

Where did everyone go?

by Suzanne Musial

I'm tired, frustrated and, admittedly, a little grumpy. I can see how I might not seem like the most appealing person to hang out with, but the fact is that I do crave *normal* human interaction during these seemingly endless hospital stays – even though I may appear about as an inviting as a barbed wire fence.

In the beginning, you have a stream of friends and family who want to be there with you while your child is hospitalized. "So-and-so's baby is in the NICU! I'm going to visit them today!" I imagine them telling their friends with a sense of urgency. But as the weeks turn into years, and the hospitalizations continue to come rapid fire, they stop showing up. And so this life becomes increasingly more isolating.

People like to tell you in the beginning that "it" gets better. I'm not exactly sure what they were referring to – her health? My mental state? So far, nothing has really gotten better. And I don't say that to invite pity, I say it because it's the honest truth. The hospitalizations have gone from being spaced out over a few months to every few weeks. As she gets older, I become more exhausted. Her care becomes more involved. She is getting bigger and now we must worry about accommodations to our home and vehicle. Fears of what will happen to her as she continues to get older – as we, her parents, continue to get older – creep in almost daily. And worry about her fragile health is constant.

There was shock, grief and fear in the beginning, of course, but I had no idea the depths of this life. The company was nice and definitely welcomed back then, but it's not like I have just "gotten over it" during the past four years. I still have waves of those same feelings as issues with my daughter's

health progress; as I see children younger than her doing so much more than she will likely ever accomplish. I still mourn the typical child I didn't have. I would rather be watching her twirl around at ballet lessons than lying in a bed at the hospital, that's for sure. But that isn't my reality and I have to accept that. The people in my life do too.



I know that saying these things out loud is akin to throwing a stink bomb in the middle of a crowded room, which is why I most often keep these thoughts to myself. Thankfully, I do have some friends whose lives and children are similar to mine, but most of them live in the computer. The ones that do live nearby proximity-wise are busy taking care of their own high-maintenance children. And, yes, it is often easier to talk to a mom of a medically fragile child whom I have never met before than a friend I have known for years who has typical children. It is very difficult to relate, and I'm sure the feeling is mutual. I know they are scared they will say something wrong, or inadvertently hurt my feelings or make me feel worse – and the truth is that they may, but I know that it's not on purpose. That is the ongoing battle in my own mind that I'm afraid will never end: the one where you are so thankful for your child and love them unconditionally that fights the part that hates the disability and illness.

I think the key for both sides is to focus on separating the child from the disability. Definitely easier said than done. So whether it's an hour-long conversation at my daughter's bedside, or meeting for a quick lunch around the corner from the hospital, I

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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.

Where did everyone go?

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promise that I would welcome the distraction. I will appreciate the effort and the friendship as awkward as it may feel at first. If nothing else, the non-hospital food should break the ice!! ■

Suzanne is the mother of the Ella Grace, the 'best-dressed baby in the NICU.' Ella Grace has Cornelia de Lange and practically has her own suite in the hospital. Suzanne wrote this article from the heart, not to hurt feelings, but to let everyone know the ongoing struggles of being on the 'frequent guests plan' at the hospital. If you would like to help FOCUS support families while in the hospital, please email Elizabeth@focus-ga.org.

**From the Editor**

by Lucy Cusick

This is the time of year that I just can't find enough time to write a from-the-heart editorial!! So ... here's a re-run of an article from 1997, back when I was a young mom!! Enjoy!

I used to dread days off school. When the children were younger, they required more entertaining, more supervision, more energy. Now, at 11 and 7, they enjoy days of nothing, late mornings in pajamas, eating breakfast at lunchtime. They will spend hours pulling all the towels and blankets out and playing fort or flood or some other wonderful imagination game.

Recently, we had two teacher workdays. Great! A break from the routine and homework. First day we do doctor appointments. By the end of the second day, we're getting bored. So we check the movies and decide on one. Oops, power chair is on the blink. Dad's not home to fix it. Push chair has to be assembled. It's okay, we'll take the walker. He's supposed to walk as much as possible. We'll park right outside the door. He can walk right in. He agrees. We can have fun.

Not. The handicapped parking spaces are right outside the theater door. But you can't enter through the theater door. You must go down to the mall entrance – where there is no handicapped parking – and go through a store. A big store. Okay. Fine. We can do that.

