



## A Different Kind of Miracle

by Amy Grynol

Last January, the halls of Duke University Hospital teemed with friends and family anxiously awaiting the birth of our precious daughter, Claire. Just months earlier, we had learned that she would be born with severe hydrocephalus and that she likely would never walk, talk, eat, or breathe on her own. While we knew that Claire would have challenges, we fully expected that she would surpass the doctors' grim predictions. Quite frankly, we expected a miracle. To us, that meant that she would meet and exceed all of her therapy goals with ease and would be running marathons, reciting Shakespeare, and doing quantum physics by Kindergarten.

Claire, however, had other things in store. Within just a few hours of birth, Claire developed seizures and spent five days hooked up to a continuous video-monitored EEG while doctors tried one medicine after another to get them to stop. A few months later, we learned that Claire was visually impaired. Then, after we noticed she did not seem to respond to sound, we had her tested for hearing loss and learned of yet another obstacle Claire would have to overcome. Finally, just as we seemed to have found our rhythm, Claire developed infantile spasms, a "catastrophic childhood epilepsy" with a poor prognosis.

With each new challenge, the miracle that we were hoping for seemed more and more unattainable. Yet, through these experiences, my husband Brad and I have grown and changed. We have had to pull together as a team in order to keep up with Claire's ever-changing medicine, feeding, and

sleep schedules and her numerous doctor's appointments, tests, and therapies. We have had to learn to communicate better to coordinate her care and help make difficult decisions about which treatments to pursue. We have had to recognize one another's strengths and weaknesses to delegate duties and

have had to swallow our pride every now and then and admit that we might not know everything all of the time. We have pushed our own abilities beyond limits we never knew existed and have done things we never thought we would be capable of doing.

In the nine short months since Claire's birth, we have learned a lot more about one another and about ourselves than we had in the previous ten years of courtship and marriage. We have laughed harder and cried more violently, but have also loved more deeply than either one of us could have expected. We have brought out the best in one another. We have learned the humility of relying on others for love and support and the beauty of feeling that love and support. I have been overwhelmed by how my heart just swells with pride when someone pays a compliment to Claire.

As I recently reflected on the past nine months, I realized that even though Claire has faced a number of challenges in her short little life, we still got our miracle. It just didn't manifest itself in the way we expected. The miracle is not what Claire can do, but how she has transformed us. ■



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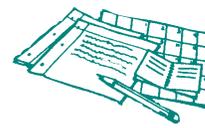
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**MISSION STATEMENT**

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](http://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

September and October were filled with FOCUS activities, and the FOCUS staff worked double shifts, alongside our wonderful volunteers. November and December slow down a little, as families gear up for the holidays. We use that time to plan for 2012 and maybe even spend time with our own families! Our families start wondering why we're home so much!!

2011 has been quite a year! We now reach well over 3,000 families each year; many of our programs have waiting lists; we've updated our 'look' and joined social media to interact with families daily. We continue to subsidize every program at FOCUS so the cost (if any) is reasonable for families. We also offer scholarships to most programs to those families with more financial need. We are always on the lookout for funding sources, sponsors for events, winning lottery tickets, and bags of cash.

We are grateful for the support of our FOCUS community throughout these past 28 years. Some of our contributors have supported FOCUS for many years and maintain that they continue to help because 'FOCUS stretches dollars into more programs than any other organization in Georgia' and because 'FOCUS serves a variety of disabilities so we all feel like a big extended family.'

During this season of Thanksgiving, we are thankful for: our boards of directors and advisors for their leadership and commitment; our donors who have helped us weather the last couple of years in a struggling economy; and our families who find unique ways to support FOCUS – from tasting wine to requesting gifts to FOCUS on birthdays to running and biking for FOCUS.

We hope you feel the love and have the best of holiday seasons!

### Special Events for Medically Fragile Families ...

... are ongoing. Please call FOCUS or email [Elizabeth@focus-ga.org](mailto:Elizabeth@focus-ga.org) if your child is homebound, hospitalized frequently, has a tracheostomy or a G-tube, or is at significant medical risk.

### Teen/Young Adult Activities ...

... are ongoing. Please call FOCUS or email [annie@focus-ga.org](mailto:annie@focus-ga.org) 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.



### ATLANTA PARENT FAMILY BLOCK PARTY

FOCUS was one recipient of the proceeds from the *Atlanta Parent Magazine's* Family Block Party on October 8. Thanks to all the families and children who stopped by to say hello and to the volunteers who helped at this event!

