January/ February 2012

Volume 29 Number 1



# **Super Dad!**

by Rick Roberts

Make room for Super Dad – no Cape needed! Recently, I had the experience of being a single parent with twins, one with special needs. Luckily, my wife was just on a business trip for a few days!! Super Dad prepared to run the household which included assuring that the children would be fed, cleaned and delivered to school; homework assignments would be completed by the kids and not Dad; medications would be given at the right time and dosage. My wife, Sue, was scheduled to leave Monday morning.

First set-back: Matthew, who is 8 and has cerebral palsy, epilepsy and clonic-tonic seizure activity, managed to have a seizure requiring 911 transport to Scottish Rite. Sue rode in the ambulance, but he was discharged after a few hours. So, our daughter Sarah and I drive to Scottish Rite to pick them up. As we get Matthew in the car, we notice he's having a focal seizure with his right arm, but he's not eaten nor had afternoon meds, so we head home for both. After a nap, he has more generalized seizure activity, and his private duty nurse has arrived and goes into action. Before you know it, our family room is transformed into a trauma unit to rival Scottish Rite: pulse oximeter, oxygen tanks and other equipment that I had no knowledge we stored in the house. The nurse administers the antiseizure medication and we wait. No effect, so another 911 call.

Once the "call" is made, everyone busies themselves with their "911 job." Sarah secures our dog Fulton in his kennel, or coaxes him in a bedroom, with toys and a blanket. This can be a challenge since Fulton weighs twice as much she does and towers three feet over her when he stands on his hind legs! She then makes sure that the outside lights are on, if it's dark, waits by the front door to let the emergency personnel in the house, and directs them to wherever Matthew is in the house.

In the meantime, Sue and I decide who should go with Matthew in the ambulance, pack his medications and insurance information, and arm ourselves with clothes, toiletries, books, magazines and a laptop. Sue elects to go with Matthew since she's due to fly out for work on Monday.

Matthew is stabilized, and admitted. Sue leaves the hospital Sunday evening to attend Sarah's brownie troop meeting. In the meantime, the hospital calls to let us know that Matthew is seizing again – with a flash I am out the door. I stay for the night.

Monday morning, I awake after a restful sleep on the hospital couch, also called a fold- out, make-believe bed. For those of you who have extended stays at Scottish Rite, I have a wonderful chiropractor who can put back bones and all aliments from your disjointed night's sleep. For those readers who have never had the 'pleasure' of 'sleeping' at the hospital, I have one word of advice: bring an air mattress and sleeping bag, you'll have a better night's sleep and thank me in the morning!

Sue gets Sarah off to school and heads to the airport. I make sure that Matthew eats breakfast, has a couple of activities at hand, and the TV is tuned to his favorite channel. I am in treatment for thyroid cancer and have a scan scheduled at Northside Hospital that morning. What I failed to understand, or just failed to listen to, is that I am supposed to return each morning for two days for an injection, followed by medication in a pill form of radiation the third day, isolation the fourth day, and MRI on the fifth day. Hhmmm.....

So Super Dad is not feeling too super. I should have planned better. Monday, I return to find Matthew happy and content, I feed him, see if the nurse has

(Continued on page 5)

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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.



#### FOCUS



### From the Editor by Lucy Cusick

Time to say good-bye to 2011 ... and say hello to a new year. I'm not so good with good-byes, so I'm having a hard time here in FOCUSland right now. Angela's article about "Letting Go" hit home – as FOCUS parents, we've all probably 'let go' in many ways. I should be an expert at letting go by now!

After Josh was born, I decided to let go of my job as a microbiologist at the Centers for Disease Control. I loved my work in the lab, but I loved Josh more. His medical needs, and then his therapy schedule, were more important than any career. Over the years, I've let go of hopes and dreams – I've also let go of anger and fears. It's a conscious and constant decision to live a happy life, to make the best of situations, to enjoy every day for what it is – a gift.

