

## Fragile What??

by Lisa Bryan

It was March 2003, and I still remember the doctor's words, "Your son has Fragile X Syndrome." My response? "He has WHAT?" I had never heard of this condition and yet Fragile X Syndrome is the most common known cause of inherited intellectual disability and the leading known genetic cause of autism. According to the National Fragile X Foundation's website, [www.fragilex.org](http://www.fragilex.org), approximately 1 in 3,600 to 4,000 males and approximately 1 in 4,000 to 6,000 females have the full mutation of Fragile X, and as many as 1 in every 250 women are carriers of the Fragile X gene. Our journey into the world of special needs had begun.

Our son, Matthew, was born in April of 1999. My pregnancy had been normal, with nothing to worry about. Matthew was a healthy, 9 lb. 8 oz. boy, and Mom, Dad and older sister, Kelly, were so excited! Our first signs that something was different in Matthew were small. His umbilical cord did not fall off on its own, the doctor had to remove it. He was delayed in meeting all of his milestones in his first year, but the doctor kept assuring me that he was a boy, and boys developed slower than girls. One of our bigger concerns was that Matthew had many ear infections and wasn't speaking like he should be. We would take antibiotics for an ear infection, and as soon as it cleared up, another one would set in. An ENT recommended ear tubes about the same time we started Babies Can't Wait for evaluations.

We learned that Matthew was developmentally delayed in speech, fine motor, and gross motor

skills. We began speech therapy and occupational therapy. Our ENT performed several hearing tests; his hearing was fine and thus not the cause of his speech delay. We didn't know what was going on with our son. We just knew that he was a lot more difficult to handle than his sister had been. Matthew cried a lot, didn't sleep well, and didn't like to be cuddled or rocked. He seemed to be

frustrated that he couldn't communicate. He had trouble walking, and his body seemed "floppy." He didn't like crowded places – in fact, he would frequently vomit when he was in crowded or loud places. Once, on a visit to Walt Disney World, Matthew developed a fever just from being in

the Magic Kingdom; it was too overstimulating, and his body could not handle it. On and on and on it went. So we pushed on. We continued down this path of evaluations, tests, doctors, therapists, etc. for several years. It was an emotional roller coaster ride. This was not the "perfect little life" that we had envisioned – it was a lot more difficult.

We finally got a diagnosis in 2003. At a visit to our second developmental pediatrician, he was tested for Fragile X Syndrome (FXS). We had already gone through a barrage of blood tests that other doctors had suggested, and this was a new idea. In March of 2003, we finally had a diagnosis of FXS. A sense of relief flooded over me, as well as an incredible sense of sadness. On one hand, it was nice to know that there was a name to this condition. On the other hand, all of this was really true – it was not a nightmare that we had

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**MISSION STATEMENT**

FOCUS understands and supports the unique needs of families with children who are medically fragile or have significant developmental or physical disabilities. FOCUS offers comfort, hope and information to parents; accessible recreational and social programs for children and teens; and fun, inclusive activities for the entire family. A nonprofit founded by parents in 1983, FOCUS continues to embrace and strengthen metro Atlanta families.

**SUBSCRIPTION INFORMATION**

For subscription information, please call FOCUS at (770) 234-9111 or visit our website at [www.focus-ga.org](http://www.focus-ga.org). Annual subscriptions to the newsletter are \$15 for families (waived if necessary) and \$30 for professionals.



## From the Editor

by Lucy Cusick

*(Reprinted from November / December 2012. I am still amazed!)*

I am feeling particularly amazed today, as I arrange all the heartfelt articles in this newsletter. I love selecting the photos for the Looking Back section; I am blown away by the generosity of our sponsors and donors. I may be in the spirit of Thanksgiving a little early, but I am amazed by the support of some friends for almost the entire 30 years of FOCUS.

I am amazed by the volunteers who show up at every FOCUS event. We see all ages: middle school, high school, college, twenty-somethings, middle age, and grandparents. They come in with energy and enthusiasm; they love on our kids, pamper our families, and bring new ideas to the table.