# Looking Back ...

## 2nd Annual Run the Farm for FOCUS 5 & 10k Trail Run & 1 Mile Family Walk

Over 250 runners and walkers hit the trails at beautiful Cedargate Farms in Newnan on September 24. All participants enjoyed the early morning exercise, breakfast and awards, and family fun. Thanks to the sponsors, contributors, volunteers, runners, walkers and to Phil & Ann Beegle for their generosity and willingness to share their lovely farm!



## TEAM FOCUS Triumphs at Spin for Kids!

TEAM FOCUS grew to 75 in 2011!! FOCUS kids, families, and friends gathered at Camp Twin Lakes on October 22 & 23 to spin for kids and raise money to support FOCUS programs at Camp Twin Lakes! Thanks to TEAM FOCUS Captain Wayne Cusick for leading us to victory – #1 Partner Fund Raising – and to all the riders & contributors!! TEAM FOCUS Rocks!



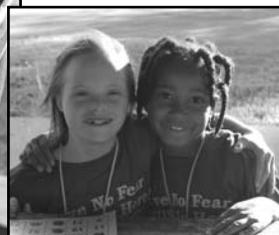
Under the Stars 2 Family Camp



FOCUS Day at the Georgia Aquarium



FOCUS Day at Zoo Atlanta



*FOCUS Family Activities are affordable and accessible, so FOCUS families can have fun together!*

## FOCUS and Facebook

Are you a Facebook junkie? FOCUS has entered the 21<sup>st</sup> century and has an active Facebook page! We're a little difficult to find, since "FOCUS" is a popular acronym so we created a tiny url to help you ... impressed? Yep, we are just techies over here! "Like" us at <http://tinyurl.com/focusgeorgia> and join the Facebook fun!

Here are some favorite posts and responses:

**FOCUS Post:** *FB Support Group!! What's the ONE 'rote response' or 'saying' that people say (trying to make you feel better) that you really wish they wouldn't say ... and what do you wish they would say??*

- "God only gives you what you can handle." Grrrr. If I hear that one more time, I am gonna punch someone. The person that says that usually has no clue of what my family goes through.
- "She'll calm down when she's older or she'll talk when she's ready." They don't have to say anything just offer support. I have 4 children and it would be nice if they offered for her to come play instead of always one of my typical children :(.  
Sorry you hit me in my vulnerable moment.
- I don't care for it when people tell me that they were 'blessed' with typical children. They don't seem to understand that I was blessed too with a special needs child. One of my biggest blessings being FOCUS of course :)
- It takes a special person to handle a special child. Really? I am a plain old mom. Not a special thing about me.
- "There's a reason God gave him to you. He knew you could handle it. And you're so good with him." These people have NO idea of what my family goes through. I could write a whole chapter on this!!
- My little angel is only a month old so I keep getting "Oh, I'm so sorry" when they hear she has Down Syndrome. Just tell me "congrats" on your new blessing or something like any new baby being born!
- It makes me crazy when people tell me miracle stories (e.g., a child was severely impaired, the doctors said he would never walk and the miracle occurred and he walks without any problems).
- "I'm sorry" or "Call me if you need." However, as soon as you do call them, they give you a reaction

as if you are asking for \$5000 and put me on a guilt trip of not having patience. "Your child is like a typical busy child." No she isn't; she does not process unsafe situations. MY WISH is for these people to be silent for a minute and LISTEN. Stop thinking and LISTEN and let us speak up to what "IS." And, stop the grimacing face!

- I hate when someone says "at least you have a child. Some people can't." Well, that is true but if they were given the choice, I bet they would still be childless. That's always my return statement. I love my son and I thank God for him, but it is a very difficult life raising our children.
- @the mom of baby: congratulations! She'll fill your heart with joy. Trust me!
- As a father of two medically fragile/special needs with rare condition children, I constantly get "I don't know how you do it." NEWS FLASH PEOPLE ... LIKE I HAVE A CHOICE!?!?! It's not like I can just wake up tomorrow morning and say to myself "Well, I think I will only take care of my son today. My daughter can wait until later." Sheesh.

**FOCUS Post:** *Circle Time! What's the BEST advice a medical professional has given you ... and what's the worst??*

- The worst: Trust me, I think I've seen this before!
- The best: Listen to your instincts even if people give you heck for it!
- The best: give him space, when he is ready, he will do it.
- The worst: too many to choose, but being told "it isn't their problem" tops the cake.....
- The best advice was a fabulous pediatric neurosurgeon who said 75% of his job was treating the parents ... the worst advice was when a doctor said 'based on her MRI, I wouldn't recommend the most aggressive treatment.' Don't treat the MRI, treat the child :) ... and the parents per remark #1
- "We'll help J be the best he can be." We scoffed, thinking it was just a trite statement by a busy neonatologist. We wanted details: would he walk, talk, etc.? In truth, it was the best we received: work hard, set no limits, expect the best.

