



FOCUS

**Extraordinary Families
★ & Kool Kidz ★**

FOCUS

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On Your Mark, Get Set, Go ...

By Simone Mayweather

We started running our race with Kennedy much like other first-time parents; born at almost 38 weeks by C-section, she arrived on February 29 ... our Leap Year baby! Kennedy was diagnosed with cerebral palsy just before her first birthday. I have yet to process her diagnosis, I'm too busy running the race. But late last year, our race took a new course, and the previous race was just a dry run.

Most typical mornings began with 'on your mark, get set, go!' My husband and I rolled out of bed, took our daughter Kennedy to daycare, and traveled to work. The daycare called around lunch time; Kennedy had a fever and needed to be picked up. Immediately, I called my husband who agreed



to go get her. I also left work and called her pediatrician. I stopped at the grocery store near home to pick up some things we might need if she was sick and home all weekend. My husband called, his tone was very concerned; he had pulled into the grocery store parking lot. He said Kennedy looked like she was having a seizure. I immediately burst into tears, dropped my bank card and

groceries on the counter and ran out of the store. I could see my husband; we called 911. I know many of you can relate to this moment where you feel like life just stops and nothing else in the world matters other than getting your child to a safe place.

The ambulance transported Kennedy to the local hospital to stabilize her. She was then air lifted to Children's Healthcare of Atlanta. I watched my heart fly into the sky. Everything blurred; after a battery of tests, the doctors said that Kennedy had the flu. Her fever kept spiking, and we literally just waited for her temperature to stay down. After 24 hours, she seemed better, then the fever returned with a vengeance. Kennedy looked nothing like the child we dropped off at daycare just two days earlier. How could she get so sick so fast? This roller coaster ride continued for two weeks; she finally left the Pediatric Intensive Care Unit (PICU) and moved to a regular room.

Now the race to recover her strength and skills began. She was so weak; she needed physical, occupational, and speech therapies to recover. Christmas was less than a week away, and the only thing on my list was therapy for our daughter. I broke the news to our family that we would be in the rehab unit of the hospital for the holidays. They immediately changed all plans to celebrate the holidays with Kennedy at the hospital! I finally remembered to call FOCUS to let them know Kennedy was in the hospital. To my surprise, a FOCUS visitor appeared that very same day, bringing treats and hope from FOCUS!

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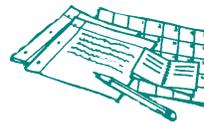
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FOCUS offers emotional, informational, and physical support to families of children with disabilities or with ongoing medical conditions through a variety of programs such as support groups, respite care, and summer day camps. FOCUS networks parents who share common experiences and information with each other, providing a sense of community to families with children with disabilities.

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.

*Josh & Lucy**Josh in the hospital***From the Editor***by Lucy Cusick*

This month has been so busy, so Josh is filling in for me. Here's the speech Josh gave at the 28th annual For the Love of Children, entertaining guests about growing up with FOCUS and listing his Top Ten FOCUS Programs!

Hi, my name is Josh Cusick. My mom asked me to talk about the FOCUS programs that I grew up with. I agreed, because.... if you think she's bossy at FOCUS, you should see her at home!! I was born prematurely and have cerebral palsy. I was in the hospital for three months after I was born. My parents don't really talk about all of that. I think I was pretty sick. My family found FOCUS when I was two; my mom liked having other moms to talk to so she could help me. She quit her job because I had all kinds of therapy to help me progress. Of course, I don't remember any of this, but I do remember the fun I have had through the years with FOCUS!

So, starting with the ones when I was just a kid, here are my Top Ten FOCUS Programs:

#10 – FOCUS respite – Now called Extra Special Saturdays. My parents would take me to FOCUS respite so I could play and they could go run endless errands. I had seizures when I was little and FOCUS respites always have a nurse, so my mom felt safe leaving me there. I started going when I was 4. My sister could go, too, which was fun.

#9 – FOCUS Day Camps – I went to Camp Hollywood. We had fun doing cooking, science, art & music – and hanging out with my friends. I probably went to more weeks of Camp Hollywood than most kids – hey, I got my perks where I could!

#8 – Moms Day Off – I can't really go on FOCUS Moms Day Off on Lake Lanier, but my mom comes home relaxed and happy after having a day on a houseboat! And you know the old saying ... if mama ain't happy...

