



Comfort. Hope. Fun.

Support – Only a Few Clicks Away

by Amy Grynol

A few weeks ago, on a sunny Saturday in June, my husband, daughter, and I gathered with sixteen other families in a park in Nashville, Tennessee, to enjoy an afternoon together. The families hailed from across the United States—from nearby cities like Chattanooga, Tennessee, to places as far away as Milwaukee, Wisconsin, Roanoke, Virginia, and Kennewick, Washington. Among our group were an accountant, a tax manager, a nuclear technician, a masseuse, a professional violinist, a mechanic, an ER nurse, and even a female body-builder. Unquestionably, we were a diverse group, but every family had one thing in common: Each had a child with hydrocephalus.

Although we had never met in-person before, we felt like we were among old friends, having known many for almost two years. We first encountered these families online while I was pregnant with our daughter, Claire, who is now nineteen months old. When I was fifteen weeks pregnant, doctors detected too much fluid on Claire's brain and diagnosed her with severe hydrocephalus. After being given a grim prognosis, my husband and I researched frantically, trying to learn as much as we could about the condition. We read every website, article, message board and blog we could find in our countless Google searches.

As we did, we came across several blogs written by families who were raising children just like

Claire. As we clicked through each one, we began to realize that life wouldn't stop simply because our child was disabled. We took comfort in reading about birthday celebrations, trips to the state fair, and family vacations.

At the same time, we began engaging with families on message boards and receiving words of encouragement and support from people who had gone through the same things we were experiencing. Our new friends sent us videos, photographs, and emails to show us that things really do get better.

As our network grew, we gained a wealth of information about what to expect after Claire was born. We learned about NICU stays, seizure medications, g-tubes, early intervention programs, AFOs, standers, gait trainers, and Katie Beckett waivers. By the time Claire arrived, we felt well-equipped to handle the challenges before us and secure in the knowledge that we had a wonderful support network that could help us answer any questions we weren't prepared for.

Although our online friends provided us with a national network of support, we were lacking local connections; that is, until we found FOCUS. FOCUS has enabled us to meet other Georgia families with children just like Claire. Because these families live nearby, we have been able to compare notes on which

(Continued on page 4)



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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.

**From the Editor**

by Lucy Cusick

The end of August marks a special time in the history of FOCUS – we begin our 30th year of support!! We've come a long way since the Calhouns and the Conboys shared a hospital room at Eggleston Hospital. Their children were both medically fragile, with many medical complications and conditions, and, up to that hospitalization, the Calhouns and Conboys had no one to talk to, other than the doctors and therapists who treated their children. The floodgates opened as these parents cried and laughed, sharing their fears, joys, and dreams for their children. They stayed in touch with each other and began hearing from other parents who also needed a 'place' to talk, get information, and connect with other families. Thus FOCUS began, as a living room support group.

We began our 30th year feeling the love of FOCUS families and friends. On the night of July 26, the FOCUS office was burglarized; we arrived to no computers, monitors, or Diet Coke! The burglars ransacked the place, leaving us with a mess, just 24 hours before we were leaving for Camp Infinity. But FOCUS board members, friends, and families rallied around us – before long Channel 2 Action News was here for an interview; Parent to Parent of Georgia showed up with the gift of a new computer; and a board member and her son surprised us with lunch. By the next day, perfect strangers, along with FOCUS friends and parents, were emailing, Facebooking, and calling with gifts and offers of computers, monitors, laptops, donations, Diet Coke, AND a security system! We are overwhelmed and began our 30th year feeling very loved!

The love continues as we prepare to receive over 300 'Roll-Up' bags from Mary Kay cosmetics! Jennifer Dicello, bereaved FOCUS mom and independent consultant for Mary Kay, began a campaign called "Pampering with a Purpose" to help parents (especially moms) who are in the hospital with their children. Jen and her Mary Kay unit banded together and worked hard, giving all their profit to purchase cosmetics to include in the roll-up bag. Each bag contains over \$200 of full-size Mary Kay products, from makeup remover to cleanser and moisturizer!! We can hardly wait to visit our FOCUS kiddos in the hospital and share the love. Happy 30th, FOCUS! ■



Go to Facebook "Pampering With A Purpose" to read the story behind Jen Dicello's campaign to support parents whose children are hospitalized frequently.



