About the XXYY Project

The XXYY Project was organized by founding members of the XXYY Parent Network, an informal association of parents, founded in 1998. We currently operate under the umbrella of AXYS, the association for x & y chromosome variations.

The XXYY Project offers support and information for affected individuals and family members world-wide. We have events throughout the world and are part of the biennial conferences put on by AXYS. We work with clinics that serve people with x & y chromosome variations and help to open new clinics. We also foster research on XXYY.

Contact the XXYY Project

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What is XXYY Syndrome?

Typical males are born with only one X and one Y chromosome. Males with XXYY have two of each. XXYY is one of several conditions known as X&Y Chromosome variations. Approximately 1:17,000-18,000 boys are born with XXYY. XXYY is characterized as a developmental disability and a neurodevelopmental disorder.

XXYY Syndrome was once considered a variation of another condition called Klinefelter Syndrome (XXY). New research has shown that XXYY has its own unique characteristics, making it a separate condition, with unique treatment needs.

How is XXYY diagnosed?

A diagnosis for XXYY is done through genetic testing called a karyotype. The test involves taking a blood sample to analyze chromosomes. In some cases, a male may have some normal XY cells and some XXYY cells.

Is there a cure?

There is no cure for XXYY. However, new research on the syndrome is helping us to formulate treatment that can improve the lives of affected boys and men.

What are the symptoms?

XXYY is often mistaken for other syndromes. The most common symptoms and characteristics that would be noticeable by parents and medical professionals are:

- Developmental delays
- Speech impairment
- Tall, considering family history
- Behavior outbursts & mood swings
- Learning disabilities and possibly low IQ
- ADHD symptoms
- Autism Spectrum Disorder symptoms
- Allergies, asthma & other respiratory illnesses
- Tremors
- Curved pinky finger
- Flat feet
- Infertility
- Delayed or lack of sexual development
- Undescended testes
- Testosterone deficiency
- Significant dental problems
- Seizures
- Breast development
- Low muscle tone
- Heart problems

Not all males with XXYY experience all of these symptoms.

What is the treatment?

Males with XXYY receive a variety of individualized treatments including hormone replacement therapy (to replace testosterone that the body may not create on its own), ADHD and other medications that assist with attention span and behavior.

Common myths

Over the many years we have existed as a support group and organization, we have heard that many people have been told myths about XXYY. Contrary to what you may have read in old medical literature:

- Not all males with XXYY have intellectual disability. Recent research on 95 patients showed only 26% actually did.
- Males with XXYY are no more likely than any other person with a developmental disability to be criminals.
- Some males with XXYY may, at some point, require supervision in a residential setting, but many can do very well with community supports in a less restrictive environment.
- People with XXYY are typically born male and do not have ambiguous genitalia.