#7 – FOCUS Fashion Show – I modeled with my pediatrician, Dr. Verras. A lot of my other doctors modeled, too. It was fun seeing Dr. Verras, Dr. Bruce, and Dr. Weissman out of their offices ... and it was cool being on stage!

#6 – FOCUS Family Activities – Annual Days at Six Flags, Georgia Aquarium, Zoo Atlanta, and a holiday party. FOCUS family days are like big family parties. FOCUS plans family activities to avoid large crowds, so children in wheelchairs can move around and see. They also always include a meal, which I love! It's fun to be part of a group that understands and can help each other. One year, my dad couldn't come to Six Flags Day and my mom doesn't ride roller coasters. So, another FOCUS dad rode coasters with me. That's FOCUS at its best ... everybody helping each other.

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From BCW to IEPs: Transition Tips and How To Get What's Best for Your Child

By Lisa Newbern

Happy Graduation?? What happens when your baby graduates from Babies Can't Wait at age 3? You've just learned the lingo and gotten to know your Service Coordinator and you have to move on to another state agency!! The Department of Community Health manages Babies Can't Wait, and the Department of Education manages education. State law mandates that a child with special needs can receive services beginning on the child's third birthday. You trade in your IFSP (Individualized Family Service Plan) for an IEP (Individual Education Plan) and enter a whole new world.

How do you decide which school is best for your child – and how much 'say-so' do you, the parent, have? Here's one family's story about finding the best school for their child.



Like so many of you, I stay in touch with FOCUS and with Lucy Cusick. She is a wealth of information, and I am open to everything she has to say. This time, though, she has asked me to do the "talking," which brings me to writing this article about the individualized education plan (IEP) process.

My husband and I recently transitioned our son, Griffin, who has Down syndrome, from the Babies Can't Wait (BCW) program into a county public school system. This is a process not to be underestimated, but it is one that, at times, can only be described as murky at best. Our drive to get it right for Griffin (and to take notes for others) came from knowing the importance in making decisions that are certain to make a difference for all our children as they grow, learn and become involved members of our communities.

With the experience still quite fresh in our minds, we offer the suggestions below for your consideration to get what's best for your child:

- **Know the steps involved in the transition** – an initial meeting about six months before your child turns three, an evaluation about one to two months before your child turns three and a follow-up IEP meeting several weeks after the evaluation. For us, our first meeting was in April 2010, our evaluation in early November, our first IEP meeting in late November and our second IEP meeting in December (the last day of school before the holiday break). During the IEP meeting, the order is to discuss evaluation results/standard deviations, agree services are needed and

that you want the county to provide services, agree on goals and discuss placement options. The process is certain to vary from county to county, so please keep that in mind.

- **Remember it's a team process** – that includes working with your BCW coordinator, representatives from the county and those who are your personal support system to make the best decisions for your child.
- **Ask if your BCW coordinator is willing to communicate your expectations**, if you know them, at the time of the evaluation. For example, your coordinator could mention a particular service you know your child will need, a specific school you'd like your child to attend, etc. This could help the county representatives as they review the evaluation results in preparation for the IEP meeting/s.
- **Ask your BCW coordinator to obtain for you a current copy of the school system's Parents' Rights.** It will be helpful for you to read these rights before any of your evaluation/IEP meetings. Yes, read every word!
- **Know which schools in your area serve children with special needs**, and know this before you begin the evaluation/IEP process. I called more than 30 schools to determine which ones offer special education programs for three and four year olds, and then I asked questions of parents with children in these schools.
- **Allow the county to conduct a full evaluation of your child.** You can provide private therapy reports to supplement the county evaluation, but do so after the county evaluation, not before. In an effort to be helpful, we provided the reports upfront; in hindsight, we wish we had waited to do so.
- **Bring at least one person with you to the IEP meeting who really knows your child.** Be prepared for it to be an emotional discussion with a lot of information shared about your child. The extra person can help you truly hear what is being said, can help take notes for future reference and consideration, and can keep you focused on making the right decisions versus making quick decisions, which, at times, we felt pressured to do.
- **Share the evaluation results and the IEP goals with your private therapists.** It will be helpful if you can have at least one of your therapists at the

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Coming Up at FOCUS

Always check the FOCUS website at www.focus-ga.org for more details! Are you our Facebook Friend?
Check us out at <http://tinyurl.com/focusgeorgia>

May 1: FOCUS Day at Six Flags Over Georgia

June & July: FOCUS Day Camps – Camp Hollywood and Camp TEAM

Brochures and applications for Six Flags Day and all day camps were mailed to active FOCUS families on February 23 (by bulk mail). Families are encouraged to apply quickly since programs often fill up.