I am amazed by the FOCUS staff. They leave their own families at night and on the weekends to work FOCUS programs. Check out the calendar ([www.focus-ga.org](http://www.focus-ga.org)) and you'll see that almost every weekend in September and October had multiple events. Every event had at least one FOCUS staffer there. They work weeks to plan, the weekend to manage, and the week after to unpack and re-organize for the next event! They pore over evaluations and make notes for adjustments for the next year – and they treasure the sweet notes from families.

I am amazed by our children – all of them, siblings and extra-special ones, too. Our children with disabilities endure hours of therapies and doctor visits; they work hard to perform a task that we just do, without even thinking. And they rarely complain; in fact, they often smile, even after painful procedures. Siblings are often required to tag along to all these medical appointments; they are often the extra hands and eyes a parent needs at trying times. They often grow up with more knowledge and compassion than other children their own age.

I am amazed by our parents – they learn to be tough and loving at the same time. They learn to live with a broken heart and put on a happy face. They adjust, re-adjust, and re-re-adjust their lives and dreams. They love fiercely and unconditionally.

Yep, today is a realization that I am living an amazing life, working alongside amazing people, for amazing children and their amazing families. In the spirit of Thanksgiving, thank you all for your amazing partnership. ■

### Have you moved or changed email addresses?

Please keep us up-to-date so you receive the most current info from FOCUS!

Find us on Facebook at  
<http://tinyurl.com/focusgeorgia>

## Endless Worry

By Tammy Chandler

Oh, how we as parents worry about everything. Having a special needs child seems to “max out” my quota for worry. I feel as though we have to hold so much in, so our precious children see our brave faces, while inside we may be scared out of our wits!



Six years ago, I worried that my twins, Jenna and Mary, would not even make it into the world; during my pregnancy, they were diagnosed with a rare condition called twin to twin transfusion syndrome. I had surgery in utero, and they were born very early at 27 weeks. Jenna had three surgeries in her first three months of life in the NICU. Around ten months of age, she was diagnosed with cerebral palsy.

Both girls have been through a lot, but they have come such a long way in their 6 ½ years. Jenna walks in a walker, but is more independent every day. I still worry though: what if Jenna loses her balance and takes a tumble, or if Mary falls because she walks backwards when having a conversation with Jenna? They are quite the chatterboxes nowadays! I cringe when I cannot find a handicap parking spot mostly because distances are so hard for Jenna (I am also annoyed because people who do not need them park there for convenience!). The very thought of Jenna having her first orthopedic surgery really terrifies me ... beyond worrying! Then, I fast forward 10 or 15 years, and become anxious about Jenna driving or “yikes” needing to take public transportation alone! Yes, yes, I know, I know, “take it one day at a time,” but we all know that is hard to do.

Life is quite difficult these days as a single mother. This year brought an unexpected transition into a new school for first grade. The new school has almost three times the number of students as their old one. Once again, Jenna is the only physically challenged child. Jenna and Mary have had a hard time with the change. Let’s face it, the girls tend to “stand out” just as they are: Jenna with her AFOs, her funky walker, wheelchair and pink glasses and Mary with her blue glasses. But, in the new school, they have had more stares and some not-very-nice comments. Thankfully, Helene, the director of Lekotek, offered to go to school and give a presentation on sensitivity and disability awareness.

I am so grateful for FOCUS, Lekotek and the friends I have made through both organizations. The FOCUS staff and moms are bundles of knowledge and resources. I have enough worries in this world and am glad to know that I am not alone! ■

## Welcome, Mackenzie!

FOCUS officially (and finally!) welcomes Mackenzie Suttles to the FOCUS staff! Mackenzie coordinates volunteers for all programs, organizes outings for Teen & Young Adult Groups, and assists with all other programs. Mackenzie graduated from Auburn University in 2012 and started working for FOCUS early in 2013. Her inspiration, in her own words:

*“My exposure to special needs started young because I am blessed to have a cousin, John, who has Down Syndrome. My passion for working with the Teens & Young Adults here at FOCUS stems from my relationship with John. These monthly outings give these incredible teens and young adults independence, a community and a social environment to blossom! I also love working with volunteers – they quickly learn that ‘our’ kids are lots of fun and have lots of gifts to share! In the 11 months that I have been with FOCUS, I learn something at every program!”*

So, welcome to FOCUS, Mackenzie! We’re glad you’re with us!



