



Peek Inside the Secret Life

by Kathryn Jackson

I have a special needs child. There. I said it.

Before our accident, I didn't know any other family with a special needs child. I was blissfully ignorant of this hidden world in which I now find myself.

The first secret is that there are a ton of special needs children! Just visit any reputable pediatric therapy center, and it will be PACKED. There are so many families struggling in this secret world. It makes me realize how miraculous a healthy child is!

The second secret is that even though our government goes to extremes to make our country accessible to the disabled (and I'm grateful), accessibility is still a huge challenge for our family. For example, a simple trip to the pool is difficult for us. In my limited experience, pools are sometimes not wheelchair friendly, so I have to carry Anne into the pool area. Doing regular life is difficult – especially running errands. Lifting Anne and her wheelchair in and out of the van is part of my normal life routine. But I've found that I only have the energy for one outing a day with Anne. So grocery shopping, back to school shopping and general "running around" has to be spaced out.

The third secret is that even though there are tons of special needs families, it is still incredibly isolating to have a special needs child. The world goes by at lightning speed and leaves us in the dust. In many ways, this is painful – and if I'm not careful, I can lean a little towards self-pity. Seeing pictures of families enjoying vacations at the beach or amusement parks twinges a little. Watching



families bustle about without the physical limitations of a disabled child makes me long for an easier life. It's times like this that I cling to the fourth secret of having a special needs child...

The fourth secret is the best. I am still surprised at how much joy Anne brings our family and others. The time I get to spend with Anne is beautifully rewarding. She's a treasure, and everyone who spends time with her comes away better for it.

Recently, someone asked Eric to describe his relationship with his children. He said, "My oldest thrives academically so I share my love of technology with him. My youngest is gifted athletically, so I share my love of running with her. My middle daughter (Anne) struggles with most everything, yet she teaches me the most about life." Anne is our glue. I can't imagine life with her any other way. ■

Kathryn and her family are new to FOCUS. She also writes a blog at www.kathrynjackson.com

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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. Annual subscriptions to the newsletter are \$15 for families (waived if necessary) and \$30 for professionals.



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

Donations Offer Comfort, Hope, Fun

FOCUS depends on generous individuals, corporations, and foundations to support the programs we offer children with disabilities and their families. Donations can be made on-line at www.focus-ga.org or checks can be made to FOCUS and mailed to 3825 Presidential Parkway, Ste 103, Atlanta 30340. FOCUS is a nonprofit organization and contributions are tax-deductible to the fullest extent of the law.

**From the Editor**

by Lucy Cusick

Summer is full of FUN at FOCUS, with little time to put together a newsletter so I sent a panicked email to several parents and received fabulous articles practically overnight! Looking over them, I realized there was a pattern to the stories: remembering diagnosis day (*D-Day*), deciding to have another child (*Bringing Home Baby Sister*), and successfully transitioning to college (*Happily Ever After*). The cherry on the top of these great stories is a wonderful description of life that includes a child with disabilities, *A Peek Inside the Secret Life*. My work here is done! ■

Check the Calendar!

Remember to check the calendar on our website for upcoming events! We have "Fridays at FOCUS," a party just for parents, and several great fund raisers.

Now's a good time to get involved. Come to FOCUS for Comfort, Hope, Fun!

www.focus-ga.org/calendar/

Have You Moved or Changed Your Email Address?

If you do not receive weekly emails from FOCUS through Constant Contact, we either do not have your current email OR your email provider thinks we are spam.

Call 770-234-9111 or email inquiry@focus-ga.org and we'll try to fix the problem!

Ongoing at FOCUS**MVP Events for Medically Fragile Families**

For more information,
 email elizabeth@focus-ga.org.

Teen/Young Adult Activities for ages 13 to 29

Please email Mackenzie@focus-ga.org for information on monthly social outings and other events for teens/young adults who enjoy socializing but require only a 1:8 ratio and do not need a nurse.

Share Groups, Hospital Visits, and more!

Email lucy@focus-ga.org if you want to get involved at FOCUS but can't figure out how to start!!

