



The Magnifying Glass – A Newsletter

December 2014

Vol. 5, Issue 2

Featuring:

Year End Giving

Fall Accomplishments

Continued and New Research

DeXY's Corner: Social Anxiety

Dear Friends and Families,

Holiday celebrations are near as well as some much needed down time for children and adults alike! I would like to thank all of you for your continued trust, support and generosity. **2014 has been a landmark year for The Focus Foundation. Our news is wonderful with increased awareness, improved care, and children thriving in school, at home, and in the community.**

Yet, our work is far from finished! Your help is needed more than ever. After our Oktoberfest event and the FOX News story, many families contacted us - the 16 year old boy who was recently diagnosed after a diagnostic odyssey NO one should go through, or the 9-year old being bullied as school officials appear unresponsive, or the infant who needs and deserves services and professionals who would prefer to look, wait and watch. There is much to do!

2015 marks our Tenth Year! Let's make it our best year yet! Join us in ending the suffering of the undiagnosed, improve the care of all our children and optimize the strengths in each and every child!

Sincerely,

Dr. Carole

YEAR END GIVING

The Focus Foundation relies on the generous support of individuals to help those affected by X & Y Variations, Dyslexia, and/or Developmental Dyspraxia. It is private giving that pushes us towards excellence in our mission and helps us identify and treat

more people every year. As you consider your charitable gifts this holiday season, remember that The Focus Foundation is a 501c(3) corporation and donations made to us now can provide tax deductions that could help reduce your 2014 tax bill.

Donating online through PayPal at www.thefocusfoundation.org. It is easier than ever and you won't have to worry about getting contributions in the mail before the end of the year. Now is the time to give!

Upcoming Fundraiser

The Focus Foundation will be hosting a BLACK AND WHITE CASINO NIGHT in San Francisco on January 24, 2015. It is a night that promises to be great fun for all with amazing silent auction items, a signature drink with DeXY and a wine wall! Visit our website for updates, information, details and tickets.



CONFERENCES & RESEARCH



Dr. Carole Samango-Sprouse and Teresa Dixon, MA CCC-SLP presented at the American Speech-Language-Hearing Association (ASHA) conference in Orlando, FL on *the Intersection Between 47, XXY (Klinefelter Syndrome) and Speech & Language Deficits: Implications, Identification, & Management.*

The Focus Foundation has been quite busy since the start of 2014. In line with its mission to research and raise awareness for children living with X and Y Chromosomal Variations and associated neurodevelopmental disorders, here is all that we have accomplished this fall...

SCIENTIFIC PUBLICATIONS

- Samango-Sprouse, C. A., Stapleton, E. J., Mitchell, F. L., Sadeghin, T., Donahue, T. P., & Gropman, A. L. (2014). Expanding the phenotypic profile of boys with 47, XXY: The impact of familial learning disabilities. *American Journal of Medical Genetics Part A*, 164(6), 1464-1469.
- Samango-Sprouse, C., Stapleton, E., Sadeghin, T., Gibbs, D. C., & Gropman, A. L. (2014, October). Impact of Early Hormonal Treatment (EHT) on the Neurobehavioral

Profile of Boys with 47, XXY (Klinefelter syndrome) at 9 Years of Age. In *Journal Of Intellectual Disability Research* (Vol. 58, No. 10, pp. 887-888).

- Gibbs DC, Samango-Sprouse C, Sadeghin T, and Gropman AL. Neurodevelopmental variability in three young girls with a rare chromosomal disorder, 48,XXXX. (In review, 2014)
- Samango-Sprouse C., Gibbs D.C., Sprouse C, Stapleton E., Sisson D., Sadeghin T., and Gropman A.L. Expanding the Phenotypic Profile of Kleeftstra Syndrome: a Female with Near-Normal Intelligence and Developmental Dyspraxia. (In review, 2014)

POSTERS and PRESENTATIONS

- Samango-Sprouse C., Stapleton E., Sadeghin T., Gibbs D.C. and Gropman A.L. *“The Impact of Early Hormonal Treatment (EHT) on the Neurobehavioral Profile of Boys with 47,XXY (Klinefelter Syndrome) at 9 Years of Age.”* Society for the Study of Behavioral Phenotypes & the American Society for Human Genetics, Oral Presentation (Oct 2014)



- Gibbs DC, Gropman AL, Sadeghin T and Sprouse CS. *“Neurodevelopmental Profile and Cognitive Variability in Two Females with the Rare 48, XXXX Chromosomal Disorder.”* American Society for Human Genetics Annual Meeting, Poster Presentation (Oct 2014)

- Dixon T., Samango-Sprouse C., Gibbs D.C., Sadeghin T., Gropman A.L. *“The intersection between 47,XXY (Klinefelter Syndrome) and Speech and Language-Deficits: Implications, Identification and Management.”* Annual American Speech-Language-Hearing Association Convention, Oral Presentation (Nov 2014).