We at FOCUS are trying to let go with happiness. "Our" Annie is leaving FOCUS after many years of volunteering and then working on staff. She started with FOCUS as a volunteer in middle school at Camp Hollywood and continued all through high school. After her freshman year at Furman, we hired her to help at FOCUS day camps. She made herself indispensable, and we begged her to help on busy FOCUS weekends. She came home from college to help at Under the Stars family camp, FOCUS on Fashion show, and For the Love of Children dinner, dance, and silent auction. Being young, she was quick with technology, long on patience, and, best of all, adored by loved our children.

Annie graduated with her degree in psychology from Furman at the same time that the economy tanked. Jobs were scarce, so we kept her busy here at FOCUS, first doing this and that. She quickly created a niche for herself, expanding the FOCUS Teen & Young Adult program through monthly outings, Camp Infinity overnight camp, and OctoberFest retreat. She recruited, trained, and managed hundreds of volunteers. She organized our newest fund raiser "SummerFest" at SweetWater Brewery. While spearheading her own programs, she assisted with other programs at FOCUS, working many weekends without complaint. She patiently tolerated her eight 'moms' and her nickname "Baby," suffering through hundreds of lunches filled with marital advice and life lessons. We educated her – teaching her songs from before her time and telling her how we used to do things back in the dark ages!

And now we are letting go. Annie has a wonderful opportunity for a full-time position as Camp Coordinator at Camp Twin Lakes. She will continue to coordinate Camp Infinity for 2012 and hopes to volunteer with the Teen & Young Adult socials. We look forward to seeing what 'our' Annie will accomplish in life, and we know that she will always be a champion for children with disabilities AND their families.

Good luck to our sweet Annie. We will miss you every single day, just as peanut butter would miss jelly. You take with you a little piece of our hearts – all eight moms and countless children and families!

### Looking Back ...

#### **FOCUS on Fashion**

The 12<sup>th</sup> annual fashion show, starring FOCUS children and the professionals who care for them, held at Oglethorpe University on November 6 was a fashionable success!! Guests enjoyed performances by Fleetwood Dance Theater and Dance for Fun, music by pianist Christopher Cannon, and our beautiful children showing off the latest fashions from Belk. A special thanks to the doctors, nurses, therapists, and teachers who modeled with the children and to Lane Howard and Patrick Cusick for emceeing another wonderful show. For a complete list of sponsors, please see the contributor list on page 7.













#### Annual FOCUS / Lekotek Holiday Party

The annual FOCUS / Lekotek Holiday Party was another grand affair. Families from all over metro Atlanta gathered at Eastminster Presbyterian Church in Stone Mountain for lunch, arts and crafts, the Secret Santa Shop, Santa Claus, and the surprise visit from the Webkinz Van!! Many thanks to Eastminster Presbyterian for their hospitality, Zesto for the yummy fried chicken, the Northlake Kiwanis for their support, the FAA for donating Pillow Pets and volunteering as Santa's elves, Lekotek, all the volunteers, and the Webkinz Van for visiting and giving out Webkinz to our fabulous kids! A perfect way to begin the holiday season!!







# "Letting Go" ... Once Again

by Angela & Luke Lenahan

When you are a parent of a special needs child, you are forever "letting go." You let go of those first milestones, an education without an IEP, a month without a doctor's visit or therapy session, being able to just jump into the car and go without preparation, that special event you dreamed of with your child, and so on... Each "letting go" comes with its own grieving but you find you replace it with a joy that only a special needs' parent can understand; that first smile or laugh from your child, their adaptability to "anything" new, finally finding a medication that is working for them, less visits to the doctor, and more...

