I’m sure most of you in FOCUS-land can relate to this scenario: It’s 5 pm and a tired mom in dress clothes is pushing her child’s wheelchair with one hand and pulling the grocery cart with the other hand up and down the aisles of the supermarket while her other child is running around, being way too loud. She imagines that she looks like the circus train and thinks it just might be another Fruit-Loops-for-dinner night. As she turns a corner, it happens. A well-meaning stranger who has observed this parade for several minutes strikes up a conversation. The stranger wants to know all: the diagnosis, the fact that she works, the fact that she is shopping without help, and then says, “Wow! You must be a supermom! How do you do it?”

After the last time this happened to me, I started thinking about how I DID get here and how DO I do it! I’ve heard these questions for almost six years now. My daughter Hannah was born naturally three weeks before her scheduled C-section. She had problems with feeding and reflux almost immediately. She began to reflux, choke, and turn blue and went back to the hospital at 9 days old. She never really hit any milestones, and at 4 months old, an MRI found massive subdural hematomas (blood) on her brain. Because of this, Hannah needed a shunt at 6 months old. Shortly thereafter, we spent a week at Children’s Healthcare of Atlanta at Scottish Rite “The Scottish Ritz” with methicillin resistant Staphylococcus aureus (MRSA) shunt infection. At 9 months old, the neurologist diagnosed Hannah with cerebral palsy. I cried my eyes out on that June day. A day or so after, I got myself together and remembered a pamphlet that the hospital had given me for something called FOCUS. I called the number sort of in disbelief that this was really happening. Lucy was so kind; she told me that it was going to be okay and that I should go to the Gwinnett Share Group when it started back in the fall.

My first share group was a lifeline! Right in the middle of learning about this whole new world, I met all these other moms who had been there and knew what it was like. I remember asking them “how they did it.” The best piece of advice was to establish a support system. I took it to heart. I quickly found out that people genuinely want to help, but need to be told how. I am so fortunate that my parents live close and are very involved in our lives. I have great friends at church who babysit, bring meals or do just about anything I ask them to do! I also went to everything FOCUS offered just so I could be around other parents. At the time, I was building my support network, I didn’t realize just how valuable they would become.

When Hannah was 3, her father and I divorced. He has basically been out of the picture since then. Suddenly, I moved from a stay-at-home mom in an upper-middle class family to a single mom of two kids with no job and no source of income. I had no idea how we were going to make it. But God provided for us in so many ways. That support system that I built rallied around us and held

(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.

October 19 & 20, 2013
TEAM FOCUS in Spin for Kids
All funds raised by TEAM FOCUS go directly to FOCUS programs at Camp Twin Lakes – ride or support TEAM FOCUS and help FOCUS children and families go to camp!

Contact lucy@focus-ga.org for more information.

From the Editor

by Lucy Cusick

Julius Caesar said “Experience is the teacher of all things.” Every experience we have is a learning one – although, of course, it might take several “experiences” to make us pay attention! My experiences of the past six months have caused a lot of reflection and brought up many memories – good and bad. I’ve likely lived over half my life, and I’ve realized that all of these experiences have come together in a rather related way.

My earliest life-changing experience was when I was just 11 and my father died very suddenly. I watched my mom learn a whole new life. She went to work after being a homemaker for almost 20 years, put the three of us kids through college, and always had homemade desserts even if we just popped by unannounced. I’m sure that at times she was lonely and sad, but she forged on, making the best of her situation by doing the best for her children.

In college, I studied microbiology. After graduation, I worked in both the food and medical micro fields. After Josh was born at 28 weeks, he spent 3 months in the neonatal intensive care unit. Because of my micro experience, I hounded the poor nurses who worked with Josh. GermX wasn’t on every ICU wall back then, so I was the self-appointed handwashing police. My micro experience also helped me understand the medical lingo, and I learned to visit Josh when the doctors made rounds so I could be in the know. Usually, I told them what was going on.

As the mom of two children, one with and one without special needs, my experiences continued. My microbiology training went by the wayside when Josh learned to commando crawl. I was so happy he was moving independently that I adopted the ‘you have to eat a pound of dirt before you die’ philosophy. I decided the dirt and germs were worth the risk. I also learned to be persistent and persnickety, but polite. Our typical daughter, who was very strong-willed as a toddler taught me different lessons; pick your battles but once you choose to battle, stand firm.

