



November 2018

The Magnifying Glass: A Newsletter

Our Promise: For all families, The Focus Foundation promises to develop the latest and most innovative care. The Focus Foundation believes in novel and "out of the box" thinking that produces scientific breakthroughs that enable children with neurogenetic disorders to lead better and more fruitful lives.

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The Focus Foundation is grateful for your support today and every day. Your efforts are helping ensure a brighter future for all of our children and we wish you love, happiness, and cherished memories throughout this entire holiday season.

Accolades

Focus Foundation Article Included in the Top 20 Most Downloaded Papers

Our article in **Prenatal Diagnosis: The Benefits and Limitations of Cell-Free DNA Screening for 47,XXY (Klinefelter Syndrome)** has become one of the journal's top 20 most downloaded papers in 2018 for Wiley publications!

- The article raised the visibility of non invasive prenatal testing (NIPT) as a prenatal screening test for low risk mothers. NIPT will result in more boys being identified with 47, XXY, instead of the long diagnostic odyssey that more than 75% of families typically experience just to attain a diagnosis.

Congratulations to Dr. Sprouse on Her Outstanding Achievement of Acceptance into the International Women's Forum.



The International Women's Forum is an invitation only membership which connects the world's most preeminent women of significant and diverse achievement. The IWF brings together an unprecedented global membership to exchange ideas, to learn and inspire, and to promote better leadership for a changing world. Members are committed to bettering global leadership today and cultivating women leaders of tomorrow. The Focus Foundation is so proud of you.

Fundraising Happenings

Thank you... for your support to deliver on our promise of targeted and innovative care for all of our boys and girls worldwide. Because of your fundraising efforts, we are providing "a home for our kiddos" that is full of optimism and creativity, that promises to 'reach for the moon' for each and every child.

Our fundraising events are stronger and bigger every year! Take a look...

The 4th Annual Drive Shop Pine Block Charity Invitational

At the Red Hook Brewery in Woodinville, WA

Many thanks to The Drakes!

A Rare Affair: Colton's XXXtraordinary Cause

Hudson Valley, NY.

Many thanks to The Hutchinsons!

The 8th Annual Oktoberfest: SAFARI Night

At the Ben in Philadelphia, Pa

Many thanks to The Stratts!

[CLICK HERE](#)

to learn about easy ways to give,
without even having to spend more!!

Science Around the World... See Where We've Been!

Science is moving fast and furiously at the Focus Foundation! We have presented at six specialty conferences in 2018, increasing awareness and networking with various professionals. Here is a sample of our recent travels, to see where we've been...

International Society for Prenatal Diagnosis (ISPD) in Antwerp, Belgium



This is one of the largest gatherings of specialists in prenatal medicine throughout the world. **Dr. Samango-Sprouse** gave an oral presentation titled, “**FILL IN!!!!!!**”. The paper describes how boys with 47,XXY often exhibit motor planning deficits, language-based learning disabilities, ADHD, and executive dysfunction. Testosterone replacement in babies and now between 5 and 10 years of age may mitigate many of the neurodevelopmental differences. The possible combinative as well as beneficial effect of prenatal

diagnosis and testosterone treatment on several aspects of neurodevelopmental dysfunction is described.

Exciting findings:

- Treated boys improved in executive function and planning. And boys who were prenatally identified and treated with Testosterone more than once had greater gains.
-

American Society of Human Genetics (ASHG) in San Diego, California



This Society's mission is to advance human genetics in science, health, and society through excellence in research, education, and advocacy. Patricia Lasutschinkow, a Focus Foundation Researcher, described our study on boys with 48,XXX Y based on multidisciplinary team evaluations. It is the first large study describing the phenotypic presentation of the boy with 48, XXX Y and the impact of two additive Xs.

Interesting findings:

- There are greater deficits in planning, speech, and motor function than boys with 47, XXY (Klinefelter syndrome), although similar in constellation.
- The variability of the boys with 48, XXX Y was extensive, with the boys performing better and more capable than previously reported.

National Society of Genetic Counselors (NSGC) in Atlanta, Georgia

This Society advances the various roles of genetic counselors in health care by fostering education, research, and public policy to ensure the availability of quality genetic services. Focus Foundation Researcher, Selena Chea, presented our investigation of the relationship between 47,XX Y behavioral traits and Early Hormonal Therapy (EHT).

What did this tell us?

- Boys who received EHT had significant improvement in their social cognitive pathway with an increase in more appropriate social interaction.