## TEAM FOCUS “Spins for Kids”

Thanks to TEAM FOCUS for raising over \$14,000 in Spin for Kids to support the programs FOCUS offers at Camp Twin Lakes: Under the Stars 1 & 2, Camp Infinity, and OctoberFest. TEAM FOCUS had 55 riders this year – thanks for helping FOCUS keep the cost of these programs low for families & campers!



## Coming Up at FOCUS!

Always check out the calendar at [www.focus-ga.org](http://www.focus-ga.org) for a complete list of programs!

### November 2

Extreme Home Modification Tour –  
angie@focus-ga.org

### November 3

FOCUS on Fashion –  
lucy@focus-ga.org

### November 9

FOCUS Day at ZooAtlanta – All tickets sold

### December 1

Snacks with Santa for Medically Fragile Children –  
elizabeth@focus-ga.org

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Check the calendar for Extra Special Saturday respite and other on-going programs!

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### Saturday, December 14

Annual FOCUS & Lekotek Holiday Party  
11:30 am to 2 pm  
Eastminster Presbyterian Church  
5801 Hugh Howell Road, Stone Mountain

Join FOCUS & Lekotek for food, fun, arts, crafts, and music. FOCUS will provide the fried chicken and Lekotek will provide the drinks and paper goods. If your name begins with:

A-N Please bring a vegetable or side dish  
O-T Please bring a dessert  
U-Z Please bring bread

For easy clean-up, please bring food for 10 or more people in a disposable dish with a disposable serving utensil. Call FOCUS or email [angie@focus-ga.org](mailto:angie@focus-ga.org) by December 4 and register the number of adults and children attending. Santa brings each child a small gift so we need an accurate count; please limit attendees to immediate family since we have limited space and Santa's workshop is pretty busy this time of year!!

*Directions to Eastminster Presbyterian:*

Take I-285 to 78 East. Take Exit 7 (Hugh Howell Road) and go up the hill to the second church on the left. Families should enter the church through Founders Hall – follow signs & look for balloons!

### Fragile What??

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been hoping to wake up from. We started to learn all we could about FXS. We were referred to a geneticist – we had now learned the difficult truth that FXS is a genetic condition, and it was transferred to our son by me, his mother. Talk about a kick to my stomach. For me, this was the hardest part of all. I felt a tremendous amount of guilt. My husband was so supportive and loving – telling me it was not my fault – I hadn't done anything wrong. But it was so, so hard.

The next several years brought more doctor visits, therapy visits, long and sleepless nights, struggles, and tears. We learned more and more about our precious son. We also worked very hard to keep life as "normal" as possible for our daughter. We frequently divided – one of us took our daughter out, while the other stayed at home with our son. A new normal began, and we learned how to handle anxiety meltdowns and to improve motor skills, speech, and transitions. Always learning, always coping, always loving.

Fast forward to 2013 – our son is now 14 and our daughter is 17. Matthew's main struggles continue to be with anxiety, overstimulation, sensory processing, and transitions. He is also on the Autism spectrum. Daily life can be difficult – but we've learned new ways to live. Our lives are so different now than they were 14 years ago. We have found new things that we can do together as a family – we frequently go camping in a travel trailer at the many wonderful state parks in Georgia. We have bonded together with lots more family time. We enjoy the "little" things in life – birds in our backyard; music of the Wiggles; the names of every sports stadium, team and mascot for the entire US; the weather patterns for the entire world; unconditional love; less materialism; less need for "stuff;" genuine joy; and a readjustment of our priorities – what is really important in this life. Is it easy? Absolutely not – we struggle with anxiety meltdowns, difficult transitions, food challenges, school challenges, weight challenges, developmental delays, etc. But this life has brought us some incredible friends that we never would have met; incredible opportunities to be involved with great organizations like FOCUS and the Special Needs Schools of Gwinnett; a greater appreciation for the world around us; a stronger love for one another; and an understanding for those who are different than we are. I strongly believe that we are better people than we were 14 years ago. What I once viewed as a "curse" to my family has now proven to be "the best blessing that we never would have asked for." ■