D-Day

By Kim Fishman

Our special needs journey started back on June 20, 2006, D-Day (“Diagnosis Day”). Our beautiful daughter Emily was delayed in reaching many of her milestones but was still a busy toddler, despite the fact that she wasn’t walking at 19 months. The neurologist suggested genetic testing after he couldn’t find any causes for her delays and since we were interested in expanding our family, we got her tested right away. They tested for a variety of things and on that fateful day in June, the results were in: Rett syndrome.

As my husband, Jason, and I researched this unknown disorder and found pictures of girls and women confined to wheelchairs and descriptions about all of the medical issues that come along with this diagnosis, we were beyond devastated. All of our hopes and dreams for our daughter began to vanish and our outlook for the future became bleak.

Now eight years later, Emily is a happy, nine-year old girl. Our family moved from South Florida to Atlanta in 2012, and we couldn’t be more pleased with the move. Emily attends Lake Windward Elementary, along with her six-year old brother, Daniel. They have a wonderful program for children with special needs, and the teachers and therapists have been wonderful.

Over the years, our family has learned to adapt to her needs. She has never walked independently but can walk with assistance wearing AFOs (ankle foot orthoses). She can use a gait trainer, but prefers to walk by having someone support her hands or trunk. She is completely non-verbal, but she can make choices by touching the object that she wants. She maintains a healthy weight now since she had her G-tube placed in 2010 but still loves to eat chicken nuggets and potato chips by mouth. She experienced her first seizure this past November, so we have our emergency medication on hand, just in case it happens again.

We’ve been extremely lucky this far, though, as many girls with Rett syndrome have to deal with far worse issues: scoliosis, recurring seizures, pneumonia, hospital stays, etc. ... Emily is not on any prescription medication and is generally content, especially watching her favorite show, *Dora the Explorer*. We consider ourselves very fortunate



that we have not yet had to deal with these issues, although they are totally possible in her future. What is certain however, is that she will need round-the-clock care for the rest of her life.

One of the benefits of living in Atlanta has been getting involved with FOCUS. Emily attended Camp Hollywood in Alpharetta for the first time this summer. We were very nervous about her going somewhere that we were unfamiliar with, but, after so many wonderful referrals from parents of other special needs children, we decided to give it a shot. She ended up having an awesome time and was very happy during her week there. Our options for her care during the summertime are limited to home care, so we were thrilled to see her enjoy herself at camp for one week of the long break. It is going to be very nice to look forward to this camp each year from now on – for all of us!

Camp Hollywood does provide us with some hope for Emily’s future, as well as ongoing clinical trials for medications to help with some of the effects of Rett syndrome. These positives help balance out the negatives as we continue on our special needs journey. The main positive is that we get to enjoy Emily every day; her laughter and kisses are completely pure, and we are extremely blessed to experience her unconditional love. ■

Coming Up at FOCUS!

(Always check www.focus-ga.org for details!)

Saturday, July 12 Special Summer Workshop

9:30 am to noon

NOW/COMP Waivers

1 to 3 pm

Deeming Waiver/Katie Beckett Waiver

Sunday, August 3

Game time 2:05 pm

“FOCUS on Dads” at Gwinnett Braves Game

Saturday, August 23

9:45 am – 2:00 pm

“FOCUS on Moms”

First Christian Atlanta

4532 Lavista Rd., Tucker 30084

Join us for a time of comfort, hope,

FUN, and chocolate!

Saturday, September 6

7:00 – 10:00 pm

Book Your Sitter Now

“Time Out” Parent Party

Holy Cross Catholic Church

3773 Chamblee-Tucker Road, Atlanta 30341

FRIDAYS AT FOCUS

All workshops are at the FOCUS Office.

RSVP to elizabeth@focus-ga.org

Friday, August 15

10:00 – 11:30 am

Bonding & Relaxation Techniques

Friday, August 22

10:00 – 11:30 am

Social Skills

Friday, August 29

10:00 – 11:30 am

Guardianship

Friday, September 5

10:00 – 11:30 am

Wills and Trusts

Under the Stars Family Camps

August 8 – 10

at Camp Twin Lakes Rutledge.

(Full, wait list only)

October 3 – 5

at Camp Twin Lakes Will-A-Way.

Still space available – register quickly!

Questions to joy@focus-ga.org

Happily Ever After

By Marjie Shindler

“Mom, guess what? I just found out that I got that seven week internship in Jerusalem I was telling you about!” I told my son how proud we are, hung up the phone and sat on the couch in awe. Never in a million years did I think this was possible!



