The Focus Foundation presents...

A PARENT'S GUIDE TO A 47,XYY DIAGNOSIS

You've just found out your son has an extra Y chromosome. **What's next?**







Critical info and hope for today...

and every day forward, based on 20 years of experience!

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What is 47,XYY?



If you've just heard the term "47,XYY," it's normal to feel worried, overwhelmed, or unsure of what comes next. 47,XYY means your son was born with an extra Y chromosome. It occurs in as many as 1 in 1,000 boys worldwide, yet 90% or more are never diagnosed.

Boys with 47,XYY are typically tall, and many are active and athletic. The extra chromosome does not define who your son is—it simply means he may need some targeted support in specific areas, particularly around language, learning and attention.

Each child is unique. Some boys will require more support than others, but with early intervention and the appropriate specialists, children with 47,XYY grow, learn, and reach their goals. They go on to live full, independent, and meaningful lives!

Common Challenges

Every boy with 47,XYY is unique, but there are patterns that parents and educators should know about. Recognizing these early gives your son the best possible head start!

- **Language & Learning**
  - The majority of boys with 47,XYY experience language-based learning disabilities (LLD). This most commonly shows up as dyslexia, word recall and expressing language difficulties. Reading dysfunction occurs in up to 95% of boys with 47,XYY but with the proper support, it can be significantly reduced.
- **Dysgraphia & Dyspraxia**
  - Many boys struggle with handwriting and fine motor planning. This can affect how they perform in school even when they are bright and capable. It is important to understand this is a neurological difference, not a lack of effort or intelligence!
- **Attention & Anxiety**
  - Boys with 47,XYY have an increased likelihood of ADHD (particularly inattentive subtype), as well as anxiety.
- **Physical Traits**
  - Boys are typically taller than average, typically reaching over 6 feet. Many may have lower muscle tone in the upper extremities and trunk, and mild motor delays, though many are athletic and active.

"Watching my son grow into the person he is today has been one of the greatest joys of my life. These days, the challenge is simply keeping up with him. He has big dreams, big plans, and the confidence to make them happen."

-Tara, mom to 16 year old with XYY

Interventions & Support

- **Specialized Reading Programs**
  - Reading dysfunction affects up to 95% of boys with 47,XYY, but the right program makes a real difference. Structured, multisensory literacy approaches have proven highly effective and can dramatically improve reading difficulties.

- **Occupational Therapy (OT)**
  - OT helps boys build the fine motor and motor planning skills needed for writing and daily tasks. For boys with dysgraphia or dyspraxia, keyboarding or assistive technology can also be valuable classroom tools.

- **Speech-Language Therapy**
  - Boys with 47,XYY often struggle with language processing as much as reading. An SLP experienced with language-based learning disabilities can address both, building a stronger foundation for academic success.

- **ADHD & Anxiety Support**
  - Boys with 47,XYY are more likely to experience ADHD and some have anxiety, both of which can affect learning and social confidence. Early identification and a tailored support plan can significantly improve your son's quality of life.

Benefits of early diagnosis

- Prenatal and early diagnosis of 47,XYY is one of the most important steps you can take in ensuring a positive outcome for your son. Boys who are identified early are able to access targeted interventions during critical windows of development, when the impact is greatest.
- Research has shown that boys with 47,XYY who receive early intervention services consistently present with fewer neurocognitive delays. Prenatally diagnosed boys in particular tend to present as less severe, with milder or no learning difficulties when support is put in place promptly in our experience.
- Early identification is especially powerful when it comes to language-based learning disabilities, dyslexia, and attention difficulties—the core challenges associated with 47,XYY. Addressing these areas before they begin to affect your son's confidence and academic experience can make a profound and lasting difference.

47,XYY: Fact vs. Fiction

Many people haven't heard of 47,XYY, so it can be misunderstood and myths can spread—*especially* online. Here are a few common myths and what the research actually shows:

"Boys with 47,XYY are aggressive."

This myth came from flawed early studies of men in the incarcerated population and has been thoroughly discredited. Boys with 47,XYY are no more violent than any other child.

"Boys with 47,XYY will have an intellectual disability."

Most boys with 47,XYY have intelligence in the normal range. The real challenges are usually language-based (reading, processing, and expressing language), which respond well to the right support, and are very different from intellectual disability.

"Boys with 47,XYY can't succeed in school."

Learning differences like dyslexia are common, but they are highly treatable. With structured, specialized instruction and the right accommodations, boys with 47,XYY read, learn, and thrive academically.

"47,XYY is so rare there's nothing that can really be done."

47,XYY is more common than most people realize, and a great deal can be done. Early identification and targeted support — reading programs, therapies, and school accommodations — make a real, lasting difference.

"You'd be able to tell if a boy has 47,XYY by looking at him."

Most boys with 47,XYY look just like any other child, which is exactly why the majority are never diagnosed. The differences are in how they learn and process, not in how they look.

"If you've met one boy with 47,XYY, you've met them all."

