

The Magnifying Glass – A Newsletter

September 2013

Vol 3, Issue 1

Dear Focus Foundation Friends and Families,

As school gears up and fall approaches The Focus Foundation would like to wish everyone a happy start to the school year! While homework and IEP meetings consume our time, remember to take a deep breath and check out **DeXY's corner** for some helpful Math games, books and apps that might make life a little easier for the student in your family.

We'd also like to take a moment to reminisce on this past summer and spring. Our accomplishments for the year are already far beyond what we imagined! We have seen over 1,000 boys and girls with X and Y Chromosomal Variations in the last decade and hundreds of children with dyspraxia and dyslexia. So much to write about!

Following the groundbreaking publication of the **American Journal of Medical Genetics Part C**, we have received an onslaught of calls from all over the world including Europe, Asia and South America. The Focus Foundation has made significant progress in working towards a better life for children around the world! As we build international awareness we will improve medical and neurodevelopmental care for children everywhere. We have ancillary health care personnel helping us *find our children who are hiding in plain sight*. it is both exciting and encouraging!

Through your support, we now have had our 10th annual 49ers conference. We now have 14 specialties participating including neurology/genetics, dental, endocrinology, orthopedic, and vestibular physical therapist, and immunology.. We are in the process of developing treatment modules, for our 49ers, with tutorials to address upper extremity deficits and improve shoulder girdle function. Please stay tuned as we develop treatment modules for our boys and girls with 47, XXY, XYY and XXX.

We have also started the task of documenting the benefits of hormonal treatment in our boys with XXY given at 12 months and again between 6 and 9 years and again at 11 years. So that perhaps the statement, "your son with XXY does not need testosterone until he is a teenager," will never be heard again.

Our efforts will continue this fall with **upcoming events** like our 3rd annual **Oktoberfest** fundraiser - when we started this event in 2011 we never dreamed it would get this big! Our Greater Philadelphia Fundraising Committee has become a critical part of our fundraising team and their efforts shine through this incredible event. So please join us this year at the Crystal Tea Room in Philadelphia on October 17th. The Oktoberfest is one of the many magical events that has guaranteed our exponential progress in the last seven years.

If you can't be there in person, there are always other ways to help. Just a few of the other items on our list you can contribute towards include: curriculums for school resources, brochures for

health professionals, a Center of Excellence, and a documentary for newly diagnosed parents and children.

Our accomplishments are the shared endeavors of all our fabulous supporters. We are grateful for all you do, which allows us to do so much! As I close this letter, i would like to brag about our boys and girls and their accomplishments. Some of our older boys and are currently in college and we have children now participating in sports such as basketball, soccer, water polo and state level ski teams. We've also been told that one of our Triple X girls aspires to be a famous fashion designer and actively dreams of being the next Vera Wang!

My wish is that every family will want to brag about their child and how well he or she is doing, so medical personnel will understand that children with X and Y Chromosomal Variations, dyspraxia and/or dyslexia bring profound gifts to our world, especially when identified early, provided with targeted and timely treatment, as well as when surrounded by a nurturing and supportive environment. Enjoy the fall weather!

Sincerely,

Dr. Carole

What's New? Upcoming Fundraisers and Events!



Our 3rd Annual **OKTOBERFEST** will take place this October 17th, in Philadelphia, PA at the spectacular Crystal Tea Room at the Wanamaker. Last year's event raised more than \$100,000, brought out over 200 people and was sponsored by more than 30 companies including Chartis, Towers Watson, Liberty Mutual and AON. Come partake in the fun with us by attending the event or becoming a sponsor! Click here for ticket and event information

(https://www.eventbrite.com/event/6730239327/?ref=enivtefor001&invite=NDEzNzY1Ny9raW5nZXJ5bWFkaXNvbkbNbnWFpbC5jb20vMA%3D%3D&utm_source=eb_email&utm_medium=email&utm_campaign=inviteformal001&utm_term=eventpage)

-Our Florida friends and families can join us for a cocktail hour and FUNdraiser in Ft. Lauderdale in 2014. Contact us if you would like to get involved and stay tuned for information on times and locations!

-Thanks for matching contributions from companies nationwide! Partnerships for giving campaigns have increased, with **matching donations** from Merck, BNY Mellon, IBM, AIG, Travelers and Washington Post. We have a **brokerage account** with Ameritrade started by one of our many donors!

-HOW CAN YOU HELP? Parents and children have been staging **grassroots fundraising campaigns** across the United States, hosting FF awareness and fundraising events in lieu of birthday parties and gathering groups to run in local races! Contact us for ideas on how you can raise funds for The Focus Foundation.