Let me give you some background information to help you understand.

Our son, Ryan, was diagnosed with PDD-NOS (Pervasive Developmental Disorder, Not Otherwise Specified) at the age of three. Layman’s term: he has Asperger Syndrome. Ryan was delayed at EVERYTHING ... walking, crawling, talking, potty training, eye contact, making friends, you name it, Ryan wasn’t doing it! That said, Ryan loved to sing (kind of weird because he wasn’t talking!), knew his alphabet at 18 months, could read at age four and could name every country in Europe and Africa. We had a feeling he was smart, but he never met any milestones at his yearly check-ups. Ryan went to physical therapy, occupational therapy, speech therapy, horse therapy, hiking with Clay White, social skills class and much more. Ryan was in special needs pre-school and kindergarten and, when he started elementary school, he had a facilitator to keep him on task and help with social skills. Ryan always did very well academically, but in other areas, he really struggled and was extremely delayed. Things like riding a bike, driving a car, dating, having a Bar Mitzvah, sleepovers with friends, are things that other kids did, not my son ...

Fast-forward 15 years ... I am happy to tell you that Ryan is a freshman at Elon University in North Carolina. He is a College of Arts and Science “Fellow” and received two scholarships from Elon, and many offers from other universities. Never in my wildest dreams did I think my son would be away (5 hours) at a university and thriving in every way! And he did learn to ride a bike, drive a car, go on dates, have a Bar Mitzvah and make friends. Is Ryan kind of quirky ... yes. Are social situations difficult for him ... yeah, they are. Is Ryan one of the kindest, friendliest and most loving person you’ll ever meet ... yes he is!!!

My words of wisdom from over the years:

1. Always be your child’s advocate, even if it means not being a nice person.
2. You know your child better than anyone else. So if the school psychologist tells you that your child will “plateau” and never amount to much, (like he told me) don’t believe them!
3. Be patient.
4. Make time for yourself and your spouse, it is hard to be a good parent when you put yourself last.
5. Never give up or lose hope. ■

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Fund Raising at FOCUS!

Contact lucy@focus-ga.org with
questions or to register!

Tuesday, August 5 is the first FOCUS at Chick-fil-A Night!

Eat Mor Chikin' with FOCUS families, friends,
and volunteers at various CFA locations.
Watch your email for specifics!



Saturday, August 16, 2014 5th Annual SummerFest at SweetWater Brewery

Cheers to another great summer of FOCUS
camps! Enjoy Willy's Mexicana Grill food
truck, live music by The Eastside Ramblers,
cornhole, and brewery tastings and tours. And,
no whining – we'll have wine, too! Go to [www.
focus-ga.org](http://www.focus-ga.org) to purchase a ticket or contact
lucy@focus-ga.org with questions.

CLIMBS FOR KIDS

September 28, 2014
Inaugural
"FOCUS Climbs for Kids!"

at Stone Summit Climbing & Fitness Center,
3701 Presidential Parkway, Atlanta 30340

Climb for a FOCUS kiddo and support FOCUS!
Watch your email for details!



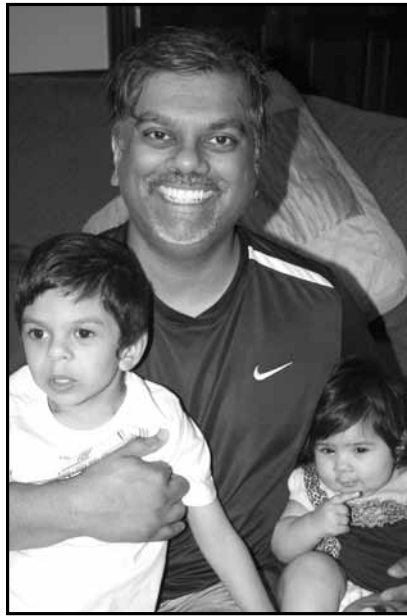
October 19, 2014 Spin for Kids

Ride for TEAM FOCUS and the money you
raise supports FOCUS programs at Camp Twin
Lakes!