- Gibbs DC, Gropman AL, Sadeghin T and Sprouse CS. *“Neurodevelopmental Profile and Cognitive Variability in Two Females with the Rare 48, XXXX Chromosomal Disorder.”* Society for the Study of Behavioral Phenotypes Annual Meeting, Poster Presentation (2014)

- Sisson D, Samango-Sprouse C, Gibbs DC, Sadeghin T, Lutz-Armstrong M3, and Gropman AL. *“Expanding the Phenotypic Profile of Kleeftstra Syndrome (KS): Normal*

Intelligence and Childhood Apraxia of Speech (CAS).” American Society for Human Genetics Annual Meeting, Poster Presentation (Oct 2014)

RESEARCH

Phase III of our Baby study is well underway. We have teamed up with Lineagen, a company specializing in innovative genetic testing to aid in early detection and counseling for all neurodevelopmental disorders. This partnership will result in several novel studies throughout the DC area to identify children with X and Y chromosomal variations and developmental dyspraxia younger and sooner. Our Goal is to Help the children, Hope for families and Hurry !

We are also in the midst of publishing several exciting scientific papers. Our paper sustained positive effects of Early Hormonal replacement (EHT) on brain function, social behavior and intellectual capacities at now 9 years of age. We are very excited because these findings lay the groundwork for so many exciting possibilities for all the boys with XXY. We have several papers underway for expanding the phenotypic profile of poorly characterized, rare chromosomal disorders including 48, XXXX, 9q34 deletion syndrome (Kleefstra syndrome) and XYY with Prader-Willi. With every publication, children here in the USA as well as throughout the world are helped.



Dr. Sprouse's book **X & Y Chromosomal Variations: Hormones, Brain Development, and Neurodevelopmental Performance** will be available for purchase on March 1, 2015.



Dexy's Corner – Social Anxiety!

The holidays can be a stressful time for all of us. Working together to lower anxiety involves good communication skills and a healthy helping of fun!

Social anxiety is very common in the children helped by the Focus Foundation. Anxiety has many faces and affects every aspect of their life. It may alter their performance in school, their ability to make friends, or even sleep! Whether its nerves before a presentation or a party or a holiday – everyone gets anxious. But children with X and Y Chromosomal Variations, Developmental Dyspraxia and Dyslexia may be more severely impacted by this anxiety. Here are some helpful tips to keep everyone calm this holiday season:

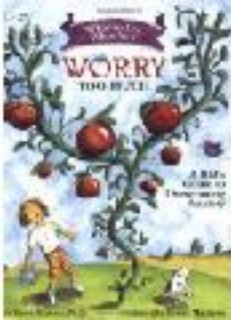
1. **Awareness:** Recognize that children often "act angry" when anxious. A child who appears "stubborn", angry or obstinate may in fact be suffering from an anxiety attack at that very moment! Remember, anxiety is a feeling of out of control, panic and nowhere to go.
2. **Triggers:** Figure out what sets these moods off.
3. **Remain calm:** When children are anxious, pushing them to complete the activity will increase their anxiety and will only make the situation worse. As parents, try to remain calm, quiet and patient. When children are anxious they look to others for stability - you are your child anchor, model and support!

Here are a few other general tips:

- Help your child learn to work through their anxiety with the help of professionals
- **Don't avoid** things they are anxious about because they need to learn to cope with that situation with your help and guidance. Express confidentially that together your child will learn to manage these feelings and together, we will manage the anxiety.
- **Be positive and realistic.** With help, your child will develop better strategies to address the various anxious inducing situations.
- **Teach calm breathing.**
 - Have your young child practice blowing bubbles. It's the same as what is used for calm breathing.
 - For the older child, take a slow breath in through the nose for about 4 seconds, hold for 1 - 2 seconds. Exhale slowly through the mouth for about 4 seconds. Wait 2 - 3 seconds before taking another breath. Repeat 5 - 10 breaths.

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.

For more information, visit www.anxietybc.com



What To Do When You Worry Too Much by Dawn Huebner
This book is designed to guide 6 - 12 year olds and their parents through anxious situations.

Wilma Jean the Worry Machine by Julia Cook
Written for kids in grades 2 - 5 this book is special for age. It offers creative strategies for parents



Written for children at any age and children.



Anxiety-Free Kids: an Interactive Guide for Parents and Children by Bonnie Zucker, PhD
This unique two-books-in-one is for parents and a workbook for children. Offers techniques for a variety of anxiety disorders.

Tangle Relax Therapy: Twistable therapy new ergonomic approach to stress relief and Use Tangle Relax Therapy for hand and mind excellent calming toy for anxious moments.



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We want to thank everyone for their continued support and enthusiasm for The Focus Foundation. The combination of research publications, conference presentations, press releases, and our new website, is making a huge impact. None of this would be possible without your help!