New Research Opportunities... Seeking Volunteers!

Two new exciting research studies...

1) For Children Between 6 and 36 Months of Age

Purpose of this Study: To examine the presence of stranger anxiety in infants with X and Y Chromosomal Variations.

It's easy to participate! ...If you have:

- An infant/toddler between the ages of 6 - 36 months of age, who has a...
- Diagnosis of an X & Y Chromosome Variation

Participation involves:

- Remaining with your child for the entire session.
- Watching a computer screen while wearing a fingertip sensor.
- A study evaluation of your child using games and pictures.

2) For Children Between 3 and 18 Years of Age

Purpose of this Study: To examine the profile and characteristics of children with OAVS/FAV/HFM (Oculo-Auriculo-Vertebral Spectrum/Facio-Auriculo-Vertebral/Hemifacial Microsomia).

It's easy to participate in this one too! ... If you have:

- A child between the ages of 3 - 18 years of age, who has a...
- Confirmed diagnosis of OAVS/FAV/HFM, and is an...
- English speaker

Participation involves:

- Completion of questionnaires by the parent/guardian.
- A study evaluation of your child using games and pictures, as well as a consultation with a neurologist/clinical geneticist.

Interested? Please contact us at research@thefocusfoundation.org.

Thanks for your consideration and we hope to see you soon!

Upcoming Events

Join us for a Facebook Live! With Dr. Sprouse on Tuesday, 12/11 at 12pm EST.

Dr. Sprouse will be live on The Focus Foundation Facebook page on 12/11 and we want YOU to choose the topic. Send us the topics or questions you want answered to



cbedard@thefocusfoundation.org by 12/9 and Dr. Sprouse will answer them live.

FOLLOW US ON FACEBOOK



We are thrilled to add Dr. Laura Ball to our specialized X and Y Chromosome Variation team.

Dr. Ball is an affiliate of the Children's National Medical Center and specializes in oral motor and speech. She will be bringing her expertise to our Focus Family! Welcome, Dr. Ball!



The Focus Foundation is excited to return to Thornton Manor in the UK from December 1st – December 3rd.

All X and Y Chromosome Variations are welcome at this conference to meet with our entire team of specialists. Should you be interested in attending any portion of this conference, please contact us immediately at cbedard@thefocusfoundation.org to check on availability.



AUSTRALIA, We're coming. April 2019.

The Focus Foundation cannot wait to come meet you and your family in the beautiful Down Under! Join us for our very first [Australian X and Y Chromosome Variation Conference](#) in Brisbane, Australia from April 10th – April 16th, 2019. Accommodations available through our website.



The Focus Foundation's 16th Annual 49er Conference, focusing on 49, XXXXY.

We are hosting our 16th Annual 49er Conference this summer in Annapolis, MD.

All specialists return for patient consultations and informational conference sessions:
Neurodevelopment, Neurogenetics, Endocrinology, Orthopedics, Physical Therapy, Dental, Immunology, Speech and Language, Oral Motor, Executive Functioning.

Specific dates to be announced Winter 2019.

Want to Help Support the Focus Foundation This Holiday Season?



Donate Miles

Did you know that you can donate your frequent flier miles to The Focus Foundation to support families in need?

Your miles can help bring families from across the globe to educational conferences they may otherwise miss out on, at home and Internationally.

Consider donating. It could be life changing for another family.



AmazonSmile

Planning on any online shopping this holiday season? Select The Focus Foundation as your organization when you shop through AmazonSmile.

[AmazonSmile](#) is a website operated by **Amazon** with the same products, prices, and shopping features at Amazon.com. The difference is that when you shop on AmazonSmile, the AmazonSmile Foundation will donate 0.5% of the purchase price of eligible products to the charitable organization of your choice.



#GivingTuesday

#GivingTuesday is a global day of giving fueled by the power of social media and collaboration.

Celebrated on the Tuesday following Thanksgiving (in the U.S.) and the widely recognized shopping events Black Friday and

Cyber Monday, #GivingTuesday kicks off the charitable season, when many focus on their holiday and end-of-year giving.

To support a corporate or personal [donation to The Focus Foundation](#), please visit our website.