Not. We make it halfway to the theater and he's tired. Okay. Pick him up. All 68 pounds of him. His legs get tangled in mine when I walk. Jessica handles the walker. Get to the ticket line. Line of 15 people in front of us. He stands and leans on me. Jessica bumps the walker into me. I'm getting tense. But, we're supposed to have fun.

Up to the ticket counter. Movie is sold out. I'm fighting back tears. Ticket lady is bored. Jessica bumps me with the walker. Josh collapses. I catch him and tell the ticket lady that I want three tickets to any child's movie. Any movie. No, I don't care if it has started. By golly, we will see a movie. I will not leave. We will have fun.

We get into the theater. Movie is 20 minutes into the plot. It's okay; it's a kid's movie. Surely we can catch up. Oops. Part of the movie is the candy and popcorn, and they brought their allowance so they can get what they want. Both give their orders. I go, leaving them to the child snatchers just waiting for some mother to leave them alone. Don't have what Jessica wants. Back to the theater. She comes with me. We leave Josh to the child snatchers. Back in 70 seconds. I count and watch the door the whole time.

Movie is over. Back to the van. Seems like 20 miles. Everybody walks halfway. Josh stumbles. I catch him. Jessica takes the walker. Bumps me with it. It's okay. We had fun. My back hurts, but we had fun. I won't plan another outing for awhile. Should it be so difficult? But we had fun and sang on the way home. ■

Aydan

by Melissa Henry

I never thought that I would be a mother who would face complications with a child's development. Prior to Aydan, I had two healthy children, and Aydan seemed perfectly healthy, with 'normal' development until he was a toddler. In fact, Aydan reached some developmental milestones very early – he sat on his own when he was almost 4 months old and said his first word at only 9 months old!

Aydan's speech development was the first clue that he was falling behind. At 16 months, Aydan knew about 30 words, but he could not use these words to create a two-word sentence. By the time he was 20 months old, his vocabulary increased, but his speech was much less understandable. Some people might think I expected too much, but he started talking at 9 months!! Somehow, I expected his speech to improve, not digress! I faced a series of challenges as I tried to find the reason for his speech problems; several specialists blamed his difficulties on being a boy or because we have a bilingual household. The first official diagnosis was speech delay; I disagreed since he did not have trouble learning vocabulary. His problem was putting the words together.

As Aydan got older, I felt more and more helpless. People tried to assure me that Aydan would grow out of his slump and that he was still too young to truly be of concern. Despite what other parents and specialists were telling me, I knew that something wasn't right. My ten years of experience as a preschool teacher taught me the difference between typical and atypical child development. I knew there was a reason that my child could not say those cute toddler sentences that everyone loves to hear.

I finally contacted Babies Can't Wait (Georgia's statewide interagency service delivery system for infants and toddlers with developmental delays or disabilities), and Aydan was officially evaluated. I remember very vividly the puzzled expression on the faces of the therapist and the coordinator. They agreed with my informal 'mommy' assessment. Aydan became eligible at 22 months for receiving services through this agency.

Aydan had therapy with Babies Can't Wait once a week but I felt this was not enough. I wanted to play a direct hand in helping Ayden by giving him more support at home. I closely observed the strategies and techniques his therapist used during his sessions. Through my observations, I noticed that she used toys to give him a break from his 'work.' Although I had years of experience as a teacher, I had no idea what to look for when buying

toys for Aydan that would also facilitate and reinforce all that he was learning in therapy. I asked his therapist what kind of toys would be good for Aydan. She told me that a lot of the parents ask her the same question!!

Aydan is now 3 1/2 years old. I still have no 'one' diagnosis for Aydan, but here is a list of possible diagnoses: speech delay, expressive language disorder, articulation disorder, Eustachian tube dysfunction, apraxia of speech, auditory processing disorder, and the most recent-- lack of coordination, and dysarthria. Even though this journey has been filled with unexpected turns and frustrations, I know that God put Aydan in my arms and care for a reason. I have learned to be more patient and to trust my instincts and inner thoughts. Also, all obstacles teach valuable lessons and it is up to the individual to take the challenges and turn them into an opportunity that benefits others. ■

Because of her experiences with Aydan, Melissa founded an online toy store, Momo's Special Toys, to help parents find toys best suited for their child's unique needs, specific to their development. Her mission is to give parents options and choices. Parents can check out Momo's at www.momospecialtoys.com.



