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

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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 Egleston 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!
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 this: You can never be everything. You can never be 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

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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.

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!)
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.

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, Embry 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!
Corporate/Foundation
Anonymous – Security System and free monitoring for 3 years!
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Dekalb School Employees Foundation
IBM Employee Services Center
HP Company Foundation
Matching Gift Program
Emby Hills UMC Vacation Bible School for Aquarium Day

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Diane & Derek Tabor
Willie Turner & friends
Cynthia & Faron Wiseman
Nada & Saed Zakaria
Cheryl & Jerry Ziegler
Weda Zoller

Memorials
In memory of Caleb Michael Eanes by:
Jan & Al Pittman
John Remiszewski
The St. Ives Country Club Homeowners Association
Winter Capriola Zenner
In memory of Julie Anderson by:
Kurt Burdack & Carolyn Sica
Marijo & Jerry Culwell
Peggy Powell
In memory of Julie Klee by
Susan & Doug Klee
In memory of Noah Anderson by the Mt. Zion UMC Youth Sports Ministry

Honorariums
In honor of Kai Jeyaram’s 3rd Birthday by:
Alysa Freeman
Cooley Fales
James Sullivan
In honor of Amari Smith by
Nita Stephens
In honor of Jim & Susan Calhoun’s 40th Wedding Anniversary by Tom & Bev Mahon
In honor of Marianne Schlinkert’s Birthday by Earl & Marianne Volpert
In honor of Margaret Hansen’s Birthday by Golfo & Greg Pappas
In appreciation of the Campus Ministry at Marist School by Vaughn Moore

Summerfest at Sweetwater Sponsors
Englert & Associates
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Willy’s Mexicana Grill
And a special THANKS to our DJ:
Jason Bruorton

Donations:
Diane & Joseph Wilush
Francine & Harrison Kohler
Ray Culver

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

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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 = $______________
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 it’s 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.