TRT).

[Learn More](#)



## SURVEY: Non-Invasive Prenatal Testing (NIPT)

- *all variations*

Emory University is recruiting participants for a study about Non-Invasive Prenatal Testing. If you are 18 years of age or older, have had recent NIPT, or at any time in the past showed increased risk for X & Y chromosome variations, you are eligible to participate.

The purpose of this study is to gather information about people who have had an NIPT experience showing increased risk for X & Y chromosome variations, whether they had genetic counseling support, and their understanding about NIPT. The results from this study will help to develop a future program that helps prospective parents understand more about NIPT and more about X & Y chromosome variations.

Details about the above survey, including how to enroll, along with many other opportunities for families to participate in research, can be found using the Learn More button.

Ongoing research is taking place at:

- **National Institutes of Health (NIH)**
- **Nemours/DuPont Hospital for Children**
- **University of Colorado Denver**

*and other locations!*

[Learn More](#)

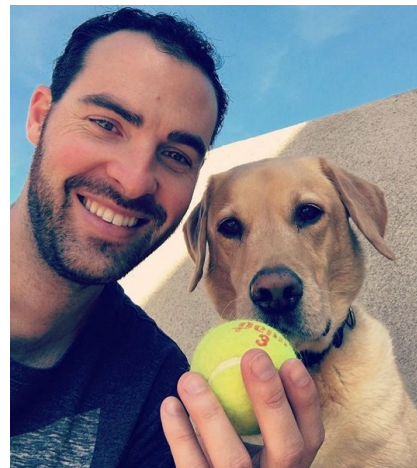
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## Ryan Bregante's Mission to Build a Klinefelter Community

When Ryan Bregante sees statistics estimating that 1 in 500 males has the extra X chromosome that causes Klinefelter syndrome (KS), he is acutely aware of his minority status as the “1” in that equation. Another statistic is ever present to him as well: as far as researchers have been able to determine, only some 3 in 10 males with Klinefelter even know they have the condition.

That makes Bregante a minority of a minority, because unlike the 70 percent of males who must deal with the challenges posed by KS without any context for understanding their source, Bregante has known about his extra X since he was 9 years old. That's when his parents, in consultation with his pediatrician, decided the time was ripe to let him know. The result of that conversation? It would seem to fit the classic dictum, “Knowledge is power.”

*(Read the whole story [here](#))*



[Learn More](#)



## The Bregante Family's Matching Grant Campaign



The Bregante Family of San Diego, CA has generously offered to make a \$5,000 donation to AXYS once the organization raises the same amount from its supporters. The Bregantes are particularly interested in improving knowledge about adults with an X or Y variation, and their contribution will be targeted to that part of our mission and



## XXYY Project

February 17th marked the 48th day of the year and the start of the Project's XXYY Awareness Days!

The XXYY Project Facebook page has been sharing a series of stories/photos from our XXYY Community to raise awareness for 48,XXYY Syndrome.

This year, the suggested theme is "**How your guy has changed your life for the better.**" There are always great submissions, including some from the boys and men in our XXYY Community. Please check out the posts on our Facebook page at [XXYY Project Facebook Page](#)

XXYY Awareness days are designed to increase knowledge around the world about XXYY and the challenges the diagnosis presents. Being a relatively uncommon syndrome, gaining awareness is crucial! Research efforts are mainly donation-funded and really essential to learning more about XXYY. With increased awareness, we also hope to increase interest within the medical profession, ultimately leading to more research and support.

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## What's New at Genetic.org

- [Legal Resources](#)
- [Transitioning to Adulthood](#)
- [Professional Directory](#)
- [Featured Research Papers](#)

## Upcoming Events

### Webinars (click [here](#) to view prior webinars)

- March 13, 2018 Darius Paduch, MD – Testosterone Treatment in XXY Adults and Adolescents
- March 22, 2018 Pete Wright of Wrightslaw – IEP and 504 Plans for Students with X and Y Variations
- April 10, 2018 Larry Dubin, Esq – Online Safety for Individuals with X and Y Variations
- April 19, 2018 Shanlee Davis, MD – Health and Fitness in X & Y Variations
- May 16, 2018 Susan Howell, MA, CGC – Disclosing the Diagnosis in X and Y Variations

### Support Groups (click [here](#) for more detail about support groups and meetings)

- March 25: Mid Atlantic Support Group Meeting, 1-4pm, Wilmington, DE
- April 8, Upstate New York Support Group Meeting, 11am - 2pm, Rochester, NY
- June 8-10, 2018: Western Europe XXYY Family Gathering, Reinhardshagen, Germany

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