DeXY's Corner

Activities to improve attention (ADHD):

- The app, **Simon Says – Classic All in One Vocal Memory Game for Kids HD** is an addictive & super fun enhancement of the famous “Simon Says” game. This game features many educational and engaging activities including: colors, shapes, letters and numbers. Improves memory and concentration. Improves fine motor skills. Kids learn words, colors, alphabet, numbers and shapes. Recommended for ages 2 – 6.
- Although we dislike the name of this app, we cannot deny its usefulness! Use **The Moron Test** to tap, twist, and shake your way through fun and tricky challenges! Particularly helpful for children working on attention issues. It is a great app for developing frontal lobe function, nuances of language, details, and process. For all ages.
- With **Creamy Ice** app you serve tasty ice cream to your customers by tapping the correct ingredients in the right order. It's all about concentration, skill, speed and fun. Ages 5 – 99.
- To assist learning to pay attention in order to follow what is happening, **play games** such as Parcheesi, Crazy Eights or Uno. More complex board games — such as checkers, chess and Scrabble — become appropriate as attention spans increase.
- Use an **interactive metronome** to work on attention and perseverance. This can be done in conjunction with OT or tutoring. It should not be a separate therapeutic intervention.

Activities to improve motor planning:

- The **Busy Shapes** app provides fine motor skills along with visual and cognitive challenges. Ages 2 - 5.

- Use the **Sound Matching (SM)** app to build phonological awareness with an emphasis on sound placement and sound order within a word. Building awareness of sounds in words helps bridge motor planning for speech production of words while fostering early literacy skills. Ages 4 and up.
- **ABC Maze** app works on letter and word recognition, as well as motor skills. Children will tilt the device with two hands to move the little chick through the maze and collect all of the letters in the word. The mazes are rather simple to navigate, as it is designed primarily for younger children. The full version has up to 36 levels of play with the option to use upper or lower case letters. Ages 3 – 7.
- **Dexterity Dots 2** is a fun, engaging, entertaining math App that also works on fine motor skills and visual tracking, brilliant! Ages 5 – 12.
- **Obstacle courses** promote the use of multiple large muscle groups, thereby practicing a variety of gross motor skills. These include running, climbing, jumping and crawling.
- **Purchase Retro Baby** by Anne H. Zachry, PhD for simple, easy ways to promote a baby's motor development without overexposure to technology and expensive gear.
- Simple **play helps to develop fine motor skills**. Shake, bang, reach and hold rattles. Pop or catch bubbles.
- **Work on following targets**. Targets can be made of anything and can be holes in boxes, cones to knock over, chalk on sidewalks or paper forms on walls. Throw a ball or a beanbag at a target. Kick a ball at a target.

Games and Apps with social cognitive skill-building:

Balls can help encourage socialization in a game of back and forth rolling or catching. Don't forget that balls, especially ones which are fun to shake, encourage gross motor skills and hand-eye coordination. Or get a soft spiky ball for extra sensory stimulation!

- With the app **iCommunicate**- Create pictures, flashcards, storyboards, routines, visual schedules and record custom audio in any language with this versatile program; incorporates pictures from your camera or Google images. Helps to teach social skills. All ages.
- Use the **Smarty Ears App, Social Quest**, to improve pragmatic language comprehension and expression in a variety of social situations. Grades 5 and up.
- **MindShift** is an app designed to help teens and young adults cope with anxiety. It can help you change how you think about anxiety. Rather than trying to avoid anxiety, you can make an important shift and face it. The app includes strategies to deal with everyday anxiety, as well as tackle social anxiety and more. Recommended for middle school and high school.
- **Balls** can help encourage socialization in a game of back and forth rolling or catching. Don't forget that balls, especially ones which are fun to shake, encourage gross motor skills and hand-eye coordination. Or get a soft spiky ball for extra sensory stimulation!
- Read the book *1-2-3 Magic* to help in behavioral modeling.
- **Using rhymes helps to foster social interaction** and speech and language development. Read *Miss Mary Mack and other Children's Street Rhymes* by Joanna

Share Your Successes

**" IF EVERYONE IS
MOVING FORWARD
TOGETHER, THEN
SUCCESS TAKES
CARE OF ITSELF. "
~ HENRY FORD**

We want to celebrate the accomplishments of our children. If you have any success stories to share (great or small) please email them along with any photos. Names will not be shared. Please email: cbedard@thefocusfoundation.org

Donations



You can give more without spending more. **Many companies will match your donation to The Focus Foundation.** Check with your personnel or human resources office to see if your company participates in a matching program. Many thanks to the Families employed at the companies below who have doubled their donations through community partnership programs.

Visit thefocusfoundation.org or click the button below to donate.

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