The Decapitated Doll

by Kim Forester

In a corner of our entryway lies a small plastic Barbie-style Tinkerbell doll, which happens to be decapitated. In the course of an average day, I pass and notice this doll easily five to ten times, and every day, for some reason, I leave it there. Now, I am not a stellar housekeeper, but I have my standards, and typically picking up toys at the end of the day and relocating them all to the playroom is one of them. Owen is pretty good about picking up after himself when asked, though since he's related to Daniel, I suspect we'll always be working on tidiness... :) Evelyn, given her physical limitations, is pretty neat and tidy herself; and I suspect even if she were more physically able she would still be neat as a pin. There are little things that just have to get done, like wiping down the kitchen counter tops and keeping dirty dishes washed or in the dishwasher, sweeping every day (too much dog and cat hair this time of year!) and spot cleaning bathrooms ... blah blah blah. I guess what I'm saying is that we don't live in a hovel, and I like for things to be in their place – but something keeps stopping me from picking up this poor decapitated doll.

And here's what I think it is: defiance. defeat. celebration? In my life, and I suspect in many other mom's lives, there is this quiet pressure to be perfect. Our homes should look like the pages of a Pottery Barn magazine, our children should be polite, well behaved and occasionally adorably precocious. Our selves should be fit and strong of mind, body and spirit. And our to-do lists should be checked off at the end of each day, or week. Does anyone's life fit that description? Mine certainly doesn't. I was talking with another mom a couple of days ago; she is new to the world of special needs and one thing I wanted to tell her, because I have to tell myself over and over again is this: You can never be everything. You can never be enough. The spiritual reason is that only God can complete us, only God is perfect and true and always there, always enough. The simple truth is that we just can't do it all. We can try, but if we look closely enough, we'll see that we fail every time. There will always be a headless Barbie doll in a corner somewhere; be it an actual, physical doll, or a long unused toilet in need

(Continued on page 8)

Extra Special Saturday Respite – Fall 2012

New registration option for registering your child/children for Extra Special Saturday Respite!! To register your child, email karen@focus-ga.org OR call FOCUS with your child's name and age and the location for which you wish to register. Please note the registration restrictions of each location. If you are registering your child for the first time and would like to talk with someone, indicate that on your message.

Not to insult anyone's intelligence, but here's an example of how to register, using the FOCUS voicemail at 770-234-9111. I would like to register Betty and Jack Smith for respite at Mt. Bethel Daycare on September 22 and December 1 and be on the waiting list for October 13 and November 3. Betty is 5 years old and has cerebral palsy; Jack is 3 years old and has no extra needs. I can be reached at 770-000-0000 if you need to call me about this reservation."

Please bring lunch, extra clothes & diapers, and any medication (must be in prescription bottle, with correct dosage on label). We look forward to sharing an Extra Special Saturday with your child - enjoy your time off!! Register soon since locations fill up quickly!!

Acworth at Summit Baptist Church, 4310 Moon Station Lane
(You may register for two months, choose wait list for two months)

- September 8, 10 am to 2 pm
- October 13, 10 am to 2 pm
- November 3, 10 am to 2 pm
- December 1, 10 am to 2 pm

Alpharetta at Alpharetta Presbyterian Church, 180 Academy Street
(You may register for two months, choose wait list for two months)

- September 22, 10 am to 2 pm
- October 27, 10 am to 2 pm
- November 17, 10 am to 2 pm
- December 15, 10 am to 2 pm

Chamblee at Embury Hills United Methodist Church, 3304 Henderson Mill Road
(You may register for two months, choose wait list for one month)

- September 22, 10 am to 2 pm
- October 13, 10 am to 2 pm
- November 3, 10 am to 2 pm
- No December ESS

Cumming at Christ the King Lutheran, 1125 Bettis-Tribble Gap Road
(You may register for all dates.)