I recently became a member of the ‘sandwich generation,’ those caring for their own families and also for their aging parents. My mom moved into assisted living in Atlanta and had a pretty rough summer. All of my experiences are back in play, from handwashing patrol to picking my battles. I’ve cried buckets with and for her, and I’m learning to move through my day, regardless of how her day is. Most days, I just feel like a piece of wilted lettuce in the sandwich of life.

Our experiences weave together to tell our life stories, whether you live a life filled with adventure, family, friends, or a little of all. For me, there are several truths: Life isn’t fair; continue to move forward; and never depend on me for homemade desserts.
The Best Advice I Didn’t Believe

By Amber Chase

When Caroline was still a baby, I got the best piece of advice about being the parent of a child with special needs from a dad with an adorable 5-year-old son with Down Syndrome. I’ll admit that I didn’t immediately appreciate it; he said it in the same way that strangers say to new mothers, “Enjoy your children, the time will go by so quickly.” He told me, “You’ll be fine. Just treat her the same way you treat all of your children.” Well, duh, I thought, that’s so basic and obvious. Our Caroline has Down Syndrome, but no medical challenges, and was cruising through her milestones. So for all intents and purposes, she was the same as any other 6 month old. I remember just shaking my head and discarding his advice.

Now, five years later, I totally get it! His experience had shown him what I have now seen. It is so easy to stop treating them the same; it may be gradual, but it often happens. As our children get older, the challenges become more obvious and harder; they start to fall further and further behind their peers. I try to avoid the common pitfalls, but it is so hard to avoid them: making excuses for behavior instead of understanding behavior, looking for handouts or leg-ups instead of finding ways for them to achieve their own goals, expecting others to lower their expectations because some things are too hard. Learning how to parent any child is trial and error, often two steps forward and one step back. I freely admit that we struggle with all of these issues and more. But there are a few things that we have tried to adhere to more strictly, and I feel they have only helped Caroline.

Manners are not optional. Good manners are some of the most basic of lessons all children should learn to practice from a young age. Always say hello/goodbye, please/thank you, excuse me (signing counts, too!). Look people in the eyes when you are speaking with them or being spoken to. Practice good table manners. Be considerate and respectful. Learning manners requires lots of prompting and repetition. It’s worth the time and effort. What’s cute at 5 isn’t cute at 12.

Temper tantrums are never tolerated. It is our job to prepare our children for life. Sometimes we have to do things we don’t like. Sometimes unfair things happen. Life is hard. These sound like cliches, but they are the realities of life. If we always give our children what they want, or always shelter them from things that are hard or unfair, we are not preparing them for real life. Managing temper tantrums – especially those in public – are challenging. I’ve not perfected this by any means, but I’ll keep trying!

Always expect AND demand their best. This one is tricky because we don’t always know what their best is! Some tasks are just so difficult and challenging for them that it is easy to step in and do it for them when we are short on time or patience. Am I holding Caroline back because it is simply easier for me to allow her to give a half-effort, or, even worse, do things for her? I mean, let’s be real. I’m busy. I’m exhausted. I’m tired of everything taking twice as long. But if I don’t raise that bar and help her reach it, then who will?

Don’t underestimate the power of childhood. How many of your greatest memories from your life are from your childhood? Therapy and interventions of all kinds are not only important for our children, but some would argue they are major contributors to the increase in quality of life and overall successes that our children have benefitted from in the past decade or two. However, they don’t take the place of the joys of childhood, and should not come with the expense of having at least some typical childhood experiences. FOCUS is the most amazing resource for our families to find activities that our kids and families can participate in. Find something that your children can be a part of, a community for them to grow with.

We set the tone for what is expected of our children. If we want them to be treated the same, then we can’t expect others to always make exceptions for them or give them a freebie; granted, there are times an exception is necessary. For instance, Caroline loves to dance, but being in a typical ballet group would be hard for her. We found a wonderful ballet program for children with Down Syndrome called Foster-Schmidt that is directed by Charlotte Foster. Students are required to audition and students with talent are chosen to participate. Charlotte is familiar with the difficulties these students might have, but she always demands excellence and treats them the way she would treat any of her dancers. If you were at FOCUS Family Camp “Under the Stars,” you may have seen Caroline perform her ballet recital in the Talent Show. I feel that this is a wonderful message to send to the community about all children with special needs: all children have gifts and should be recognized and rewarded for those gifts.

This brings me back to that sage advice given by that dad all those years ago. I think the heart of what he was saying – which, in itself, is a very fine line to walk – is while in your heart you know that your child is different, treat them the same as your other children. In reality, aren’t we all the same ... but different?
Coming Up at FOCUS!
Always check www.focus-ga.org for details!