CONFERENCES & RESEARCH

-In September, Dr. Samango-Sprouse and Research Assistant, Emily Stapleton presented at the **16th SSBP International Research Symposium and Educational Day**. Poster presentations focused on *Mathematic Capabilities of Boys with XXY* and *The Effects of Early Hormonal Replacement on the Anthropometric Measurements of Boys with XXY*. This symposium highlighted a wide variety of research and clinical work in neurodevelopmental and neurobehavioral aspects of genetic disorders and biologically determined syndromes and featured researchers from all over the world.

This month, Dr. Samango-Sprouse will be presenting at the **American Society of Human Genetics in Boston**.

In the next 12 months, several other presentations are planned throughout the country and abroad.

WHY OUR RESEARCH MATTERS: Making a Difference One Family at a Time

We recently received this letter and couldn't help but smile at the glowing confirmation from this parent on how much early identification and treatment matters in the life of each and every child. These boys are doing great in school, in life and in the community!

We are also proud to say that our research is changing the face of all three disorders. Our goal is that no family will EVER have to navigate scary, outdated information about their child and his/her needs. These boys are in good physical shape, avid readers, and honor roll students, with friends. This is exactly why The Focus Foundation exists!

***This letter was written to Dr. Samango-Sprouse and another Doctor close to the family, and all names in the letter below have been changed to respect the privacy of this family.* as you read this story, both boys have above average IQ, participate in many school activities and read voraciously and as teenage boys often do --- get into silliness but innocent adventurers!**

Today was one of those monumental days as a parent when I just couldn't go to bed without speaking up about the greatness of my kids, which is something that I don't do enough. It is not that I am not exceptionally proud of my kids, it is just that I probably expect so much from them that I often overlook how great they really are. Today, Josh and Tim* were hired for their first jobs!*

It was almost 16 years ago that my husband and I learned that we were carrying twins who were chromosomally "abnormal". When I think back on this time, it makes me cry only because I feel sorry for those women who are going through this same experience right now and I wish they could just peek into their lives 15 years from now just to see that life is not so bad. In fact, I remember crying and saying those words..."I just want to look at how these boys will be in the future and see that hopefully it will all be ok". It was an awful feeling.

I was at work the day I received the results of the amnio. I was told that one twin was mosaic XY/XXY and that the majority of the cells were XY. I can't remember if it was twin A or B, but the other twin had normal chromosomes. I cried and asked what my options were and you were a bit taken aback and said that sometimes one of a set of twins could be terminated, but that it wasn't recommended. You told me that the most important thing one can give to a child was love and a stable home environment. Yes, you really said this! You said that they might struggle just like many (most) other kids do, but that even the infertility issues were so far in the future that it shouldn't be something that we should worry about at that time. About a week later, we received a call that the other twin had more cells tested due to the mosaicism of his brother and sure enough, some XXY cells were found. Again, the percentage of affected cells was low, but nonetheless, it wasn't all normal. More tears.

My husband and I made the decision to share this news with no one! Not out of embarrassment, but the more we educated ourselves and read, the more we knew that the information that was out there could probably only do more harm than good. We did our best to enjoy the remainder of our pregnancy and we managed to do so. To this day, the only people we have shared our boy's diagnosis with, other than both of you, has been their pediatrician, and of course, them. Some may criticize us, but at this stage, it is up to them to decide who knows. Today when they were dressed in their ties and held their little notebooks with nothing written on the pages, I was so moved and proud by how far they have come. They are such amazing kids! They are so sweet, they are so smart... sometimes so much that their sarcasm gets them in to

trouble whenever they can find the opportunity! They are each other's best friends and I can't imagine them without each other or us without them. They are amazing! My husband was out of town today when they had their interviews and they both couldn't wait to tell him they got the job. When I spoke with my husband tonight, I could tell we both felt the same. So proud for these boys who are now young men who we have worried about since before they were born as all parents do, but who appreciate the little "wins" more than any parent of a "normal" child does and we are sure of that. We do our best to provide that stable home environment that you said is so important, and this is something that I reiterate regularly.

Thank you both for your optimism in the very beginning at a time when so many other parents' were/are told to terminate. My husband and I both struggled on what the best decision was for all of us, and thankfully, it was you two who were the ones we were talking to. We cannot imagine our lives without our crazy boys!

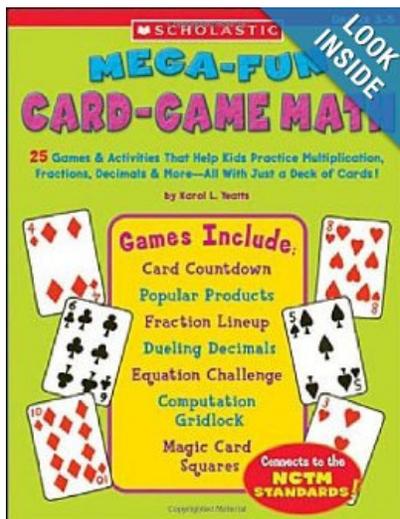


Dexy's Corner – Back to School

Math class can be tricky, especially for younger students. We've compiled a list of books and games that help with concepts from simple addition and subtraction to more complex multiplication and division. With these fun books they won't even realize they are sharpening their skills or learning something new!

