



**The Magnifying Glass –
A Newsletter
Fall 2016
Volume 7, Issue 2**



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.

The Sixth Annual Oktoberfest

**The Gatsby Era—
Fun, Drinks & Fundraising**

WHEN:

Thursday, Oct. 6
from 6 to 10 pm

WHERE:

The Ballroom at the Ben on
834 Chestnut Street
in Philadelphia, PA



Science is Moving Fast and Furiously!



**The Book is Here! Spread the Word –
To your physician, to your therapists, and to other families**

X and Y Chromosomal Variations

*Hormones, Brain Development, and
Neurodevelopmental Performance*

Available through The Colloquium Digital Library of Life Sciences, an innovative information resource for researchers, instructors, and students in the biomedical life science community, including clinicians. Each PDF e-book available in the Colloquium Digital Library is an accessible overview of a

fast-moving basic science research topic, authored by a prominent expert in the field. For the full list of available books, please visit: colloquium.morganclaypool.com. Please e-mail info@morganclaypool.com for more information.

New Publication in the Public Library of Science ONE (PLOS ONE):

Incidence of X and Y Chromosomal Aneuploidy in a Large Child Bearing Population

Authors: Carole Samango-Sprouse, Eser Kirkizlar, Megan P. Hall, Patrick Lawson, Zachary Demko, Susan M. Zneimer, Kirsten J. Curnow, Susan Gross, Andrea Gropman

This paper expands our understanding of the human biology of XY chromosomal disorders in adults, and this further increases our comprehension about these disorders.

Going Global—Presentations throughout Canada and Europe

In July of this year, the annual meeting for the **International Society for Prenatal diagnosis (ISPD)** was held in Berlin, Germany. This hosts the largest collection of physicians and specialists in prenatal medicine from all over the world. It is an ideal opportunity to inform medical practitioners about the positive outcomes of boys with XXY. Dr. Samango-Sprouse discussed the foundation's findings in her presentation regarding a "Large Prospective Study of the Neurodevelopmental Outcome in Prenatally Diagnosed Males with 47, XXY".

The **Society for the Study of Behavioral Phenotypes (SSBP)** held their 19th annual conference in Siena, Italy this September. The theme of the meeting was "early/late-life adversities and behavioral phenotypes". Dr. Samango-Sprouse gave an oral presentation focused on characterizing neurodevelopmental outcomes in a large, prenatally diagnosed population of boys with 47, XXY and the positive effects of early hormonal treatment. Additionally, two posters were presented, which were entitled "Neurodevelopmental Aspects of 48, XXXY: A Rare Variant of 47, XXY (Klinefelter Syndrome)" and "Neurodevelopmental Profile for Boy with 47, XYY and Prader-Willi Syndrome". This was a lovely conference to attend!

The **American Society of Human Genetics (ASHG)** Annual Meeting is being held in Vancouver, Canada this fall. It is typically attended by more than 10,000 participants throughout the world and is a wonderful opportunity to spread our information globally. Here are our presentations for the upcoming conference:

Dr. Carole Samango-Sprouse- Neurodevelopmental indications of increased vulnerability for executive dysfunction in boys with 47,XXY

Chris Cappello- Novel copy number variant (CNV) and neurodevelopmental profile (NDP) in boy with neurofibromatosis type 1

Colleen Keen- The combinative effect of copy number variation (CNV) in 47,XXY, a sex chromosome variation (SCV)

Collaborative investigations: from the Bench to improved Clinical Care

- With collaborations from Johns Hopkins, the David Page Lab, and the Kennedy Krieger Institute, the impact of genetic expression and structure on clinical outcome will be explored

- The George Washington University School of Medicine curriculum will be updating and expanding upon its information on genetic disorders
- A “welcome packet” of information and resources is now available for families with newly diagnosed children with 47, XXY

Conference Announcements

Topics will include:

Sessions for Parents of children ages 0-5
 The Where, When, and Why of Testosterone
 Academic Red Flags at Preschool
 Panel of Adolescent Boys and Parent Panel
 Linking Baby Behaviors to Academic Success—Advocacy for best IEP—Social Learning

Children with an X or Y Chromosome Variation:

San Francisco: January 28th and 29th, 2017
 Annapolis: June 23th and 24th, 2017

49 ers Conferences:

December 1-5 2016: Thornton Manor, Liverpool, England
 April 27-30, 2017: Bari, Italy (exact location TBD)
 July 19-21, 2017: Annapolis (14th annual 49 ers conference)

Learn from the Experts

Dr. Andrea Gropman (neurologist, Children’s National)
 Dr. Darius Paduch (pediatric endocrinologist, Cornell)
 Dr. Carole Samango-Sprouse (neurodevelopmentalist, GWU)
 Dr. Bressler (research scientist, Johns Hopkins)
 Michelle Garcia Winner (Speech Language Pathologist)
 Dr. Francine Mitchell (Physical Therapy)
 and Many More...

Let’s Celebrate!