For more information about Fragile X Syndrome, visit [www.fragilex.org](http://www.fragilex.org).

# Thank You

## Corporate/Foundation

IBM Employee Services Center  
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Rock to the Rescue

Car Wash donation by the daughter  
of Ji Kim & her friends

## Individual Contributions

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Ashley & Jason Rigsby  
Marianne Schlinkert  
Sabrina Smith  
Karla Stafford  
Nita Stevens  
Debby Stone  
Cathy & Walter Vinson  
Nancy Wolff

## Memorials

In memory of Rusty Townsend by

Barbara & Matt Battiatto  
Sharon Rivera

Wayne & Lucy Cusick, to TEAM  
FOCUS & Spin for Kids

In memory of Jordan Dicello by  
Cynthia Acker

In memory of the mother/  
grandmother of Sylvia Mallarino,  
Bert Bras & Jackson Harris, by  
Asher, Rachel & Meitav Vilensky  
for the Liam Vilensky Camp  
Scholarship Fund

## Honorarium

In honor of Kai Jeyaram's 4<sup>th</sup>

Birthday, by Lynda Lee Moser

In honor of Lindsey Welch & family,  
by Debbie Schmidt

## How to Celebrate Your Wife's Birthday (Or, now NOT to celebrate your wife's birthday, depending on your point of view)

By Frank Lawton

It is hard to believe another year has gone by, and what that means is it is time for another birthday. I have never been a big celebrator of birthdays, but I try to do my best since I know they are important to most people. For me, celebrating a birthday is renting a DVD and sitting at home and watching it. I know, it doesn't sound like much, but it's what I like.

Anyway, this is not about my birthday, but about my wife's birthday. We have been married for 22 years, and I do remember my wife's birthday each year. (I used to get the day mixed up, but I always had the right month.) This year I decided to go all out. Here are some excerpts of our enjoyable night on the town.

*To start the day off, the kids and I took her shopping around the city.*

**Translation:** We hit not one, but two garage sales in the neighborhood.

*I decided she needed a night out, so I took her and the kids to a fancy dinner and a live dinner show.*

**Translation:** We went to the diner down the street. There was a man playing a guitar sitting in the middle of the diner.

*We had a delicious dinner that included international delicacies from around the world.*

**Translation:** She got a panini with chicken in it. I think panini is Italian.

*We had a romantic dinner and felt like we were removed from the world.*

**Translation:** There was only one other customer in the diner, and he was trying to eat something so he could sober up.

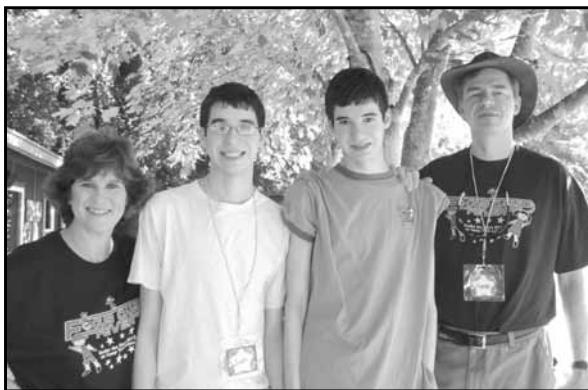
*The food was excellent, far surpassing our expectations.*

**Translation:** She didn't get sick on the panini.

*The live dinner show ensemble interrupted the show to sing her happy birthday.*

**Translation:**

The guy playing the guitar played happy birthday, and the waiter sang happy birthday to her. Note, our children, ages 16, did not sing.