- No September ESS
- October 6, 10 am to 2 pm
- November 3, 10 am to 2 pm
- December 1, 10 am to 2 pm

Marietta at Mt. Bethel United Methodist Daycare, 615 Woodlawn Road
(You may register for two months, choose wait list for two months)

- September 22, 10 am to 2 pm
- October 13, 10 am to 2 pm
- November 3, 10 am to 2 pm
- December 1, 10 am to 2 pm

Newnan at Cornerstone United Methodist Church, 2956 Sharpsburg McCullum Road

- (You may register for all dates.)
- September 8, 10 am to 2 pm
 - October 27, 10 am to 2 pm
 - November 17, 10 am to 2 pm
 - December 15, 10 am to 2 pm

Support – Only a Few Clicks Away

(Continued from page 1)

doctors and therapists to try, share information on local centers that offer services likely to benefit our children, and even pass along contact information for good, reliable, trustworthy babysitters.

It has been comforting to connect with other families who understand the struggles we have faced and who have walked similar paths themselves. It has been encouraging to see families just like ours who have managed to stick together even through the toughest of circumstances and who have been able to lead relatively “normal” lives, even in spite of a difficult diagnosis. Above all, we love being surrounded by those who truly understand what it means to celebrate an accomplishment as small as open hands!

Over the past nineteen months, our friendships both with our online friends and with other FOCUS families have grown from ones rooted in support and information-sharing to deep, meaningful relationships. We are lucky to consider these families among our closest friends, and even though some live hundreds—even thousands—of miles away, we know more about one another than we do about many of our neighbors and even some family members.

We are grateful to live in an age where such connections are not only possible, but easy, and we are excited about the community that technology has allowed us to create. We look forward to watching our friends’ children grow up and are eager to celebrate their accomplishments and milestones. At the same time, we will be there with support and encouragement when our friends face stumbling blocks, like surgeries and hospital stays. Being a parent of a child with special needs can be an isolating experience, but it is wonderful to know that families just like ours are only a few clicks away. ■

A Volunteer's Story

This summer, a donation from high school volunteer Vaughn Moore arrived unexpectedly at FOCUS. The donation was in honor of the Campus Ministry at Marist School. We asked Vaughn to write his story, but he was already at Bucknell University, preparing for soccer season! His mom proudly told us how Vaughn found FOCUS and how much volunteering at FOCUS meant to him.



Vaughn learned about FOCUS from Campus Ministry at Marist School.

Vaughn loves DIRECT community service – dealing directly with those who need help, instead of indirect service, like many volunteer opportunities. He started helping with Extra Special Saturday respites when he was in 9th grade. Vaughn gained a HUGE appreciation of the challenges of children with special needs and those who work with them; he also felt so rewarded!! He was sometimes overwhelmed when a child would have a difficult time, but one day, he was so touched because a little one had curled up and taken a nap in his lap!!

Vaughn also helped at Camp Hollywood day camp. He loved helping the campers and wanted to give back to FOCUS for giving him so many real-life experiences.

Vaughn is off to college now, but his younger sister is beginning to look for volunteer opportunities! We'll keep our fingers crossed to have another Moore in the volunteer family!

SummerFest at SweetWater Brewery

was a great success! Over 300 FOCUS friends and families came out to celebrate another wonderful summer camp season. Guests enjoyed SweetWater tasting, brewery tours, burritos and nachos from Willy's Mexicana Grill, games of cornhole and music from our fabulous DJ. Thanks to all who joined us to raise a glass to FOCUS!! (See page 7 for sponsors and contributors!)



Coming Up at FOCUS

Inaugural Daddy-Daughter Dance & Dessert September 8, 3 – 5 pm

Mt. Bethel United Methodist Church in Marietta

This very special event honors the dads (granddads, uncles, brothers!) and the support they give to their daughters! Please RSVP to Elizabeth@focus-ga.org

FOCUS Day at the Georgia Aquarium

on September 23 is full! We only have 700 tickets ... and had 1500 requests! If you were not selected, you're in good company! Hope to see you at FOCUS Day at ZooAtlanta on November 10!

Under the Stars 2 Family Weekend October 5 –6

Camp Twin Lakes Will-A-Way

We'll have more "Peace, Love ... FOCUS" at our second family camp this year!! Fifty more families will enjoy a weekend of family fun – call if you are interested in being on the waiting list. Cancellations do occur!!