September 7, 2013 – FOCUS Family FUNdraiser at Holy Cross Catholic Church (3773 Chamblee Tucker Rd, Atlanta 30341) from 5-7pm. Join FOCUS for spaghetti and dessert, raffles, games, music and a photo booth for the entire family!! To RSVP or for more information email Elizabeth@focus-ga.org.

September 15, 2013 – FOCUS Day at the Georgia Aquarium is full! We did online registration this year and had over 1000 requests for only 700 tickets! If you were not selected, you’re in good company!

September 28, 2013 – FOCUS on Moms! A day of chocolate, workshops, lunch and pampering. At First Christian Church of Atlanta, 4532 LaVista Road, Tucker. For more information or to RSVP, email elizabeth@focus-ga.org.

October 5 & 6, 2013 – Under the Stars 2 Family Weekend at Camp Twin Lakes Will-A-Way – We’ll have more “Saturday Night Camp Fever” 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!!

Saturday, October 12, 2013 – 11 am to 3 pm – Moms Day Off. FOCUS moms hope to again enjoy this fabulous day on Lake Lanier. Sadly, our captain from past years died suddenly and a new captain has not been selected. FOCUS is ‘on the books’ for October 12, and we will update you by email ASAP. For now, save the date!!

October 19 & 20, 2013 – Spin for Kids!! Join TEAM FOCUS Captain Bob Bruce and raise money for FOCUS programs at Camp Twin Lakes! See page 2 for more details!

Saturday, October 19, 2013 – FOCUS on Transition, sponsored by the Interagency Transition Council and held at Mercer University. Brochures available by email soon!

Saturday, October 26, 2013 – MVP Boo-B-Que – We invite our medically fragile children and their families to the 5th annual FOCUS Boo-b-que at Holy Cross Catholic Church, sponsored by Knights of Columbus. Contact Elizabeth@focus-ga.org for details.

Saturday, November 2, 2013 – FAST Fins IntraSquad Swim Meet – 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.

Saturday, November 9, 2013 – FOCUS Day at Zoo Atlanta! Registration will go out by email in mid-September.

Teen/Young Adult Activities – Contact Mackenzie@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.

A Look Under the Cape of a “Supermom”
(Continued from page 1)
us up. My parents are my rocks and continue to help me so much. My friends and church opened their hearts and homes to us. I found out that when life happens, my faith in God and my support system really hold me up. When I had to go back to work, I really missed and grieved over not being able to attend my FOCUS Share Group. I needed that little slice of normalcy. Last spring, I decided to start a Share Group on Saturdays for working parents. I want that Share Group to hold the capes up of all you “superparents.”

So almost three years later, I realize that the only way I can and could have “done it” is because of the army of special people who help me be that “supermom.” My support system helps with doctor appointments and therapy, they keep my son Joseph when I have to be at the doctor or hospital with Hannah, and they do the little things (like dishes and laundry!) that mean so much.

I’m not really a “supermom,” I’m a blessed mom and that’s a pretty great thing to be.

Jennifer facilitates the Grayson Share Group one Saturday a month. Go to www.focus-ga.org and check out the calendar for more information!

14th Annual FOCUS on Fashion
Sunday, November 3 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!
Our family is very excited to be moving to Atlanta, which is my first home. I grew up here, my husband, Brad, and I were married here, we lived here for several years after college, we both have family and friends here, and our first real jobs started here. We left Atlanta 15 years ago because Brad’s job transferred us to our second home in Metter, GA. We loved it in that little small town! Both of our children, Erin and Ty, were born there, and we have great friends there who we miss terribly. But an opportunity arose that we couldn’t pass up, and that opportunity brought us right back to Atlanta. We were all very scared about a new transition! Atlanta is such a big city! How will we ever choose where to live? Where will the kids go to school? How will the kids like their new schools? How will I like my new job? Will we make new friends easily? And a very important one, where will Ty play baseball? Tons of questions to answer, so we began to answer them one step at a time! And the first step started with FOCUS!

Erin has cerebral palsy, so when we realized that we were moving, I started researching programs for children with disabilities. I found FOCUS and immediately signed up for the newsletter. I wanted us to get involved! I went to the FOCUS Northside share group and met some great ladies who listened to all of my questions and offered suggestions about where to start. I listened to their experiences and learned about some of the resources that this big city had to offer Erin and our family. I left there with a couple of my questions already answered. It will be easy to make new friends! These ladies were great!!! And Erin and our family are going to have lots to do and be involved in through FOCUS. Through FOCUS, we found a summer program for Erin at the Elaine Clark Center. They made it our easiest summer ever! Erin quickly adjusted to her new environment and the teachers there made Erin’s summer fun! She had a fun, safe place to go to everyday, which made it easier to go to work. I was beginning to see how all of this was going to work out!