Our Fundraising Families

Philadelphia—Melissa and George Stratts
 San Francisco—Chandra and Shane McLaughlin
 New York—The Hutchinson's
 Seattle—The Drakes
 Europe—Dr. Andrea Kramer and Dr. Rienk van Calker

THANK YOU to all who are helping support the promise that The Focus Foundation works hard to meet every day! Your efforts are helping to ensure the brightest future for all of our children throughout the world.

“Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has.” ~Margaret Mead

DeXY's Corner

Success Story

Last night when I was putting Benjamin to bed he mentioned to me that he was having to start a new reading program. I expected a "moan" as I know he was excited that he was finishing up his last program. Instead of the moan, he was very proud to tell me that this new reading program was "advanced". He went on to tell me that he is becoming a good reader. That he remembers when he used to sit in class, look at the paper and not know what to do. That he'd try to look at the paper of the people next to him to figure it out. Now that he is getting smart, people are going to want to look at his paper. He finished by saying he's excited for his life.

You all know the impact you have on our kids and our families. I just wanted to pass along another incredible success story. After years of anguish, it is amazing to see the transformation Benjamin has experienced in the past few months. We're SO thankful to have you all in our lives.

Recipe

Cooking is wonderful for developing planning, sequencing and frontal lobe function. Best of all, the end product is delicious!

Caramel Corn Treats

Total time: Prep/Total Time: 15 min. Makes: 24 servings

Ingredients

- 5 cups caramel corn
- 2 cups miniature pretzels
- 1 cup miniature cheddar cheese fish-shaped crackers
- 1-1/4 cups Reese's pieces, divided
- 1 package (10-1/2 ounces) miniature marshmallows
- 1/4 cup butter, cubed
- 1/4 teaspoon vanilla extract



Directions

1. In a large bowl, combine the caramel corn, pretzels, crackers and 1 cup Reese's pieces. In a large microwave-safe bowl, melt marshmallows and butter; add vanilla and stir until smooth. Pour over pretzel mixture; stir until well coated.
2. Press into a greased 13 x 9-inch. pan. Sprinkle with remaining Reese's pieces; press lightly. Let stand until set. Cut into bars. Yield: 2 dozen.

From **Taste of Home**

FALLing into Books

Johnny Appleseed: My Story (Step-Into-Reading, Step 3)

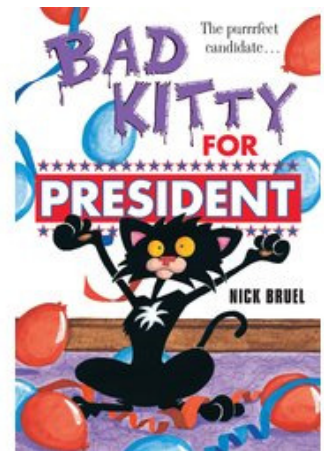
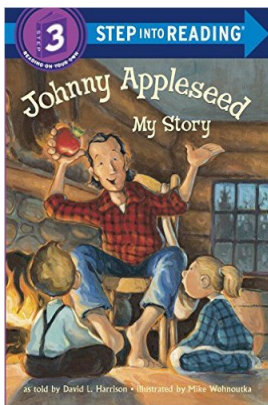
By David L. Harrison (Author), Mike Wohnoutka (Illustrator)

How I Got My Shrunken Head (Classic Goosebumps, Book #10)

By R.L. STINE Grades 3 – 7

Bad Kitty For President

By NICK BRUEL Grades 3 – 5



Get Ready to Write

Finger Aerobics is a fun way to warm up the hands before writing.

Spider Push-Ups: Place both hands together with palms and fingers touching. Push the hands away from each other at the palm. The fingertip should remain in contact.



Fingertip Touch: Touch their thumbs to the tips of each of the fingers. Do both hands at the same time or one hand at a time. Then, touch the tip of the thumb to the base of each finger. Touch the tip or base of each finger at different speeds, as they spell words, or count in various increments touch the tips or bases of each finger with the hands held behind the back or out of the field of vision.

Fist Squeeze: Make a fist with both hands. Try placing the thumb in different positions and squeezing as hard as you can. Try the thumb at the side of the fingers, wrapped over the knuckles, and tucked under the fingertips. Stretch out the fingers and then repeat.

Spider Crawl: Stand up behind the table. Place both hands with the palm and fingers flat on the desk surface. Make the hands "crawl" across the desk like spiders. Move both hands together symmetrically and individually in different directions. Keep the palm lightly positioned on the desk surface.

Visit - <http://www.sugaraunts.com/2016/08/fine-motor-skills-needed-at-school-and.html>

Stay Connected



@FocusOnDeXY



The Focus Foundation

Email: dexy@thefocusfoundation.org

Volunteers Needed

If you have any success stories to share (great or small), please email them to Teresa along with any photos: teresa@thefocusfoundation.org

The Black and White Casino Night in San Francisco (1/28/2017) is looking for volunteers. It will take place at The Great Highway in San Carlos, California. Activities will include gaming tables and a silent auction.

TODAY'S SPECIAL QUOTE

I WON'T CHANGE THE WAY MY CHILD VIEWS THE WORLD,
I WILL CHANGE THE WAY THE WORLD VIEWS MY CHILD.
- UNKNOWN



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!

