the focus foundation

The Magnifying Glass - A Newsletter

December, 2010
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Dear Friends,

2010 is drawing to a close and it has been a wonderful year. This has been a year of many firsts for The Focus Foundation. Our first E-newsletter, our first conference for boys with 48, XXXY and our first May Awareness Month for X and Y Chromosomal Variations to name just a few.

We have **Knowledge** that we learned from following children for more than 20 years. Please see the parent letter in this issue from one of our oldest patients.

We have **Optimism** from our experience with our patients and watching them reach their personal goals, whatever they may be. For all, it is a well developed self esteem and respect for themselves and their community.

We have **Humility** after seeing our kiddos beat the odds every day, accomplishing feats that were never even considered. One patient is on the ski team in his hometown, another started travel soccer at 6th grade having not played soccer for years and yet another child speaks Spanish and English and is learning Hebrew for his bar mitzvah.

We have **The Power of Hope and Dedication** because the list of accomplishments each year is endless and diverse from our kids.

The Focus Foundation wants every child with X and Y Chromosomal Variations, Dyspraxia and Dyslexia in this country to meet their potential.

Our science endeavors are moving forward and there is such exciting news. Several articles have been written by Dr. Samango-Sprouse.

- Pediatric Endocrinology Review has an article on the Young Child with XXY.
- American Journal of Medical Genetics has an article on children with 49, XXXXY
- Neurodevelopmental Treatment Association (NDTA) has online article on identifying the children with X and Y Chromosomal Variations.
- Baby study begins Phase III for identification of infants at risk for Autism and X and Y disorders by 9 months of age.

Fundraising is doing very well and we have added two new Staff Members—Madison Kingery and Joanne Schram. Madison was formerly with Voice of America and brings wonderful experience in development, production and social media. “Jo” worked for years at the University of Maryland and was instrumental in raising over 5 million dollars for their business school. She is spearheading our fundraising campaign... 10 million in 5 years!

Thank you for your help! Thank you for your dedication to your children! Thank you for supporting us!

HELP US FIND ALL THE FORGETTEN CHILDREN!

What's new?

The past couple of months have been a whirlwind here at The Focus Foundation, and from this momentum we are rocketing into 2011.

October was a busy month. We spent a few days in Pavia, Italy for the annual Society for the Study of Behavioural Phenotypes Conference. The conference was exciting and informative, and gave us a chance to talk with doctors and scientists in similar fields from all over the world. While abroad, we finalized our efforts with a group of scientists in the Netherlands. We are now working with them to research issues surrounding motor planning, attention and executive functions. We are hoping to reveal the positive effects of targeted treatment and syndrome-specific goals that we have designed. We've already started collecting pilot data on our boys and girls!

In November, we held a fundraiser in Philadelphia, PA and what a success it was! We met some wonderful people while we were there spreading the word about X and Y chromosome disorders and how The Focus Foundation is helping kids all over the world. We also spoke with many people about a Philadelphia area fundraiser in May for X and Y Chromosome Awareness Month. We can't wait to go back!

In fact, this Philadelphia fundraiser was the perfect kick-start to what we expect will be many more to come. In the next few months we are planning fundraisers in Chicago, Florida and New York City!

If you have a fundraising idea, or would like to become involved, let us know! We need your help, your ideas and of course all your support.

In January, we will start another study focused on ASD and robotics. We are working with three types of robots and social cognition. We are very excited since we are working with a major toy company on this project. Our earlier studies resulted in helping many children and great publicity for the work of The Focus Foundation. It is very exciting!

Our baby study has completed Phase II and has more than 900 babies enrolled. This study focuses on babies who are at high risk for Autism, infantile dyspraxia and X and Y chromosomal variations. We have identified three easy maneuvers that doctors can practice during well-baby visits that will help identify babies at risk for all three disorders as early as 9 months of age. This will aid in early detection, treatment and recovery. It is another means to locate the FORGOTTEN CHILDREN and provide them with appropriate treatment.

Recently, we've been trying to find a mechanism to disseminate information quicker to the families and friends of The Focus Foundation who need help, guidance, and of course, optimism! As a result this December we have started a blog for The Focus Foundation to keep the conversation flowing. We are hoping this blog could be a medium for patients, friends and anyone else to ask questions, voice concerns or simply comment about what's important to them or their child with any disorders. We will be checking the comments regularly and have posts written by Dr. Samango-Sprouse that address some of these topics.

Be sure to check it out and voice your comments at:

thefocusfoundation.blogspot.com

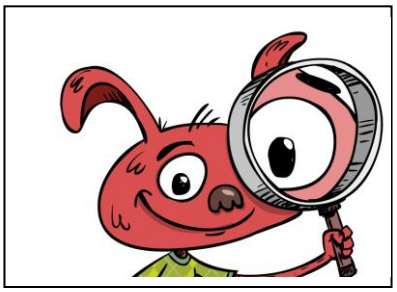
Meet DeXY

DeXY, short for Dexter is our critter spokesman created to promote improvement in children's lives with **D**evelopmental **D**yspraxia, **D**yslexia and **XY** variations.