We have finally moved into our new home and are getting settled in Marietta. Erin and Ty are both doing great and enjoying their new schools. Ty even has a new baseball team! More questions have been answered and some questions have been answered that I didn’t even know to ask! We can’t wait for the FOCUS family days at the Georgia Aquarium and at ZooAtlanta! I can’t wait to get Erin all dressed up for the FOCUS Fashion Show! Erin is going to be in a Fashion Show! WOW! So many events to be a part of and get involved in! We are very excited about the fun we are going to be having in our new home with our new friends!
L ast August, our family went to FOCUS Family Camp Under the Stars for the first time. It literally felt like we were bringing our entire house with us by the time we finished packing towels, sheets, nutritional supplements, wheelchairs, etc. When we arrived, we found out we were assigned to share Cabin 4 with the Browns, a family we had never met. We were excited to meet them, but a little apprehensive as well. We didn’t know if we would have anything in common with them or if our children would get along together. Would our schedules be compatible? I laugh now when I think about how nervous I was to meet them, because I don’t think we could have found a family more like ours, even down to the strange little “quirks” that every family has. It was like meeting ourselves! Tameche and I shared a passion for searching for new treatments and therapies that would help our girls, who share a similar diagnosis. And our husbands both clearly worship the ground their girls roll (and sometimes walk) on. Emma and Miracle quickly became best friends that week-end. More importantly, Todd and I found allies in Paul and Tameche. We did as many activities as possible together. Miracle and Emma even performed their rendition of “Five Little Monkeys Jumping on the Bed” at the annual talent show! Thus, the legend of Cabin 4 was born! I don’t know who made the cabin assignments that year, but I believe there must have been a little divine inspiration involved. (Editor’s Note: Joy Trotti assigns cabins so we’ll give credit where credit is due!)

After camp, our friendship with the Browns grew. The girls attended FOCUS activities together: Extra Special Saturdays, MVP parties, and the Daddy Daughter Dances. They even played on the same softball team this spring and attended each other’s birthday parties. Emma’s face just lights up every time she sees Miracle. Together, they inspire each other, and, yes, sometimes even get in a little trouble together. I found a pretty special friend in Tameche as well. We share information on treatments, funding sources, and activities that the girls might enjoy. When I need advice or a reality check about something going on with Emma, Tameche is the first one I call.

This year we all returned to Cabin 4, and we brought even more with us this time — bath chairs, pool toys, and Miracle’s adaptive tricycle that she let Emma try out. We planned a new “act” for the talent show, a dance with the girls and their dads to “I’ve Had the Time of My Life” from the movie Dirty Dancing. Truthfully, we spent more time laughing than practicing the dance. At the talent show, we called it “Not So Dirty Dancing.” Tameche and I were just happy that they got through the dance without either of the girls flying off the stage (which did happen during our rehearsal) or either of the men injuring themselves! Emma and Miracle really did have the time of their lives that night, laughing at their dads the whole time!

Back in the cabin after the talent show, everyone went to bed almost immediately. We were tired; camp is hard work! Then around 12:30am, I heard it – the bump in the night every parent fears. Emma was screaming before we could jump out of bed and get to her. Emma is VERY loud, especially when she is upset. I was pretty sure the walls rattled every time she sleeped. For a few minutes, I took her back to my bed and tried to calm her, thinking that she had just hit the wall with her knee, but something was obviously very wrong. The cabin was dark, and everyone else was trying (in vain) to sleep, so I took her into the lighted bathroom area so I could make sure there was no blood involved. The problem turned out to be severe leg cramps that tortured her relentlessly. Every time Todd and I would get her legs to relax, the cramps would come back suddenly, causing her to scream so hard that she actually vomited several times. So there I sat on a bench in a bathroom with a concrete floor, rocking my baby girl in a vomit-soaked towel and feeling absolutely powerless to relieve her pain. Todd saved me from a huge hairy spider that crawled toward us while we waited… and waited… My mind filled with a hundred doubts: What if we couldn’t get the cramps to stop? What if the Browns were so upset they never wanted to stay in the same cabin with us again? What if we had to call 911 and we couldn’t find the gate at the entrance to the camp to meet them? Where was that sheet of information about what to do if we had an emergency at camp anyway? Was there a spider sitting on top of it somewhere in my luggage?