We became FOCUS parents when our daughter, Erin, was born in 1989. We drove all the way to Conyers from Lilburn to meet monthly with the founders, Susan & Jim Calhoun, and a few other parents. We felt blessed to know we were not alone in our new world of having a special child. We have remained attached to FOCUS to this day. Erin had cerebral palsy and a severe seizure disorder. Our days were filled with medications, tube feedings, therapies, education, and so many doctors. Scottish Rite Hospital was like a second home to us. We felt blessed to have Erin and always told her she was such a good teacher to her mommy and daddy because only she could teach us the things we needed to learn to be good parents to her. With Erin, we "let go" of many other things than just what we missed experiencing had she not been handicapped. We let go of rushing to go anywhere and learned to be prepared. We no longer had any fears of standing up for our rights, as we were always fighting for our daughter's needs. We let go of many of the outings families take for granted, but replaced them with moments of deep family sharing. No longer would we dream of the recitals, ball games, proms, and many other milestones from childhood to adulthood. Most of all, we "let go" of the dream of walking Erin down the aisle at her wedding and all of the wishes we had for her to be able to experience so many joys of being a young woman.

Despite all of the years of letting go, we were filled with experiences that were pure blessing to our souls that can only be experienced with having a special needs child. We always felt like a normal family, just a little special, and tried to treat Erin the same as we did her older brother, Luke. He too, had much he did without, but he never complained and knew how much his sister loved him, as he did her. All of his "letting go's" and experiencing all the different things he did with his sister, have molded him into the wonderful man, Paramedic, and soon to be Physicians Assistant he is today. He too, feels Erin was his greatest teacher.

When Erin was three years old, we decided to build an accessible home to make caring for her easier. It was so wonderful and we settled into a family routine that worked for us all. We were not so sad about the "letting go's" since we always knew that some new experience with Erin would be



a better blessing to us than the milestones we missed. Unfortunately, we were not prepared for the biggest "letting go" of our lives, when on September 12, 1998, Erin could no longer battle her seizures and she decided to go to heaven and live with the angels. Her father and brother walked her casket down the aisle of the church, and her service was the most beautiful reflection of the blessed life she graced us with. Then, not only did we grieve the loss of our daughter, but all of the wonderful things she brought to our lives...there was a huge unfillable emptiness everywhere. The dreams we had for her had she not been handicapped came flooding back and the dreams we had for her as a special child were grieved, as well. Packing up Erin's belongings, giving many away, was another letting go, which like her life, was filled with sorrow and, yet, joy for the children who would be helped by the use of her equipment, wheelchair, etc.

Now, after several years, we find ourselves at that place of "letting go" once more. We have chosen to sell the house we so lovingly built for Erin. We designed our home, thought out every detail, and researched all we could to build the perfect house to accommodate Erin and us for all our years together. Again, we feel the pain that "letting go" brings, but we know from our past experiences, that letting go is not always a bad thing, and if we do not embrace change in our lives, we will not experience all of the blessings that lie before us. Our sincerest wish is that another family with a special needs child buys our house and is as blessed as we have been to make it their home. Once again, we are putting our faith in God and looking to our Angel Erin to guide us as we "let go" and open our hearts and lives to new blessings.

To contact Angela and Luke about their home, please email angelalenahan@hotmail.com

# **Coming Up at FOCUS**

Always check our website at www.focus-ga.org for updates!

#### FAST Fins Adapted Swim Team Register now – Season begins February 10

FAST Fins concentrates on perfecting swim strokes, improving stamina, developing team skills, building self confidence, following motor commands, and increasing fitness. Participants must be able to swim one lap of the pool with minimal flotation and to follow directions. Coach to swimmer ratio is 1:4. For questions, please email angie@focus-ga.org. Download a registration form at www.focus-ga.org or call FOCUS with questions.

#### February 11, 2012 FOCUS Annual Education Conference Dunwoody United Methodist Church

Keynote speakers, Julie Tennant and Derrick Tennant, known as The Love Chromosome, will inspire and entertain participants with their story.

Other topics include wills and trusts, difficult behavior, managing long-term grief, and siblings. We'll learn a lot and laugh a little. A brochure will be mailed to all FOCUS families and is at www.focus-ga.org.

#### March 17, 2012 28<sup>th</sup> Annual "For the Love of Children" Dinner, Dance & Silent Auction

Call FOCUS for sponsorship packages, ticket information, or to contribute to the silent auction.