August 12-14: Under the Stars Family Camp 1 at Camp Twin Lake in Rutledge

October 1-2: Under the Stars Family Camp 2 at Camp Twin Lakes in Winder

Brochures and applications for both Under the Stars Family Camps will be emailed to all families with email addresses on-file at FOCUS in mid April. If you would like a paper brochure mailed to you, please call FOCUS by April 1!!

Special Events at FOCUS

Fund raising events at FOCUS are fun & necessary for funds!! If you would like to help raise money for FOCUS programs, please contact lucy@focus-ga.org.

11th Annual E*TRADE Financial “FORE FOCUS” Golf Classic

April 27, 2011
Bear’s Best Suwanee

SummerFest at SweetWater Brewery

August 6, 2011
Brewery tours, cornhole tournament, DJ, and food

“Run the Farm for FOCUS” 5K Trail Run & 1 Mile Family Walk

September 24, 2011
Cedar Gate Farms in Newnan
Go to www.georgiarunner.com to register.

From BCW to IEPs
(Continued from page 3)

- IEP meeting. Your county may want you to agree to the goals and the placement all in one meeting, but it does not have to be this way.
- **Record your IEP meeting.** When you tell the county you plan to do so, the county will do so also.
- **Read the written minutes the county representatives take.** Do not sign them if you do not agree with what is or is not in the minutes. You can ask for more time to review the minutes than is given in the IEP meeting. Know this information will become part of your child’s permanent record.
- **Do not feel like the first placement the county offers is your only option.** Again, remember you are a team, and you all need to work together to make the placement decision. The first school offered to us did not meet its 2009-10 AYP goals, was on the 2009-10 closure list, and was seven miles from our home (when there were four other well-performing schools closer to us); we did not accept this option.
- **Be willing to observe the special needs class and meet with the teacher and principal** at one or more of the schools the county recommends (or in which you are interested). We observed classes at two schools; this is one of the best steps we took!
- **Know you can call an IEP meeting at any time** to review and/or update goals.
- **Make it clear you plan to be an involved parent.** This will benefit your child and the other children in his/her class.

Final piece of advice: feel good, not guilty, about wanting the best for your child. Truly, no one else is going to advocate for your child like you will, and no one else knows your child like you do.

Griffin is now receiving community-based services, one of several county IEP options. Come August, he’ll transition into our first choice school for him – one that is well-performing, close to our home and network of support, and filled with involved parents – three criteria so important to us in making the first of what we’re sure will be many educational decisions for our son. Like us, you can get what’s best for your child. Know there are many resources to help you, including FOCUS! ■

*Note: The recent FOCUS conference included a session about IEPs. Contact Angie at angie@focus-ga.org for a copy of the session handout.

My Sister

By Meitav Vilensky

I have many memories of my sister, so many that I'm not sure which is the earliest. The latest memory I have of her is on her deathbed. It wasn't even her bed. It was one we rented from a company that supplies medical equipment for the home. Many people got to know Liam just in her last year. She was the sick, tired, non-talking kid who was constantly in pain and spent most of her days in a hospital room. I grew up knowing the lively, healthy girl who loved to eat and do everything that medical books said she wasn't supposed to be able to do. Liam was always the exact opposite of what people thought she was. Liam practiced "love your neighbor as thyself." She was strong and caring and didn't care if you had tattoos or if you wore skirts down to the floor. Her attitude was one I wished to have.



Liam was born with a malformation in the left hemisphere of her brain, or in other words, she was born with half of her brain not working. Doctors predicted the worst, my parents were scared, but her little body fought. She fought for almost fifteen and a half years. There were times in her last year when we thought, this was it, but no. She would push through and keep fighting. Losing her was like nothing I have ever felt before. To sit by her and watch her slip away slowly was hard. I have never in my life felt such emptiness.