*Our relationship is so solid that giving her a trivial birthday gift would just cheapen things.*

**Translation:** I couldn't decide on what to get her. After all, Walmart has so many good choices to choose from. So in the end, I gave her cash. I know what you are thinking. How can you give cash to your wife? The answer is easy, and deep down, all men reading this will think what a great idea.

*All in all, it was a birthday to remember.*

**Translation:** We went the whole day and night without a single meltdown from the kids. The best birthday gift of all. ■

## Family Activities – the Good, the Bad, and the Registration

**W**e at FOCUS work sooooo hard to NOT burden parents with more paperwork, more rules, more 'to-do's.' But. We need your help. We offer programs that (we hope) offer families Comfort, Hope, and Fun. The comfort and hope we've got covered ... but we need your help with THE FUN!

FOCUS programs, especially our family activities, are very popular. We offer as many tickets as our budget allows: 900 for Six Flags Day; 700 for Georgia Aquarium Day; 250 for Zoo Atlanta Day. The price per ticket that parents pay is about 1/3 what FOCUS pays to each of these places; we WANT to offer this discount, we WANT parents to feel wanted and loved at these events, we WANT to continue these programs.



So. We've compiled the FOCUS Top-Five-Ways-To-Help-FOCUS-Plan-Family-Activities!

5. Email Address: Keep FOCUS up-to-date with your current email address. Add FOCUS to your 'approved' emails so we don't end up as spam. Check your email as regularly as possible and reply as quickly as possible. Family Activities fill up really fast!

4. Read FOCUS emails & follow the directions: We're not being snarky here, but most of the answers are in the e-mail so please read carefully!! We try to use bullet-points and to be as concise as possible. Pay attention to the payment details and deadlines, when tickets will be mailed to you, etc. Of course, call or email (quickly!) if you have questions (see #2).

3. Understand our limits: Because FOCUS covers 2/3 of the cost of each ticket, there are limits to who can attend an event. We allow each family to have 2 parent tickets, a ticket for the FOCUS child/teen/young adult, and a ticket for the siblings in the family under age 21. We hate that we do not have enough tickets/budget for cousins, nieces, nephews, etc.,



## Don't Forget!

**MVP Events for Medically Fragile Families** are ongoing. Please call FOCUS or email Elizabeth@focus-ga.org if your child is homebound, hospitalized frequently, has a tracheostomy or a G-tube, or is at significant medical risk.

**Teen/Young Adult Activities** are ongoing. Please call FOCUS or email mackenzie@focus-ga.org for information on monthly social outings and other events for teens and young adults who enjoy socializing but require only a 1:8 ratio and no nurse.

**Volunteers** are critical to FOCUS programs! If you are interested in volunteering, please check out our website at [www.focus-ga.org](http://www.focus-ga.org) for the age requirements or email [volunteer@focus-ga.org](mailto:volunteer@focus-ga.org).

even if they live in the house with your family. If every family brought 1 extra person, then we would not be able to take as many FOCUS families. We hate being the bad guys, so try to understand our limits!

2. Call us! If you have questions, give us a call OR email the person who is taking the RSVPs. If you need a payment plan, ASK! The fee we collect is really your commitment to attend. We have to guarantee numbers to the venue, and we pay for most events up front. If you take tickets, please use them, unless, of course, someone in your family is sick.
1. Come prepared to have FUN! Make some memories with your family, take lots of photos, make a new friend! ■

# Looking Back at the Fun ...



**FOCUS Day at the Georgia Aquarium** on September 14 was a swimming success! Families love FOCUS family activities because they love being one of a crowd, instead of standing out in the crowd, and because of the special treatment FOCUS gives them! Thanks to First Option Mortgage for supporting FOCUS family activities!