#### May 9, 2012 FORE FOCUS Golf Classic at Bear's Best

#### May 6, 2012\* FOCUS Day at Six Flags Over Georgia

#### May 29 – June 1\* Camp TEAM

at its new location!! Shirley Blumenthal Park is closed, so Mercer University is donating their campus for Camp TEAM!!! Join us for a week of outdoor fun.

#### June & July – Camp Hollywood

#### August 10-12\* Under the Stars Family Camp At Camp Twin Lakes

#### August 18 SummerFest at SweetWater Brewery! Celebrate the end of the camp season with FOCUS!

#### **Super Dad!** (Continued from page 1)

any questions, post my cell phone number all around his room, and go home to retrieve Sarah, do homework with her, make sure she has clothes for the next day, read her a story, and put her to bed. This is the first time we have ever left Matthew along in the hospital. It was a restless night; I called the nurse at least three times. Each time she reassured me that he was sleeping comfortably. I told her that I would see her in the morning. Sarah and I get up early, and she chooses Waffle House for breakfast. So at 5:30 am, we were at the counter of Waffle House; she finishes a breakfast special before I finish my second cup of coffee! I drop her at school and head to Scottish Rite. I order breakfast for Matthew and start sending emails. I realize I need some help! I learned later from the nursing staff that he had a steady stream of visitors and was not bored.

Later in the day, I called the nurse from my office to ask if there was any chance Matthew would be released since he'd had no seizures for 24 hours. "No word yet," was her response. We agreed to stay in touch. Tuesday was a rainy day, and I was achy and tired from the medication. The neurologist called – Matthew was being discharged! I dashed to Scottish Rite, finding Matthew watching Elmo. It finally all came together: IV removed, discharge papers complete, wagon delivered. Matthew and I set off for home!

Now the real fun begins! Matthew is directly behind me, and I do not have a good view of him. It's a typical Atlanta rush hour in the rain: we are going nowhere fast. I realize that I'm not going to make it to school to pick up Sarah by 6 pm. I call around to see if anyone can pick her up. Matthew's physical therapist calls – and I ask the impossible – could you pick up Sarah?? "Sure," she replies, "I'm delighted to help and then I can treat Matthew when you arrive home!" (Matthew had hip surgery just 6 weeks earlier, so his therapy was really important.)

During all this, Matthew is entertaining himself. He's tearing up his discharge papers from the hospital and dumping out the Baby Magic body soap on the floor of the car. I call to let the center know who will be pick up Sarah. The center advises me that if the person picking up Sarah is not on the list, then she will not be released without prior authorization. (I know all you

(Continued on page 6)

## **EXTRA SPECIAL SATURDAY RESPITE SCHEDULE 2012**

To register your child, email karen@focus-ga.org <u>OR</u> 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. Call 770-234-9111, select extension 4. *"I would like to register Betty and Jack Smith for respite in Acworth on February 14, April 14, and May 5. I would like to be on the wait list for January 14 and March 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."* 

Parents will receive a reminder email from Karen Greenfield the Monday or Tuesday before each respite date, requesting that you confirm your plans to attend. *Important:* **If you do not receive that email, you might not be on the respite list so call or email Karen to find out.** *Do not come to respite and hope for the best; we carefully plan our staff and volunteers based on the number of children we expect and do not want to disappoint anyone!! If your child is sick on the day of respite, please call FOCUS and let us know; we might be able to add a child from the waiting list!!* 

*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 3 months, choose wait list for 2 months)

January 14, 10 am to 2 pm February 4, 10 am to 2 pm March 3, 10 am to 2 pm April 14, 10 am to 2 pm May 5, 10 am to 2 pm

#### Alpharetta at Alpharetta Presbyterian Church 180 Academy Street

(You may register for 3 months, choose wait list for 2 months)

January 28, 10 am to 2 pm February 25, 10 am to 2 pm March 24, 10 am to 2 pm April 28, 10 am to 2 pm May 19, 10 am to 2 pm

Chamblee at Embry Hills United Methodist Church 3304 Henderson Mill Road (You may register for 3 months, choose wait list for 2 months)