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- The BEST: A pediatrician in Chicago, when our oldest was a baby told me I was his Mommy and knew better than anyone if something was wrong. Never let ANYONE tell you it is your imagination. Her advice served us well when M was born. WORST: 40 seizures in a day may be her norm.
- Babies Can't Wait evaluation for J told us S (his twin) may have a cleft palate. It wasn't, he had reflux. I will have to think about the best.

**FOCUS Post:** *From a FOCUS family: I recently saw the question below posted to a Facebook group to which I belong, and it got me thinking: If you were asked to sum up your marriage in the time since your special needs diagnosis in words words/adjectives, what would they be? What are your five words?*

- The path less traveled, but enriching!
- Hills, valleys, and between. Thankful.
- Stronger, closer, aware ... or how about "don't sweat the small stuff!"
- It takes two!
- Wouldn't change it for anything!
- My marriage: He showed his true colors. My family: Wouldn't change a thing.
- Hopeful, frightening, brave, fragile, fun!
- Difficult, survived, stronger, hopeful, togetherness
- Survived, stronger, hopeful, fun, together

**FOCUS Post:** *FOCUS Share Group! Topic: drooling ... have you found a solution to excessive drooling?*

- When J was little, I think my most frequent comment to him was 'suck up the drool!'
- I'd love some insight. Right now, we just make sure J has plenty of towels for drool mopping
- My son takes Robinul twice a day. It hasn't gone away, but has definitely decreased.
- B takes glycopyrrolate, a pill we crush. She will go days and sometimes weeks without drooling.
- Question: does the Robinul dry him/her out or constipate?
- The Robinul doesn't seem to dry him out. He gets half a pill twice a day. He is constipated from time to time, but he was that way before. The constipation hasn't gotten any worse being on the Robinul.

- I wish! R takes Robinul 4 times a day and the waterfall still continues.
- Robinul didn't really work for us.
- I would love to hear answers for that. E is a bad drooler.

**FOCUS Post:** *Caption Contest: Here's our one of our favorite photos from Camp Hollywood. Name that photo!!*



- What is that?
- I'm pretty sure that's NOT how my mom does it ...
- Ooooh! When is it my turn?
- Owwww ... you want me to do WHAT with that?
- Where is the macaroni?
- FOCUS answers: The real caption? Campers made 'dragon drool' in Science on How to Train Your Dragon day. I think this camper was looking for the dragon!
- Where's the nachos?
- Dragon Drool with the BEST!

**FOCUS Post:** *Calling all Houdinis! Do you have an escape artist? Some families use tracking devices to help keep their kids safe. Do you? Any recommendations or reviews?*

- My son has worn a bracelet 24/7 since he was 3 years old!

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## FOCUS and Facebook

(Continued from page 5)

- We used a cable clamp in the car seat on the straps so there was no escaping from the car seat while I was driving down the road.
- To begin with, home security system with door chimes, double stacked gates at the top of the stairs, door knob alarms for hotels, child car door switches turned on, always supervised, key inside/outside deadbolts, outside camera, outside motion detectors ... Yes, we have all of those things – no joke. She has escaped only once; however, while playing in the backyard. Yes, we called the police. Too many swimming pools in the neighborhood not to take proactive measures. Now, for future plans, if needed (this is a joke) we'll implant a GPS in her and/or hire a body guard, which is cheaper. And, we stay away from railings!!!
- PLS (project lifesaver bracelet). Wonderful program with the sheriff dept. A gps-like device on an arm band( we do ankle). If she gets away we call 911 they enact the frequency and find her.

### FOCUS Post: *FOCUS needs the Scoop on Poop!!! How do you manage constipation?*

- Prune juice once a day with Arbonnes Figure 8-Fiber Booster
- Miralax-and tell other caregivers (school, etc) you want details about BMs.
- Miralax and Benefiber. She can't taste either and there is no grit.
- I live my life around poop and bm's!! WATER, WATER
- And more water!! :))
- Prune juice works wonders for us. We do two ounces at a time and it usually clears up the problem in 4 hours or so.
- Some chemos really gum up the works. Drugs like Miralax were so hard to regulate for us - too many accidents. We had much better luck with apple juice daily and powdered greens ... which are much easier to take if you have a g-tube!
- What are powdered greens?
- There are several brands out there. I don't remember which I used for T ... I think it was maybe something like Power Greens ... it was organic ... and I bought the loose powder ... it comes in capsules, too, but they were large. Anyway, it is a mess of veggies from spinach to beets to tomatoes & I remember

fruits, too ... like berries ... and some seaweeds like Spirulina ... very healthy stuff. So I mixed it up & used a 60cc syringe to do a bolus feed into his g-tube. He wasn't eating any veggies at the time so I felt really good about giving it to him. I think I used to buy it at Whole Foods or Health Unlimited. Things you think you'll never forget ... ! Let me know if you need more. Now we just have to make sure we're getting apple juice pretty regularly.