Hours later, either from the extra dose of medicine or from sheer exhaustion, Emma stopped screaming, and we crawled into bed to get an hour or two of sleep. It was a fitful sleep because I kept waking up to look at Emma sleeping beside me, making sure that she was still OK. As (Continued on next page)
soon as the sky started getting lighter, I decided to shower since I smelled like vomit. On my way to the bathroom, Tameche whispered to me from the other side of the room. I went over and sat on the side of the bed next to hers to explain all that had happened the previous evening. I felt horrible that we had kept them up with us and told her so. Rather than being upset, though, Tameche told me how concerned they had all been for Emma, especially Miracle. They had prayed for us while we were with Emma and had assured Miracle that we were helping her little friend. They had even made plans to get emergency help – we FOCUS parents all think alike!

That very long night taught us a lot. We discovered the real reason behind FOCUS – forging friendships so that when you think you are alone in the dark, there is someone who has been where you are and will stand with you so you are not alone. Let’s face it: There aren’t many friends who are understanding when your child has kept them (and perhaps half the camp) awake most of the night, friends who are more worried about your child than about themselves. And it is definitely rare to find someone who will still hug you when you smell really bad and have your child’s cookies from her evening snack stuck in your hair! In the Brown’s, we found all that and more.

Dr. Phil talks about having a “soft place to land,” and we all need that, especially as parents of children with special needs. We will always have times when we feel helpless and unsure that we are doing the right thing for our children. We will have fights with the schools about things most people never even think about. Instead of deciding when to take vacation, we debate the best times to start new therapies or have surgical procedures. We wonder what our children cannot tell us and try to anticipate their dreams, fears, and wonderings so we can answer their un-asked questions. We all need camp so we can get away from those things. And we all need camp so we can make friends who will help us through the hard times when we have to return to real life.

Cabin 4 hopes to see you next year, especially if you have never been to Under the Stars Family Camp before. Who knows? Maybe next year we will set a record for the cabin bringing the most from home. HGTV might even be interested in filming the amazing job we do of refurnishing the place! But we plan to leave those pesky leg cramps at home…

Looking Back at the Fun...

Camp TEAM kicked off the summer with a week of day camp fun at Mercer University in Chamblee. Campers enjoyed sports, pottery, nature arts and crafts, and swimming – the weather was perfect and campers had a blast!

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, Discovery, 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.
Camp Hollywood left stars all over Atlanta this summer! Offered for one week in 10 locations, campers made bear claw cupcakes, planted beans in CD cases (they really grew!), learned about geysers and sound, played games and danced and sang in music therapy. Thanks to the churches that continue to welcome FOCUS: 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.

Under the Stars 1 Family Camp
FOCUS families descended into Camp Twin Lakes in Rutledge for a weekend of ‘Saturday Night Camp Fever!’ Families had a blast at the climbing wall, art cabin, pool, archery, boating and more! A special treat was the wheelchair-accessible obstacle course designed by Chessa Birrell for her Girl Scouts gold award. Thanks to Lane, Clark, Stephi, and Grant Howard for emceeing the annual talent show – entertainment at its best! Thanks to the sponsors (see donor list on page 5) and TEAM FOCUS in Spin for Kids for their support of this fabulous program and to all the volunteers who helped families make memories!
Extra Special Saturday Respite – Fall 2013

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 Alpharetta Presbyterian on September 21 and November 16 and be on the waiting list for October 19 and December 7. 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 medication. All medications must be in the 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
Summit Baptist Church
4320 Moon Station Lane
Acworth, 30101
(You may register for two months, choose wait list for two months)
September 7, October 5
November 9, December 7

ALPHARETTA
Alpharetta Presbyterian Church
180 Academy Street, Alpharetta, 30004
(You may register for two months, choose wait list for two months)
September 21, October 19
November 16, December 7

CHAMBLEE
Embry Hills United Methodist Church
3304 Henderson Mill Road
Atlanta 30340
(You may register for two months, choose wait list for one month)
September 7, October 5
November 9, No December

CUMMING
Highlands Church
433 Canton Road, Bldg. 400
Cumming, 30040
(You may register for all dates)
No September, October 5
November 2, December 7

MARIETTA
Mt. Bethel Daycare
615 Woodlawn Drive
Marietta 30068
(You may register for two months, choose wait list for one month)
September 7, October 5
November 9, No December

NEWNAN
Cornerstone UMC
2956 Sharpsburg-McCullum Road
Newnan
(First come, first serve!)
November 16
Visit www.focus-ga.org for the most current information about FOCUS activities.