**Inaugural "FOCUS on Fun" Night!** On September 7, FOCUS families enjoyed dinner, dancing, raffles, and silent auction at the first annual "FOCUS on Fun!" Our thanks to Holy Cross Catholic Church, the Knights of Columbus, and Babinelli's Italian Restaurant for hosting, cooking, and donating to this wonderful event. If you missed it, not to worry! We are already planning the 2<sup>nd</sup> annual "FOCUS on Fun!"



**"FOCUS on Moms,"** on September 28, another inaugural event, was a huge success! We planned for 30 moms to enjoy a day of Comfort, Hope, and Chocolate, but we had over 80 moms register! Thanks to First Christian Church of Atlanta for hosting this event and to Chick-fil-A for answering our 'emergency 911' call for food! Moms enjoyed lots of pampering (in between chocolate treats!), workshops by fabulous FOCUS parents, and makeovers by our Mary Kay friends and *Pampering With A Purpose*.



*(Continued on the back)*

**Looking Back**

*(Continued from page 7)*



**FOCUS Daddy-Daughter Dance** in June was so sweet that we couldn't talk about it without crying, until now! Dads and Grandads celebrated their special gals with dancing and delicious sweets!



**FOCUS Family Camp "Under the Stars 2"** at Camp Twin Lakes Will-A-Way was a wonderful fall getaway! Families love the cooler temperatures, as well as all the fun activities!

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**All FOCUS programs are offered to families at no cost, or at a very reduced, cost. We hope you will consider a donation to help FOCUS continue these programs:**

- Support Groups, Workshops & Conference, Hospital Visits
- FOCUS bi-monthly newsletter
- Extra Special Saturday respite
- Camp Hollywood & Camp TEAM summer day camps
- Camp Infinity & OctoberFest overnight camps; Teen & Young Adult Social Groups
- FAST FINS Adapted Swim Teams
- Under the Stars Family Camps
- Family Activities: Georgia Aquarium Day, Six Flags Day, Mom's Day Off, ZooAtlanta Day, MVP Events & Holiday Party

**Please renew your FOCUS membership by returning this form OR donate on-line at [www.focus-ga.org](http://www.focus-ga.org)**

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or complete the following credit card information and mail to the address below.

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| Friend of FOCUS                                       |        |       |
| I would like to support FOCUS with a gift of \$ _____ |        |       |
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| One newsletter 6 times per year                       | \$ 30  | _____ |
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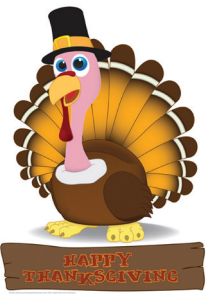
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# NOVEMBER 2013



Sun	Mon	Tue	Wed	Thu	Fri	Sat
					1 Swim: 4pm - Summit Swim 4:30pm - MTV Swim 5:45pm - MTV Swim	2 Intra-Squad Swim T/YA Group Home Modification Respite: 10am - Cumming
3 FOCUS on Fashion	4	5	6	7 Share Group: 9:30am - ExtremeNo	8 Share Group: 10am - Bereavement 10am - Cumming	9 Zoo Day Respite: 10am - Acworth 10am - Chamblee 10am - Marietta
10	11	12	13 Share Group: 9:30am - Conyers 9:30am - Dekalb 9:30am - Gwinnett 10am - 5 & Under	14	15 10am Grayson Share Respite: 10am - Alpharetta 10am - Newnan/Ptra	16
17	18	19	20 Share Group: 10am - Marietta	21	22	23
24 N'side Grp 6:30pm	25	26	27	28	29	30

# DECEMBER 2013

Sun	Mon	Tue	Wed	Thu	Fri	Sat
1 MVP Event	2	3	4	5 Share Group: 9:30am - ExtremeNo	6 T/YA Group Respite: 10am - Acworth 10am - Alpharetta 10am - Cumming	7
8	9	10	11 Share Group: 9:30am - Conyers 9:30am - Gwinnett	12 Share Group: 10am - Bereavement 10am - Cumming	13	14 Holiday Party
15	16	17	18	19	20	21 10am Grayson Share
22	23	24	25	26	27	28
29	30	31				