- Constipation is a never ending problem for us and we've had some really horrors with it. So painful. Probably one of the best things I've done is quit beating myself up over his eating and bowel habits. They are bigger than me. M has seen a gastroentologist for many years now. The doctor prescribed Miralax which at first was by prescription only and now it is OTC. We swear by it!

### FOCUS Post: *Some days, the glass just feels half-empty. Share your favorite quote that fills up your glass again!*

- My favorite isn't really a quote ... the tagline for Nike sometimes gets me through an endless day: "Just do it."
- One of our favorite quotes is from the Nemo movie – "Just keep swimming, just keep swimming." You can insert whatever you need, but you have to say it in that repeating sing songy way – just keep eating, or just keep \_\_\_\_\_ing, etc.
- "I long to accomplish a great and noble task, but it is my chief duty to accomplish humble tasks as though they were great and noble." Helen Keller
- Love that one too, and use it often :) I also believe that "anything is possible"
- I love you mommy! You are the best mommy in the whole world.
- Nothing is Impossible
- I'm not sure how uplifting it is, but it's a great reminder. "One tragedy at a time." I just step back, take a deep breath and take things one at a time and then they're much easier to handle.
- If I don't defend the galaxy, who will?
- To the world I am just a mom ... but to my kids ... I am the only MAMA! ... and "It can always be worse!"

Stay in touch with FOCUS on Facebook!! Join at <http://tinyurl.com/focusgeorgia> ■

# Thank You

Many thanks for all contributions to FOCUS. This list is through December 20, 2010. All later donations will be listed in the next FOCUS newsletter.

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A complete list of FOCUS on Fashion  
Sponsors will be listed in the next  
newsletter!

## FOCUS Hospital Visitor on Sick Leave



Rosemary Underwood, the official FOCUS visitor to Scottish Rite for over 10 years, is taking a little sick leave herself. Known for her compassion and interest in FOCUS kids of all sizes, Rosemary

develops special friendships with families whose medically fragile kids are often in the hospital. She remembers what treats the parents like, such as Coke Classic or Diet Coke and milk or dark chocolate, and notices every change in "her" kids, commenting on how much they have grown or how good they look. She is ecstatic when they are well enough to go home!

Rosemary is now battling cancer with chemotherapy and radiation. Getting cards and words of encouragement from FOCUS families warm her heart. If you'd like to help, send a card to the FOCUS office or an email to joy@focus-ga.org. We will pass them on, and we'll be ecstatic when Rosemary is well enough to go back to the hospital!

While Rosemary is out, Sarah Provow is covering Scottish Rite with Elizabeth Hewell's help. Ann and John Schramm continue to tag-team for Egleston visits. If your child goes into the hospital, please call FOCUS at 770-234-9111 or email elizabeth@focus-ga.org. We will try to get by with treats to cheer you and your family.

# Coming Up at FOCUS

**Save these dates  
for 2012!!**

**FOCUS Annual  
Education Conference  
Saturday,  
February 11, 2012**

Brochures will be emailed  
to all FOCUS families  
in January!  
Call for a 'paper' brochure!

**For the Love of Children  
29th Annual Dinner,  
Dance & Silent Auction  
Saturday,  
March 17, 2012**

**Annual FOCUS & Lekotek Holiday Party  
Saturday, December 10  
11:30 am to 2 pm  
Eastminster Presbyterian Church  
5801 Hugh Howell Road, Stone Mountain**

Join FOCUS & Lekotek for food, fun, arts, crafts, caricatures and music. FOCUS will provide the fried chicken and Lekotek will provide the drinks and papergoods. If your name begins with:

- A-N Please bring a vegetable or side dish
- O-T Please bring a dessert
- U-Z Please bring bread

For easy clean-up, please bring food for 10 or more people in a disposable dish with a disposable serving utensil. Call FOCUS or email [angie@focus-ga.org](mailto:angie@focus-ga.org) by December 3 and register the number of adults and children attending. Santa brings each child a small gift so we need an accurate count; while bringing a grandparent or out-of-town cousin is permissible, please limit attendees to immediate family since we have limited space and Santa's workshop is pretty busy this time of year!!

*Directions to Eastminster Presbyterian:*

Take I-285 to 78 East. Take Exit 7 (Hugh Howell Road) and go up the hill to the second church on the left. Families should enter the church through Founders Hall – follow signs & look for balloons!

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