Bringing Home Baby Sister

By Cassandra Jeyaram

Our son Kai has Williams Syndrome – a rare genetic condition that is present at birth and can affect anyone. It is characterized by medical problems, including cardiovascular disease, developmental delays, and cognitive disabilities. At 4 1/2, Kai is just beginning to use two and three word sentences, has significant feeding challenges and is extremely sensitive to certain sounds. However, despite these challenges, Kai is the happiest and friendliest kid you'll ever meet – there's a reason why his nickname is "The Mayor." However, The Mayor was not so happy about welcoming his new baby sister this past August.



Sensory overload doesn't even begin to justly describe our son Kai's reaction to when we brought home his new baby sister Emmy Rose. With his piercing screams and streaming crocodile tears, you would have thought we were torturing Kai. And maybe in some ways we were – unintentionally of course. With his sensitive ears, even our cat's meow would make him melt down. So when Kai's new baby sister came home and cried (and cried a lot), it sent him over the top.

The first few months were excruciating – for everyone. Kai screamed EVERY TIME his new sister cried, and he would lash out at us. There were times when my husband would come home from work to find all three of us crying because it was just too much for all of us.

However, my husband and I had decided early on (even before Emmy Rose was born) that we would make it a point to integrate the baby into Kai's life – despite the temptation to keep them separate to reduce Kai's anxiety and sensory overload. We tried to do it gradually, only subjecting Kai to Emmy's cries for limited periods of time and working to increase that time period every day. Granted, there were times when it was too much for everyone, and we would separate them, but for the most part, we've tried to plow through Kai's tears, screaming, biting and head butting.

As the weeks passed and Emmy Rose cried less and began to be more interactive, Kai slowly started to warm up to his baby sister. And perhaps too, he started to realize that she was here to stay. In the last few months (Emmy Rose is now 9 months old), Kai has gently reached out for her hand and smiled at her! They are baby steps, but we can

now see that there are times when Kai likes his little sister and *wants* to engage with her.

The addition of Emmy Rose to our lives has not only been a blessing to us as parents, but to Kai as well. At nine months, she's already teaching him things like sharing, taking turns and that sometimes you just have to wait! For four years Kai had mommy and daddy's attention for 24/7 (literally – Kai has extreme insomnia and is up all night). Now, there's someone else who needs us too. So Kai often gets a bit more "independent playtime" and TV time – but that's actually helped Kai too! He's picked up words from the TV, and he's had to figure things out on his own instead of someone always doing things for him.

Often I feel guilty for not being able to spend as much time as I once did with Kai. However, I also know that Kai's baby sister and he will make many fun memories together and thankfully, no one will remember the first few months of their lifelong relationship! ■

September 21, 2014: FOCUS Day at the Georgia Aquarium!

Watch for an email from FOCUS on July 9 with the details about FOCUS Day at the Georgia Aquarium. Please let us know right away if you need a paper application mailed to you. Tickets are \$20 each and include admission to the aquarium, a brunch in the Oceans Ballroom, and parking.

FOCUS has 700 tickets, which is not enough tickets for everyone in FOCUS. As in past years, we will give first preference to families who have never been to FOCUS Aquarium Day. If we still have tickets, we will add families who have not been to FOCUS Aquarium Day in the last three years. Of course, you can always apply, but don't be mad if we don't have enough tickets!

Watch for the email and follow the directions! If you have questions, please call or email FOCUS!

Looking Back at the Fun ...



FOCUS Six Flags was back-on-track this year with fabulous weather! Families enjoyed rollercoasters, carousels, and yummy fried chicken with 700 of their closest FOCUS friends!



FORE FOCUS Golf Classic

A great day of golf for a great cause!
Thanks to our golfers and sponsors – see page 5.



FAST Fins Swim Meet was again a swimming success! Swimmers from all seven FOCUS teams competed and enjoyed the cheers, ribbons, and snacks!

The 3rd Annual FOCUS Daddy Daughter Dance and Dessert

was June 14, just in time to celebrate Father's Day! Dads and grand-dads enjoyed a special date with their best gals. Many thanks to Mt. Bethel UMC for opening their doors, Junior League of Atlanta for providing desserts and volunteers, Marie Reynolds for creating lovely face painting designs, and DJ Tony Washington for playing all requests, with favorites being "Cinderella" and (of course) "Let It Go!"



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