Moms Day Off!! Saturday, October 13, 2012 11 am to 3 pm

FOCUS moms look forward to this annual day on Lake Lanier! Bring a dish to share, a six-pack of your favorite non-alcoholic beverage and join other FOCUS moms for a relaxing day! Directions are sent only to those who RSVP by calling or emailing elizabeth@focus-ga.org

FAST Fins IntraSquad Swim Meet Saturday, October 27, 2012

The swim team season is underway – we have six locations and 60 swimmers!! Come cheer on our swimmers at the swim meet at the soon-to-be-newly remodeled Mountain View Aquatic Center. Call FOCUS for more details.

MVP Boo-B-Que Saturday, October 27, 2012

We invite our medically fragile children and their families to the 4th annual FOCUS Boo-b-que at Holy Cross Catholic Church, sponsored by Knights of Columbus. Contact Elizabeth@focus-ga.org for details.

FOCUS on Transition Saturday, October 27, 2012

with the InterAgency Transition Council. For more information, email angie@focus-ga.org.

8th Annual Extreme Home Modification Tour Saturday, November 3, 2012

FOCUS parents who have modified their homes for their children with special needs open their homes for other parents. This is a great way to get new ideas to make your home more accessible! To offer your home for the tour, or to sign up to take the tour, please contact angie@focus-ga.org You MUST register to receive the directions and further information on the tour.

13th Annual FOCUS on Fashion Sunday, November 4 at 4 pm At Oglethorpe University Emceed by Lane Howard

Join FOCUS for a magical afternoon, celebrating FOCUS children and the professionals who care for them. We have a few more modeling opportunities! Call FOCUS or email Elizabeth@focus-ga.org if you're interested!

Teen / Young Adult Activities

Contact Patrick@focus-ga.org or call for more information on monthly social outings and other events for teens and young adults who enjoy socializing but require only a 1:8 ratio.

Workshops at FOCUS

are ongoing. Go to the calendar at www.focus-ga.org or watch weekly emails from FOCUS about upcoming workshops.

Fun & Fund Raising at FOCUS!

E*TRADE Financial presents The 3rd Annual "Run the Farm for FOCUS" 5K Trail Run and 1 Mile Family Walk Saturday, September 29, 2012 Cedargate Farms, 848 Copeland Rd., Newnan

Run or walk the trails of beautiful Cedargate Farms and support FOCUS programs! E*TRADE Financial sponsors this incredible event. For more information, go to www.focus-ga.org or email runthefarm@focus-ga.org

Spin for Kids October 20 & 21, 2012

Ride for or donate to Team FOCUS and support FOCUS programs Under the Stars and Camp Infinity in this fundraising bike ride by Camp Twin Lakes! This is an easy way to help FOCUS and our programs at Camp Twin Lakes. If every family that attended FOCUS programs at Camp Twin Lakes in 2012 donated \$10.....Team FOCUS would raise an extra \$1,000!!!! Contact lucy@focus-ga.org for details!!

Looking Back at the Fun ...

Camp TEAM – Together Everyone Achieves More! We moved to a new location this year – Mercer University in Chamblee – and camp was fabulous! Campers enjoyed sports, pottery, drama, music, and swimming. The campus is so accessible and offered great indoor and outdoor space!



Camp Hollywood: Where Everyone's A Star – stars were made all over Atlanta this summer!! Offered for one week in 10 locations, campers made ice cream in a bag, painted bird houses, tested milk for fat, played relay games, and enjoyed music therapy. Thanks to the churches that continue to welcome FOCUS and our stars: Alpharetta Presbyterian, the Cathedral of St. Philip, Cornerstone United Methodist, Embury Hills United Methodist, Johns Creek United Methodist, First United Methodist of McDonough, McKendree United Methodist, Mt. Bethel United Methodist, and Summit Baptist. Thanks for the fun and the air conditioning!!



Thanks also to the sponsors of Camp Hollywood (see donor list) and to the wonderful counselors and volunteers!!



Camp Infinity grew to include 50 teens and young adults in late July! Held at Camp Twin Lakes in Rutledge, campers worked on personal goals while enjoying zip line, archery, spirit time, pool time, and wacky Olympics. Thanks to our wonderful counselors who gave their week to help our campers make lifelong memories and to the TEAM FOCUS riders in Spin for Kids for their support of this wonderful week.