Playtime!!

Parents are often so entrenched in the world of therapy that they forget to play with their child! Never underestimate the power of play and pretend! Other companies and nonprofits that offer toys (or ways to modify toys) for purchase or loan are:

Momo's Special Toys: www.momospecialtoys.com
 Lekotek of Georgia: www.lekotekga.org
 Ablenet: www.ablenetinc.com
 Discovery Toys: Independent consultants
 Toys R Us: Toy Guide for Differently
 Abled Kids
 Enabling Devices: www.enablingdevices.com

Looking Back ...

The Tranquil Tortoise and the Hoppity Hare!!

FOCUS MVPS and children under 10 enjoyed a wonderful performance of *The Tranquil Tortoise and the Hoppity Hare* by the Alliance Theater for the Very Young. The interactive performance was a smashing success – children enjoyed burying the hare with pillows (trying to slow him down!), eating rabbit ‘energy’ food (carrots!), and rescuing the hare from the spider web!! The generous members of St. Peter Chanel Catholic Church in Roswell hosted the event, providing a delicious lunch and fun arts and crafts. Fleur de lis Cupcakery contributed yummy tortoise and hare cupcakes! We are thankful for our community partners!



For the Love of Children 29th Dinner, Dance, and Silent Auction

FOCUS celebrated 29 years of support, honoring board member Read Davis for his generosity and commitment to FOCUS on March 17, 2012. The ballroom was beautifully decorated for St. Patrick’s Day, and guests enjoyed dinner, dancing, and a fabulous silent auction. FOCUS parents John & Lauren Seidl shared their journey with their son, James, and how FOCUS has helped them; FOCUS ‘kid’ Ricardo Aranda inspired guests by singing “Love Is” and “Lean On Me.” For a complete list of sponsors, please see page 7.



A warm FOCUS welcome!



It's a new day at FOCUS!! We welcome our newest staff member, **Patrick Faulhaber**, as the Volunteer and Teen/Young Adult Coordinator. Patrick will facilitate the monthly social opportunities

and OctoberFest retreat for teens and young adults, assist with Camp Infinity for teens and young adults, and coordinate volunteers for all FOCUS programs. We're excited to have Patrick – and I'm sure he's thrilled about having a few more moms! From Patrick:

Hello everyone! My story at FOCUS is just beginning. I am the "new guy" at FOCUS, and I am so excited to be here! Before I was at FOCUS I worked for a small group home in North Carolina. While I was there I played and worked with some amazing young adults! But while I was there I also grew more and more frustrated. These wonderful people that I spent so much time with never got to see their families. There were several of our members whose parents and siblings never came to visit during all of the time I was there, though they lived minutes away! I began to think, 'there has to be an organization that does work with families, helping them learn boundaries and stay connected!'

I left North Carolina to come to Candler School of Theology at Emory University, and it took me three years to find that group that I imagined then, but now I am finally here!! I found a group that really does care for the whole family and helps them understand the strange, terrifying, lonely world that people can feel like they are in as a parent or sibling of someone born with a developmental disability. But this group also knows and celebrates the great joys, hopes, and immense love that can come from the same experience. I knew right away that I wanted to be a part of it!! As the new Volunteer and Teen/Young Adult Coordinator, I look forward to getting to know all of you!!

Ongoing Programs

We've had a wonderful spring at Extra Special Saturday Respite!! Offered in six locations each month, children enjoy playing with friends while parents enjoy taking a break!! We are thankful to these churches for opening their doors and hearts to FOCUS:



Alpharetta Presbyterian, Christ the King Lutheran (Cumming) Cornerstone United Methodist (Newnan), Embury Hills United Methodist (Chamblee), Mt. Bethel United Methodist (Marietta), and Summit Baptist (Acworth). Thanks also to the wonderful staff and volunteers who love our children at each location!

This from a wonderful volunteer at FOCUS respite:
Holy cow ... I remember our very first FOCUS Saturday respite experience. We were sooo excited and ready to get started. Our very, very first experience. Stephen was there and David was "assigned" to keep up with him. Stephen was so restless that day ... it had been raining but as soon as the rain stopped David said "Stephen, want to walk outside with me?" So out they went.