Mega-Fun Card-Game Math by Karol Yeatts

Grades 3 – 5

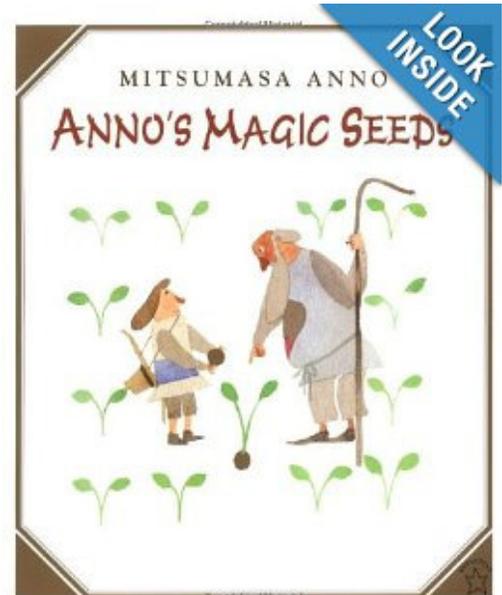


This book includes 25 different games and activities that can be played with a deck of playing cards. Games cover skills from addition and subtraction to more difficult arithmetic and even some geometry.

Anno's Magic Seeds by Mitsumasa Anno

Preschool – Grade 3

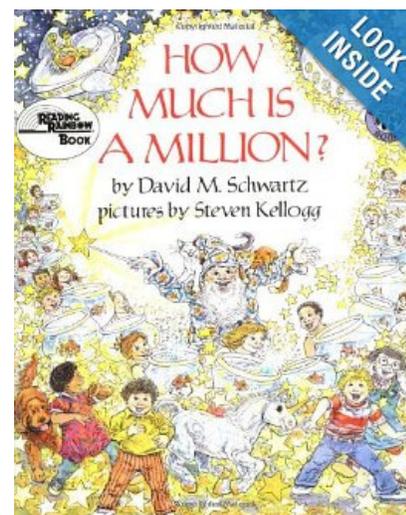
Get them counting early with this picture book that follows young Jack as he receives a gift from a wizard that grows by ones and twos. Young children will enjoy the story and pictures, while older children will have fun with the mathematics of Jack's growing fortune.



How Much Is a Million? by David Schwartz

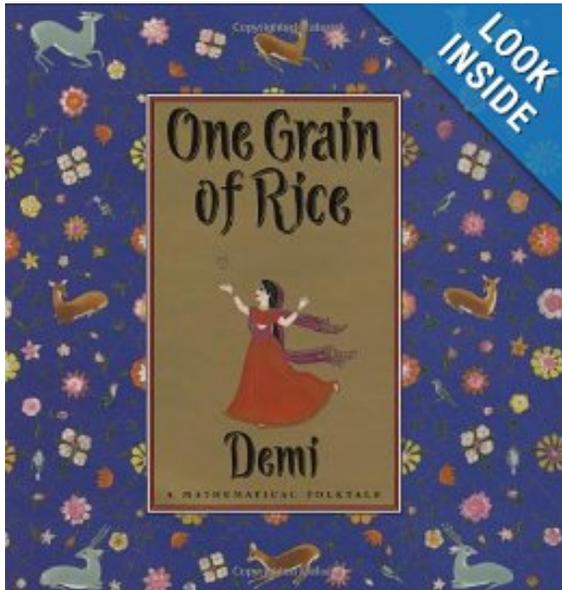
Grades K – 3

Go on a journey with Marvelosissimo the Mathematical Magician as he helps conceptualize larger numbers. Marvelosissimo uses fun examples to explain millions, billions and trillions. This is a great book for those confused about numbers too large to count or that puts them into a child's perspective.