Under the Stars 1 Family Camp FOCUS families descended into Camp Twin Lakes in Rutledge for a weekend of 'Peace, Love...FOCUS!' A pool party kicked off the weekend with DJ Tony Washington who led line dancing at pool side for those who weren't swimming!! Climbing wall, art cabin, archery, and boating (and more!) were also popular activities. Thanks to the sponsors (see donor list) and TEAM FOCUS in Spin for Kids for their support of this fabulous program and to all the volunteers who helped families make memories!



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 In appreciation of the Campus Ministry at Marist School by Vaughn Moore

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11th Annual FOCUS Day at Zoo Atlanta

Saturday, November 10, 2012

Lunch at the Ford Conservation Room and EcoHall

Zoo Day Details:

- You must purchase tickets in advance from FOCUS for your immediate family only. Children (3 and over) and Adults are \$10 each. Children under 3 are free. Lunch in the Ford Conservation Room and Eco Hall (11:15 am to 1 pm) is included!!
- Tickets must be used on November 10, rain or shine.
- Make a day of it! Go to www.zooatlanta.org for zoo hours!
- Early November is the perfect time to visit the zoo - cool enough for the animals to appear, warm enough to be comfortable with a jacket.
- Families with Zoo membership can attend for only \$5 per person (3 and over) to defray the cost of the catered meal.
- Tickets are limited – first-come, first-serve!
- To purchase Zoo tickets, you must send by October 19 this completed form, your check, and a SELF-ADDRESSED, STAMPED #10 ENVELOPE to:

FOCUS Zoo Day, 3825 Presidential Parkway, Suite 103, Atlanta, GA 30340

Name of FOCUS Child Attending & date of birth _____

Name of FOCUS Parents Attending _____

Names & Dates of Birth of Siblings (under age 21 who live in the household) attending: _____

Street Address _____

City _____ Zip _____

Phone Number _____

Email _____

Number in immediate family 3 years old & over _____ x \$10 = \$ _____

The Decapitated Doll

(Continued from page 3)

of cleaning, a friendship in need of mending or a diet that needs starting.

People often tell Daniel and me that we are doing a great job with Evelyn. We appreciate it, and we mostly believe it. After all, we both work very hard, giving love, time, energy and money to keep her as healthy, happy and independent as possible. But the truth is that it only takes a second to think of lots of ways that we've failed her. Whether its not having her wear her AFOs (ankle-foot orthotics) as frequently as prescribed, missing a dose of medication now and then, or not speaking up when someone says something disparaging about 'children like ours' – we mess up. The bottom line is that we can't help it; we aren't perfect – and that is such a nice thing to admit and accept. It gives us permission (and Evelyn definitely benefits) to invite other people to share in her care, to share in her life experience. Which means that having doctors, nurses, therapists, teachers, family, and friends – who all help us care for, teach and love Evelyn – is okay and actually a wonderful thing. It gives me room to be Owen's mommy too, and to cook dinner and play with my children, to sweep up piles of dog hair every day and to paint my toenails when I finish this blog post. It gives Daniel room to snuggle his daughter every night, wrestle with Owen before bed, go to work and do a very good job without

worrying about us – it gives us breathing room. The weight of perfection, especially in relation to our children (which is where it matters most) is off of our shoulders.

I avoid picking up that doll because to me it represents that pressure we feel to be perfect; I'm defying the Pottery Barn barometer and accepting defeat. I'm also celebrating that defeat, because I know I'm a pretty good mommy / wife / person – and I'll always try to be better at all of those things – but I'm not setting the bar at perfection, and thank goodness for that.

So, the next time you're at our house, in addition to loving our little people, you're more than welcome to toss the headless Barbie doll into the toy box where she belongs, because I'm not planning on picking her up anytime soon. :) ■

Kim has a blog called Evelyn's Army (<http://blog.evelynsarmy.org>) and writes regularly about being the mom of a medically fragile daughter and the mom of a precocious toddler. Kim is a new volunteer at FOCUS and will begin a Share Group in her home for parents of medically fragile children.

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