For 45 minutes they paced in front of the windows (the rest of us were in sight). Suddenly Stephen turned to David (we had never heard him speak and haven't heard him speak since) and worked his mouth very carefully, looked David in the eye and said, "R U N!"



David looked right back at him and clearly said "N O!"



That was the end of that. Stephen did not try to run, but David still talks about the fact that if he HAD decided to run, David may not have been able to catch him!!



Coming Up at FOCUS

Always check www.focus-ga.org for more details!

May 6

FOCUS Day at Six Flags Over Georgia

More than 900 tickets were pre-sold!
Sorry, no more tickets are available.

May 12

FAST Fins Intramural Meet

Mountain View Aquatics Center
Come cheer on our swimmers and
check out our FAST Fins program!

FOCUS Day Camps

For information on day camps, please contact FOCUS at inquiry@focus-ga.org Registration closes for day camps on May 11. Hurry!

- **May 29 to June 1. Camp TEAM** is a traditional outdoor day camp experience, offered this year at Mercer University in Chamblee for campers ages 7 to 13. Camp TEAM has openings at the time of printing – register soon!
- **June 4 to July 13. Camp Hollywood** is a mostly indoor day camp where campers enjoy arts, crafts, cooking, science, music, and recreation based on the themes of popular children's movies. Some locations of Camp Hollywood have openings – apply quickly!

Under the Stars Family Camps

August 10 – 12 at Camp Twin Lakes, Rutledge
October 6 – 7 at Camp Twin Lakes, Will-A-Way

We're having "Peace, Love, & FOCUS" at Under the Stars this year! Applications went out by email on April 13. We are overwhelmed with the number of applications that were returned within 48 hours!! We encourage everyone to complete & send applications online anyway, since cancellations always occur!!

Special Events for

Medically Fragile Families ...

... are ongoing. Please call FOCUS or email elizabeth@focus-ga.org if your child is homebound, hospitalized frequently, or is at significant medical risk.

Teen/Young Adult Activities ...

... are ongoing. Please call FOCUS or email patrick@focus-ga.org for more information on monthly social opportunities and other events for teens and young adults who enjoy socializing but require only a 1:8 ratio.

FOCUS Fund Raisers

Support FOCUS fund raisers AND the programs FOCUS offers by attending FOCUS fund raisers ... and bring friends! Proceeds go to FOCUS programs which are offered at a reduced (or no!) cost to children and families!

May 9

12th Annual

**E*TRADE Financial
FORE FOCUS Golf Classic**
at Bear's Best Atlanta
Golf for fun and "fore" FOCUS!!

August 18

3rd Annual

SummerFest at SweetWater Brewery

Cheers to summer and FOCUS camps! Enjoy brewery tours & tastings, Willy's Mexicana Grill, cornhole tournament and music! Contact lucy@focus-ga.org for more details.

September 29

3rd Annual

**Run the Farm for FOCUS
5 & 10K trail run & 1 mile family walk**

Hosted by Phil & Ann Beegle
Run or walk the trails of beautiful Cedargate Farms!
Contact lucy@focus-ga.org for more details.

"Pampering With A Purpose: Selfless Beauty"

FOCUS mom Jennifer Dicello and Mary Kay are teaming up to provide roll-up bags filled with personal care products for FOCUS moms who spend time in the hospital or are home-bound. If you would like more information about how to help, please contact FOCUS at 770-234-9111 or lucy@focus-ga.org. Be a part of this wonderful fundraiser to provide support for all of our "selfless beauties," our FOCUS moms who take care of everyone but themselves.

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**FOCUS and
 Summer Time!**

Summer Share Groups

FOCUS appreciates the parent volunteers who facilitate support groups throughout the school year. We know that summer is stressful, too, but we take a break in the summer while families are (hopefully) on vacation and children are out of school! The FOCUS staff is around, however, if you need an impromptu telephone share group!!

Extra Special Saturday

Extra Special Saturday takes a break in June, July & August while kids are having fun at Camp TEAM and Camp Hollywood! Please take a moment to thank our wonderful caregivers and volunteers at each respite in May. Because of them, FOCUS continues to offer fun for the children (and a break for the parents!) in six locations each month!