DeXY was designed by Jon Izen of Canada and named in last year's "Name This Critter" contest by Jennifer Hansen of Indiana.

Everyone thinks DeXY is clueless, but he follows the clues to find out the best ways to help his band of followers!

This year, DeXY is creating his very own club to help all of his buddies with X and Y chromosome variations. He'd like to spread the word about some of the exciting stuff we are doing and how you can help! Please join DeXY!



DeXY'S Club

Hi! I'm DeXY. Wanna help my buddies with extra X or Y chromosomes?? Join MY team and help The Focus Foundation!

Here's what your donation to The Focus Foundation will help fund in the coming year:

- Research: Identifying Babies with Autism: Phase III, Robotic Studies and the Dutch Motor planning Study
- Conferences for 2011--47 Conference in April , 49ers in July and 48's in September
- Focus: Bone health, Growth and Behavior
- Conference Scholarships: Building a fund so all families can participate in any or all studies
- International research... Italy and the Netherlands
- Major presentations at scientific meetings
- Greater Presence to the Medical and Educational Communities.

**Just a reminder to the parents of my buddies. If you work for a corporate gift match company, your contribution will double…two for the price of one. Please visit your personnel office, ask for the matching form, complete your portion and send the entire form to The Focus Foundation. We will complete our portion and return the form to the corporate gift match office for payment. It is so simple, and what an easy process to double the dollars for my buddies.*

To Make a Donation to The Focus Foundation, please visit our website at: **www.thefocusfoundation.org**

Or send your tax-deductible check to: P.O. Box 190 Davidsonville, MD 21035

Did you know???

Sensory Processing Disorder (SPD) affects at least one in twenty children. These children experience sensations in taste, touch, sound, sight, smell, movement and body awareness very differently from the way other children their ages do. What may be typical activities for most kids are a daily struggle for them that may result in social, emotional, or academic problems.

The following books are helpful guides for parents of children who have this disorder:

The Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder, Revised Edition by Carol Kranowitz and Lucy Jane Miller 2006

How does your child experience the world? This landmark book lists the common symptoms, as well as possible causes for sensory overload. It analyses the different types of children with the disorder such as the over responsive child, the under responsive child and the sensory-seeking child as well as how to identify these problems.

The second part of the book deals with how to cope with SPD, with lots of practical advice and lots of games and exercises to help the SPD child. After reading this book several parents have told us they can now deliver a better "sensory diet" to their child.

Its companion book ***The Out-of-Sync Child Has Fun*** is a great supplement. It holds a "treasure trove" of activities for use at home with your sensory challenged child.

Sensational Kids: Hope and Help for Children with Sensory Processing Disorder by Lucy Jane Miller PhD, OTR, and Doris A. Fuller 200

Most parents agree this book provides practical information and is a "must have" for the library. It provides in depth descriptions about sensory processing and how it affects all children. It takes a complex subject and makes is understandable for all.

-Teresa Sadeghin

How the iPad Could Help You

The iPod touch or iPad can be used as an excellent learning tool for disabled children. Through these touch devices some highly challenged children have been able to communicate with adults better than ever before and even learn skills that have previously eluded them. We have long been using computer technology to help educate children that present special challenges. However, the iPad provides a faster, more versatile and engaging option for younger generations.

Dr. Samango-Sprouse has been increasingly using the iPad in her work with children with developmental dyspraxia, dyslexia and other learning disabilities. Here are some of the applications she suggests to help the learning process:

First Then Visual Scheduler- Uniquely customizable to each individual, this app allows you to create and update visual schedules on the go and provides positive behavior feedback for completing each step of the schedule.

iConverse - This app functions as a picture exchange communication system and is designed specifically for autistic individuals, and individuals with other communication disabilities.

ABA Receptive Identification - This app helps teach children about the features, function and class of items, people and places. It's a great app for helping develop appropriate functional conversational skills.

These are just a few of the functional and helpful applications available for the iPod Touch or iPad. Interactive books are also another great way to engage your kids. For more information, and to browse a full library of applications, check out: **www.apple.com.** ***Look for our own personal library of APPS to come on our blog so that we can dry run the games for your child and his strengths and weaknesses!***

Looking Back... Eighteen years later

Dr. Samango-Sprouse has known many patients for more than 18 years!

What a joy it has been to watch all of our families as they learn and grow.

Below is a story from one of our early patients.

We had been married for 13 years, were the proud parents of a twelve and a one year old daughter, and had recently moved our family across two states due to a military transfer when we discovered that our family was going to grow a little larger. Due to the fact that we were in our late 30's, we decided to have an amniocentesis. Two weeks later, "the" call came...Dad was at work, so Mom had to take the call...alone, pregnant, with a one-year old in tow. "Ma'am", the caller said, "we've got the results of your amniocentesis. Congratulations, it's a boy." He went on to explain, in a foreboding voice..."However, there's a problem. Drawing from her medical background, Mom knew that her child had Klinefelter Syndrome (KS). Trained as a Registered Nurse, she had done research in genetic disorders for a class project while attending nursing school in the mid-1970's. At the time, and well into the 1990's, the information on chromosomal differences (e.g., 47-XXY) was exceptionally limited, very frightening, and mainly pointing to limited opportunities and likely negative outcomes.