Every boy is different! 47,XYY presents across a wide spectrum in language, learning, attention, and personality. Strengths and challenges vary from child to child, and no single story defines them all.



Looking Ahead

When you first hear that your child has 47,XYY, it's natural to feel unsure of what to expect. Your son can absolutely live a full, happy, and meaningful life! With the right support, boys with 47,XYY grow into confident young men who achieve their goals, build strong friendships, and thrive in their own unique ways. Many go on to attend college, pursue careers they are passionate about, and form lasting relationships. The challenges that come with 47,XYY are real, but they do not write the story—your son does!

"Understanding XYY and knowing how to best support the whole development of my son has been incredible. He is such a joy and so sweet! Having the diagnosis early helped me prepare and identify areas early that we needed to work on and he is doing fantastic because we were quick to get the appropriate supports!"
-Susan, mom to 8 year old with XYY

You're not alone in this journey. Dr. Samango-Sprouse and her staff are here to support you, care for your child and make sure he becomes the best he can be! We are here to help and have physicians, therapists and interventionists throughout the world. Together, we can help your son shine—not despite his diagnosis, but because of the strength, empathy, and perspective it helps him develop. Every boy's path is different, but with the right tools and belief in his abilities, he can flourish.

About Us

The Focus Foundation is a non-profit organization dedicated to helping children with X & Y chromosomal variations reach their full potential. For two decades, we have been at the forefront of research, early identification, and neurodevelopmental care for boys with 47,XXY, 47,XYY, 47,XXX, and related conditions.

Our Expertise

The foundation was co-founded by **Jackie Bucksbaum** and **Dr. Carole Samango-Sprouse,** a world-recognized leader in X and Y chromosomal variation research.

- She is the author of the book *X & Y Chromosomal Variations: Hormones, Brain Development, and Neurodevelopmental Performance*.
- She has published over **120 peer-reviewed scientific papers**.
- She is a Clinical Professor of Pediatrics at George Washington University, as well as an Adjunct Associate Professor at Florida International University.
- Her work has shaped how clinicians worldwide understand early development in children with X & Y chromosomal variations

What We Do

We bridge the gap between cutting-edge science & everyday life by offering:

-Syndrome-specific evaluations by experts who understand the unique developmental needs of our patients

-Guidance on early intervention + individualized support

-Access to ongoing research + the newest findings

-A family-centered approach that emphasizes strengths, progress, and hope

Glossary of Terms

Helpful terms for parents to understand their son's 47,XYY diagnosis.

47,XYY (Jacobs syndrome)-a sex chromosome variation in which a boy is born with an extra Y chromosome. It occurs in about 1 in 1,000 male births and is often undiagnosed.

Amniocentesis- a prenatal test involving extracting amniotic fluid from the uterus to screen for certain health conditions.

Attention-Deficit/Hyperactivity Disorder (ADHD)- a neurodevelopmental condition affecting attention, focus, impulse control, and activity level. In boys with 47,XYY, inattention is often more prominent than hyperactivity.

Childhood Apraxia of Speech (CAS)- a motor disorder in which a child struggles to motor plan and produce words, sentences, and speech. It is highly associated with later reading dysfunction.

Chromosomal microarray analysis (CMA)- a genetic test used to screen for chromosomal abnormalities, specifically duplications (extra chromosomal material) or deletions (missing chromosomal material).

Dyslexia- a learning difference that affects the ability to read accurately and fluently, including decoding words and spelling. It is not related to intelligence.

Dysgraphia- a learning difference that affects handwriting, spelling, and putting thoughts on paper. Boys with dysgraphia may know what they want to write but struggle to produce it.

Dyspraxia- difficulty with motor planning: knowing what movement to make and how to carry it out smoothly. It can affect handwriting, coordination, and everyday physical tasks.

Executive function-the set of mental skills used to plan, organize, hold information in mind, shift between tasks, and control impulses. Difficulties in this area can affect both learning and behavior.

Karyotype testing- a genetic test that looks at the size, shape, and number of chromosomes to further screen for abnormalities and mosaicism.

Language-based learning disability (LLD)- difficulty with understanding and use of spoken or written language, which can affect reading, writing, spelling, and listening comprehension.

Mosaicism- a condition where an individual has two or more genetically different sets of cells in their body. In 47,XYY, this can mean some cells have an extra Y chromosome (47,XYY) and others have the typical male karyotype (46,XY). Mosaicism can be associated with milder features.

Occupational therapy (OT)- therapy that builds the fine motor, motor planning, and sensory skills needed for handwriting, self-care, and everyday tasks.

Speech-language pathologist (SLP)- a specialist who evaluates and treats speech, language, and communication, including the language processing difficulties common in 47,XYY.

Structured literacy (multisensory reading instruction)- an evidence-based approach to teaching reading that explicitly teaches sound-letter relationships using multiple senses at once. It is the most effective approach for children with dyslexia.

CONTACT US

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VARIATIONS
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Check out Dr. Samango- Sprouse's book! (Linked on our website)