One Grain of Rice: A Mathematical Folktale by Demi

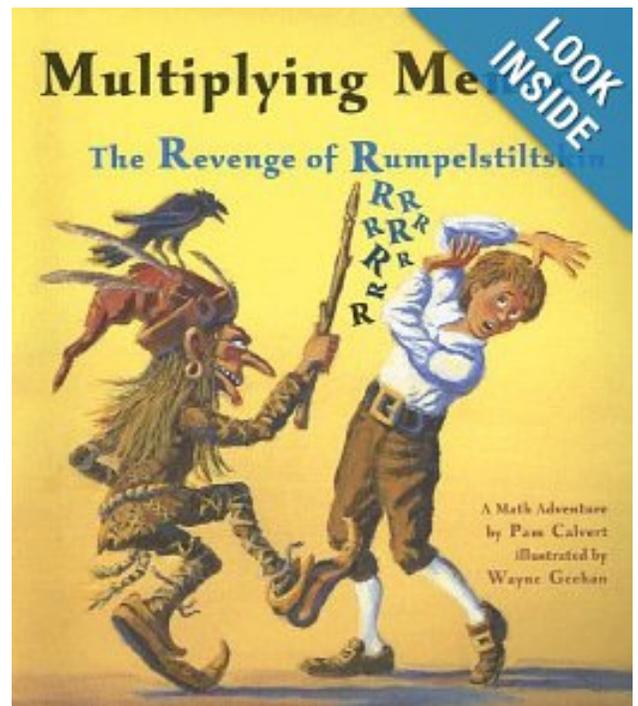
Preschool - Grade 3



This beautifully illustrated book celebrates the rich culture of India while brushing up on the doubling function of mathematics. A resourceful village girl outsmarts a greedy raja, turning a reward of one grain of rice into a feast for a hungry nation by having it doubled each day. The colorful photos and moral tale provide a fun background to this functional tale.

Multiplying Menace: The Revenge of Rumpelstiltskin (A Math Adventure)
by Pam Calverty Grades 3 And Up

Multiplying Menace covers the multiplication of numbers and fractions with the all too familiar Rumpelstiltskin character. Magic and math go hand in hand as 10-year old Peter takes on old Rumpelstiltskin and his multiplying stick. This fairy-tale is great practice for those students learning multiplication and fractions.



APPLICATIONS FOR HIGHER LEVEL MATHEMATICS

MATHMASTER



<https://itunes.apple.com/us/app/the-mathmaster/id312338867?mt=8>

This \$0.99 application allows for typed answers and customization of math problems and number ranges, making it easy to cater to different individuals. The subjects covered range from addition and subtraction to roots and powers.

WOLFRAM / ALPHA

<http://products.wolframalpha.com/mobile/>

Wolfram features applications on every math related subject from Pre-Algebra to Statistics and even has Music Theory and Chemistry! Their selection covers every formula and model imaginable and is a great place to start for those struggling in upper level math classes. Applications cost around \$3.00 and are compatible with Apple products, Android, Kindles and Nooks.

ALGEBRA SOLVER

<https://itunes.apple.com/us/app/algebra-solver/id331855056?mt=8>

Algebra Solver is great for those tricky equations you just cant seem to get right. This \$0.99 app actually SOLVES equations and formulas step by step and allows the answers to be shared via e-mail. This provides a way to check over work or view difficult equations. A full list of formulas and equations included in the app is provided in the product description.



DeXY's New Recipe for Fall (X for kisses, O for hugs)

KISSES Witch's Hat

Cookies

Ingredients

24 HERSHEY'S KISSES Brand Milk Chocolates
24 fudge bottomed striped cookies
1 cup HERSHEY'S Milk Chocolate Chips
Decorating icing or gel in tube
Chocolate sprinkles (optional)

Directions

1-Remove wrappers from chocolates. Place cookies with chocolate-coated bottom facing up on wax paper covered tray or cookie sheet.

2-Place milk chocolate chips in small microwave-safe bowl. Microwave at MEDIUM (50%) 1 minute; stir. If necessary, microwave at MEDIUM an additional 15 seconds at a time, stirring after each heating, until chips are melted and smooth when stirred. Dip bottom of chocolate piece into melted chocolate and place in center of cookie. Repeat for all the cookies. Allow chocolate to firm before continuing.

3-Pipe icing or gel around base of chocolate piece. Use chocolate sprinkles to make square buckle for hat, if desired. Refrigerate until ready to serve. Makes 24 cookies.

from: <http://www.hersheys.com/kisses/recipes>

Remember The Focus Foundation This Year!

Did you read the letter featured above in this newsletter from a relieved and happy parent? We at The Focus Foundation know how important an early diagnosis can be in the development of a child. We also know that getting the right information at the right time is crucial for parents, especially when receiving a diagnosis. We think every parent, healthcare provider and educator should be informed about early testing and treatment for X and Y Chromosome Variations and other related disorders. We can't do it alone though. Your tax-deductible donation to The Focus Foundation supports our efforts to disseminate information about and continue researching X and Y Chromosome Variations and its possible treatments. Consider The Focus Foundation in your year-end giving this year, so fewer parents have to deal with a scary, unknown diagnosis. Help us focus on research that will foster a change in the lives of children and families affected by this and related disorders. As we get closer to the end of the year, consider giving to The Focus Foundation in support of X and Y Chromosomal Variation research, awareness, and advocacy.

Donating online is easier than ever, just click on our page below. Your generosity will improve the lives of many individuals!

http://www.thefocusfoundation.org/FF/supporting_the_foundation.php