January 14, 10 am to 2 pm February 4, 10 am to 2 pm March 3, 10 am to 2 pm April 14, 10 am to 2 pm May 5, 10 am to 2 pm

#### Cumming at Christ the King Lutheran

1125 Bettis-Tribble Gap Road (You may register for all dates.)

No January February 4, 10 am to 2 pm March 3, 10 am to 2 pm No April May 5, 10 am to 2 pm

#### Marietta at Mt. Bethel United Methodist Daycare 615 Woodlawn Road

(You may register for 3 months, choose wait list for 2 months)

January 14, 10 am to 2 pm February 4, 10 am to 2 pm March 3, 10 am to 2 pm April 14, 10 am to 2 pm May 5, 10 am to 2 pm

#### Newnan at Cornerstone United Methodist

2956 Sharpsburg-McCullum Rd. (You may register for all dates.)

No January February 25, 10 am to 2 pm March 24, 10 am to 2 pm April 28, 10 am to 2 pm May 19, 10 am to 2 pm

## *Super Dad!* (Continued from page 5)

moms know this already ... this handy tip is just for dads!) She asked if I have email on my phone, I told her that the only thing I could do was send a text message. She gave me a number to use for the text. I explained to her that I was driving ... slowly... but still driving on 400 in the rain; I wrote the number on my wrist. As I was texting, I must have weaved a little, ever so slightly.

But wait, there's more! I was being followed by a Dunwoody Police Cruiser. He flashed his high beams at me, then the blue lights started. I pulled to the side and waited for what seemed like hours before the officer appeared at the passenger side window.

The first thing he says is that it is against the law to text and drive. I felt so stupid! Of course, I knew that. I admitted that I knew it, but that this was an emergency. I explained the circumstances and told him that I would show him Matthew's discharge papers ... except that he had torn them up. I showed him Matthew's blue hospital gown (he still had it on!), his name band, and my papers from my treatment at Northside Hospital. I explained my predicament about picking Sarah up on time.

Well, I'm sure he had heard a lot of stories in his time, but this must have beat them all. He looked back at Matthew, who by now has opened a bottle of blue Power Aid and managed to stain most of his face. He looked back at me and said, "Sir, please be careful. And, if you need to text, please ... please just pull off the road!"

Just another day in the life of Super Dad.



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# FOCUS

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FOCUS on Fashion

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are so thankful to all who donated, shopped and supported the Closet!!

The Kool Kidz Closet will not re-open in 2012. We

the Kool Kidz Closet. Michelle worked so well with our teens and young adults at the Kool Kidz Closet, teaching them job skills and making work fun! We are grateful for her dedication to the Closet and will miss her at FOCUS!

much ... daily emails, weekly phone calls, and annual baklava!! We like to think of her holding our sweet children in heaven who also left earth too soon. Michelle Thompson is leaving FOCUS as manager of

Underwood. Rosemary visited FOCUS children and families at Scottish Rite for almost 15 years! She kept treats in her car and chocolate in her freezer so she would always be prepared to spread 'hope and chocolate' for FOCUS. Rosemary lost her short battle with cancer last month; we at FOCUS miss her so

Sad Good Byes

The end of 2011 brought much sadness to FOCUS. In November, we said good-bye to Rosemary

### Check out their beautiful jewelry, sold at Huff Harrington HOME in Buckhead!

**Family & Friends Give Back** 

Thanks to We Are One Designs jewelry for supporting

FOCUS with 20% of their sales over the past year.

Thanks to Tatiana Cantu and her family for choosing FOCUS to receive gifts for Tatiana's 15th birthday!! We are so grateful!

The FAA donated 50 Pillow Pets for the FOCUS Holiday Party!! We are so thankful for the support of the FAA all year long!

The National Charity League of Roswell-Alpharetta donated 35 handmade fleece blankets for FOCUS hospital gifts!!

Monica DuBois, her daughter Madison, and their entire family who worked together over Thanksgiving to make 5 extra-large fleece blankets for FOCUS families! A

East Cobb County Council PTA Board donated Pillow Pets

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