The caller encouraged us to make an appointment to speak with our obstetrician. A week later, in that appointment, Mom found herself being counseled by a physician who had no knowledge of this syndrome, and who proceeded to read from his medical textbook. When he was finished; he informed her that she only had two weeks to decide what to do about the pregnancy. Angrily, she left his office and called both her mother and her husband. This began our long search for information and answers.

As we were living in a small town at the time, very little was available to us. Searching our local hospital's medical library, we were appalled by what we found. Mom knew in her heart that this couldn't possibly be all of the facts, so we went home and for the very first time, Mom learned to use a computer. In her search, she located members of a support group and talked to people who were going through the very same thing. They were very encouraging, but realistic. The research was limited and the prognosis unknown, but with the support of our family and our trust in God; we were undeterred in our commitment to have our son. We have never looked back and feel blessed to have him.

Our son turned 18 this spring. After a rough start in a public school setting where ADHD and Dyslexia were poorly understood, we found administrators and staff to be somewhat narrowly focused and inflexible. Our son spent the majority of his school years in settings specifically focused on educating children with normal or above normal intelligence, but with attention deficits and/or language-based challenges (e.g., dyslexia). Though the 13 years of his primary and secondary education were challenging and, at times, frustrating, our son passed his state's "no-child left behind" tests on his first attempt and graduated from a highly-respected program this spring. Though his graduating class was small, with only 18 students, and therefore had no formal Valedictorian declared, we were extremely proud when, during the graduation ceremony it was announced that he completed High School with the highest Grade Point Average (GPA) in his class. While noting his academic accomplishments, his teachers and the school administrators also praised his technical achievements as he satisfied his state-mandated community service. In our state, each child must perform at least 100 hours of voluntary community service in order to receive their high school diploma. His project was unique, tangible, and required him to acquire technical skills beyond those offered in his high school setting.

Dad was overseas during the majority of our son's Sophomore year. When he returned, just after the start of his Junior year, we discovered that his school had "lost" our son's community service record. While displeased, we quickly realized that we needed a

better plan. Dad and son sat down, drafted a proposal for a project and submitted it to the school for approval. The project envisioned the collection, refurbishment, and donation of used and unwanted personal computers. Our son would collect those computers (via personal contact, Free-cycle (an on-line swap site), garage sales, etc.), thus saving them from entering the waste stream (e.g., the landfill) and providing some family or individual a free, usable system. He would clear all data from the system disks by use of a disk "wiping" program and load a new, clean and free operating system, LINUX (UBUNTU), along with a set of free, open-source office tools. Over the course of the next 18 months, our son recycled over 50 machines, donating them to local charities, such as a local shelter for abused women and children; and to families in need of a working computer. He kept a log book of each machine collected, describing the work done to the machine, time expended, and the ultimate disposition of each computer. Not only did he exceed his community service requirements, but he learned very useful technical skills, learned about the value of proper documentation, and learned that it is also important to be able to defend his claims when called upon to account for them. The result of his efforts won respect and praise from many. More importantly, it provided him with tangible evidence of his own abilities. His self-respect and confidence soared.

We are very proud of our son's accomplishments as he enters his Freshman year in our local Community College. As he says often..."Don't give up on yourself! If you have a challenge; confront it and draw from your strengths." As his parents, we believe it is our responsibility to support our son to the best of our ability and tap into his greatest potential. We've assisted in his success to date by being strong advocates on his behalf, challenging the system when needed, and partnering with him as he finds his way in life. We hold great hope and expectations for our son's future. As knowledge and understanding have improved since that fateful "call", we are also very optimistic about the progress being made to assist all individuals born with genetic differences.

The key...continuing to educate ourselves, and then the members of our community, especially those who serve as gatekeepers to sources of intervention and success (educators, medical staff members, potential employers, legislators, etc.).

The Focus Foundation

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We're on the Facebook!
facebook.com/
thefocusfoundation

The Focus Foundation *is the first and only research-based agency exclusively dedicated to identifying and helping children who have* ***X & Y Variations*** *(also called X & Y Chromosomal Variations or Sex Chromosome Disorders),* ***Dyslexia*** *and/or* ***Developmental Dyspraxia****, conditions that lead to language-based disabilities, motor planning deficits, reading dysfunction, and attention and behavioral disorders. All physicians, ancillary health care providers and special educators are taught that genetic abnormalities can impact a child's development. Unfortunately, because most ' practitioners often receive insufficient information about sex chromosome disorders, they don't even consider testing for X & Y Variations when caring for a child who presents with developmental concerns.*

Early Identification + Targeted Treatment = Recovery