All of her life, Liam cared for people. She could make the saddest person laugh. She brought love and light to someone whose life had been filled with hate, anger, and darkness. We grew up in diverse community. Most of my mom's family who lived Atlanta were Orthodox Jews. We had family friends who had tattoos and piercings, neighbors who were gay, and other folks who lived near a commune. When I started school, I was surrounded by kindergarteners of many different races, and sometimes issues would pop up from it. Liam never cared. She knew the difference between everybody, but to her it didn't matter. She was the only kid in the school with a wheelchair. That didn't stop her from living life.

She loved to be active. She took dance, swimming lessons, and baseball, as well as physical therapy once a week. She could even walk a bit if you put her in a gate-trainer. She never stopped trying. Today when she is not here for me to see constantly, I keep those memories of her in my heart and use them as daily prompts to help me be a better person. Before I judge, I think about the situation of a person and keep an open heart and open mind just the way Liam did. When it comes to physical challenges, I don't give up because I know she believed in me and knew that I could succeed at whatever I put my mind to. Growing up with Liam taught me many things that some people never learn by the time they die. She was so accepting of everybody and treated everybody equally. She will always be in my heart, and I will never forget the wisdom she has given me. ■

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See the complete list of "For the Love of Children" Dinner Dance Sponsors on page 5.

On Your Mark, Get Set, Go ... (Continued from page 1)

We rang in the New Year at the hospital; just another mile on our marathon! Kennedy was making great progress with therapy. One day, she was working hard in occupational therapy when Tony Gonzalez from the Atlanta Falcons visited the rehab unit! My mouth dropped open; I am a native Atlantan and a huge Falcons fan ... I was probably more excited than Kennedy! He signed a bear for Kennedy and posed for a picture; we even made the local news!! That was such a special moment – just one month earlier, Kennedy was seizing and running a high fever.

We know other families are running a similar race; we know there will be surprises ... scary ones and good ones. We hope that you tell your friends and family when you need a rest stop; we hope your difficult moments are followed by sunshine; and we hope that you aren't afraid to smile, even when you're running in the rain. ■

Looking Back ...

Life Is an iPod Shuffle The 24th Annual FOCUS Education Conference

Parenting a child with special needs is full of challenges and unexpected detours. You must be prepared for just about anything! Joe Sara from ChildKind kicked off the day with an informative keynote on "Disability 101." Speakers then addressed issues such as Wills & Trusts, IEPs, Microboards, Siblings, and more! Thanks to each speaker, exhibitor, and volunteer who shared expertise and time with FOCUS. Thanks also to our conference sponsors: Chick-fil-A, Building Bridges Therapy and Dunwoody United Methodist Church.



FOCUS on Transition

FOCUS partnered with the InterAgency Transition Council (IATC) and offered a morning of information on the process of transitioning from high school to adult services. Thanks to each speaker, exhibitor, and volunteer who helped and to Target and Mercer University for sponsoring this event.

For the Love of Children 28th Annual Dinner, Dance, & Silent Auction

FOCUS celebrated 28 years of support with "Cabaret & Cabernet" at the Thalia N. Carlos Center. The ballroom was lovely in soft reds, glowing candlelight, and lots of feathers!! Guests enjoyed various complimentary fine wines and cabernets during the cocktail hour, the talent of fabulous cabaret singers during dinner, and the unveiling of the FOCUS Scholarship Program. Elizabeth Hewell shared her story about being Katharine's mom, and Josh Cusick outlined what FOCUS meant to him growing up and his Top Ten FOCUS Programs. We are always grateful for our sponsors, guests, auction donors, volunteers, and speakers. This year, we especially thank our Cabaret: Danielle Moore, Randall Sheffield, and Elaine Wade and their accompanist on the piano, Tara Kersey.



"Will You Be Mine" MVP Valentine Party

Over 100 children and parents enjoyed the 5th annual MVP Valentine Party at the Greek Orthodox Cathedral on February 13. Children enjoyed costumes and role play in the "Prince" and "Princess" tents, had royal photos taken with beautiful princesses from Fleetwood Dance Theater, were spellbound by Queen Glitter, and were treated to full-face painting. A special thanks to the Greek Orthodox Cathedral for the use of the beautiful church, to the Philoptochos Ladies Auxillary for providing the beautiful dessert buffet, to Fleetwood Dance Theater for providing the beautiful princesses, and to Marie Reynolds for her face-painting talent.



