



HOPE AND HELP

FOR children with X & Y chromosomal variations



Why Our Work Matters

Imagine being a parent whose child has a rare chromosomal variation and being told “*we don't know,*” “*wait and see,*” or “*we have never seen this before.*” The uncertainty is overwhelming and so frightening for these families.

That's where The Focus Foundation steps in. We offer a lifeline for families. As a leading research agency, we are driving advancements in treatment, even changing global standards. We're unique in our holistic approach, providing individualized treatment plans and crucial advocacy from prenatal care through college. We work closely with pediatricians and pediatric specialists to help these children, who are often hidden in plain sight, reach their full potential.

But there is more work to be completed. Approximately 75% of X & Y chromosomal variations are unidentified, even though they affect 1 in every 500 children. Many pediatricians and primary care providers lack training and awareness of these conditions, resulting in delayed or missed diagnoses, often during critical windows for early intervention and neurodevelopmental progress. It just takes one simple test to get a diagnosis and find answers that can change lives.

These disorders face the same awareness gap that autism spectrum disorder (ASD) faced more than 25 years ago: families searching for answers, clinicians without clear guidance, and children missing opportunities for early support. While progress has been made, the demand for research, education, and early identification far exceeds current capacity. Without continued investment, too many children will remain unseen—and unsupported.

FAMILIES ARE AT THE CENTER OF OUR WORK



Real Results

KELLEN'S MOM

“When we first got Kellen’s diagnosis of 48,XXX,Y, there were a lot of shrugged shoulders and unknowns. That was terrifying as a parent. Dr. Samango-Sprouse gave us clear marching orders. She showed us exactly how we could help our son. Within a week or two of his first testosterone treatment, it was night and day. His energy changed, he started trying to crawl, and his development took off. Kellen is 12 now, and we’re still seeing the benefits. We’ve followed her guidance every step of the way, and we’ve seen real, lasting results.”



Finding the Path to Flourish

CATIE'S MOM

“When our daughter Catie was born with a complex and rare genetic syndrome, the prognosis felt overwhelming. We were given a future defined by limitations. But then we found Dr. Sprouse and The Focus Foundation. Through their comprehensive, integrated approach, we were given something we desperately needed: clarity, direction, and hope grounded in science. Today, she’s thriving in an integrated classroom alongside her peers, far beyond what we were led to believe was possible. Seeing Catie flourish and navigate her daily life with such resilience is truly awesome, and we are incredibly grateful for the path The Focus Foundation has helped us forge.”



Finding Direction and Hope

JACK'S MOM

“The distress of not knowing where to turn is hard to put into words, but finding Dr. Samango-Sprouse changed everything for us. She truly sees who your child is and understands what they need. Our son went from screaming through his first visit to being excited to come back. And now he’s thriving socially, physically, and emotionally. I would recommend The Focus Foundation to any family who needs clarity, direction, and real results.”

Unlimited Potential is Possible

TARA'S SON

“ Dr. Sprouse helped us understand what was really going on and gave us the right support—not just for him, but for our whole family.

Today, my son is 15 and he is thriving in high school, playing varsity soccer, serving on student council, and excelling in math.

With the right supports, there is so much hope and truly unlimited potential for these children.”

Early Detection Changes Everything

MOM OF A SON WITH AN EXTRA X

“ I found out my son had an extra X when I was 12 weeks pregnant. I went down the Google rabbit hole. But it led me to Dr. Samango-Sprouse and The Focus Foundation.

Early detection was critical for my son. Likely because of targeted treatment when he was six months old, we never saw developmental delays.

He didn't need speech, physical, or occupational therapy and that made an enormous difference for our family.

The Focus Foundation didn't just treat my son; they guided us as parents so we could stay ahead of what he needed to succeed.”



Led by Dr. Carole Samango-Sprouse,
a world-renowned specialist in rare neurogenetic and neurodevelopmental disorders, The Focus Foundation is a trusted resource and a place where families find hope and a community that knows their child's issues very well.

Our Mission:

To educate families and empower children with X & Y chromosomal variations, dyslexia, and developmental dyspraxia to reach their full potential through innovative research, early identification, tailored treatment, and advocacy from pre-birth to college.



Our Impact by the Numbers

150
ENROLLEES

World leader in rare chromosomal research.
We support the largest known cohort of individuals with 49,XXXXY syndrome globally (more than 150 enrolled as of Dec. 2025).

1 IN 4
CITE OUR RESEARCH

Shaping global science and care.
As of 2024, more than one in four peer-reviewed PubMed publications on 47,XXY used our research.

2,300
SUBJECTS STUDIED

Unmatched longitudinal data.
We conducted the longest natural history study of 47,XXY, following 2,300+ boys and young men.

200+
ANNUAL REFERRALS

Early support when it matters most.
We receive 200–250 new prenatal referrals annually for 47,XXY, and we provide evidence-based guidance at a critical moment.

Fueling Research and Treatment that Changes Lives

Every breakthrough, every early diagnosis, and every family story is made possible through philanthropy. Donor support funds life-changing research, expands access to targeted treatment, and equips clinicians and families with evidence-based guidance. With donor partnership, families facing rare diagnoses are met not with uncertainty, but with answers, action, and hope for a future where the child thrives.

Make an Impact Today!



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Online**

www.thefocusfoundation.org/donate

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