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MAY 2012



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<p>Visit www.focus-ga.org for the most current information about FOCUS activities.</p>		1 CPR Class	2	3	4 Swim: 4:30pm - MTV Swim 5:45pm - MTV Swim	5 Respite: 10am - Acworth 10am - Chamblee 10am - Cumming 10am - Marietta 10am - MJCCA	
	6 Six Flags Day Swim: 3:30pm - Cumming 5:30pm - Johns Crk 5:30pm - Roswell	7 Share Group: 5:30pm - Gwinnett	8	9 Fore FOCUS Golf	10 Share Group: 9:30am - Conyers	11 Share Group: 10am - Cumming 4pm - Summit Swim 4:30pm - MTV Swim 5:45pm - MTV Swim	12 12pm - Intra-Squad
	13	14	15	16 Share Group: 6:30pm - Dad's	17 Share Group: 9am - ExtremeNort 9:30am - Dekalb	18	19 Respite: 10am - Alpharetta 10am - Newnan/Ptr
	20	21	22	23	24	25	26
	27	28	29 Camp TEAM	30	31		

JUNE 2012



Sun	Mon	Tue	Wed	Thu	Fri	Sat
					1	2
3	4 Camp Hollywood 10am - Lawrencevill 10am - Alpharetta	5	6	7	8	9
10	11 Camp Hollywood 10am - Buckhead 10am - Johns Creek	12	13	14	15	16
17	18 Camp Hollywood 10am - McDonough 10am - Marietta	19	20	21	22	23
24	25 Camp Hollywood 10am - Marietta 10am - Acworth	26	27	28	29	30

Share Groups

Conyers – 9:30am

Chick-fil-A

1610 Hwy 138 SE, Conyers 30013

May 10

Cumming – 10am

Chick-fil-A – Lanier Crossing

653 Atlanta Rd, Cumming

May 11

Dekalb – 9:30am

Old Hickory House

2202 Northlake Parkway in Tucker

May 17

Extreme North – 9am

Starbucks

4646 Woodstock Rd. Roswell

Mabry Rd. and Highway 92

May 17

Gwinnett – 5:30pm

Weather permitting, meet at Ronald Reagan Park.

If raining, meet at Chick-fil-A, Hwy 124 (Scenic Hwy)

Bring a side dish and/or paper goods to share.

FOCUS will provide chicken.

RSVP: Jeannett Schnupp 770-979-6342

or jeannettschnupp@aol.com

May 7

Share Group Calendar by Location!

Please call (770) 234-9111 or
e-mail (elizabeth@focus-ga.org)
to RSVP and for reminders, directions,
or further information.

**New
Location**

Dads – 6:30pm

For Dads Only at the office of Debra McElhaney

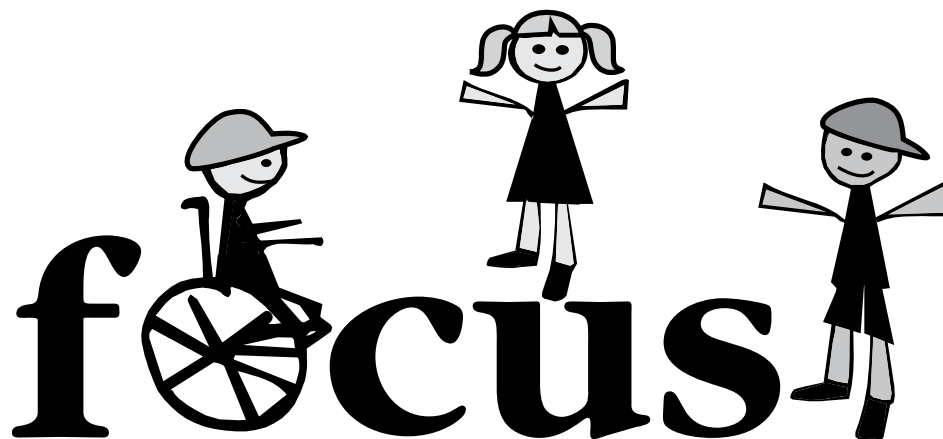
1100 Johnson Ferry Rd., Suite 230

Atlanta 30342

Snack supper to those who RSVP to FOCUS
by the day before the meeting.

May 16

**New
Time!**



Comfort. Hope. Fun.