

## Evelyn

by Kim Forester

When our first child was born four years ago, my husband Daniel and I were equally elated and devastated. We had never considered that our daughter might have serious medical needs, seizures, developmental delays, or a syndrome that most doctors haven't heard of. It came as quite a shock: that mixture of new parent love and bewilderment, coupled with fear of the unknown and a very tentative approach to parenting our 'fragile' baby girl. The first year of Evelyn's life was incredibly difficult – challenging every relationship we had – our marriage, our friendships and our families were at risk of falling apart as we grappled with an unknown world.

But as we would come to learn, fragile is not the right word to use when describing Evelyn, or the circle of people who love her. We were fortunate to have a very caring family; grandparents that would go the extra mile to help out, be at the hospital with Evelyn, or just listen as we worked through the issues at hand. Evelyn's aunts and uncle rallied around her, and us, learning about her and supporting us with a night out now and then – Aunt Megan even worked as Evelyn's nurse one day a week. Our closest friends did their best to understand our situation, and we did our best to help keep them in the loop – explaining things that they weren't familiar with, and reminding them that we still wanted and needed their friendship. We tried very hard to show our families and friends that Evelyn's syndrome did not define her, or our family – Evelyn is a person first, and while Aicardi Syndrome may consume a lot of her time and our energy, it is only a small part of who she is.

As Evelyn grew from an infant into a toddler, we became a little more comfortable with our

'new normal' and found ourselves better able to be joyful about a pretty new wheelchair instead of remorseful that Evelyn wasn't walking. We were thrilled when Evelyn began to use switches to answer yes and

no questions, and as we had with each positive step, we capitalized on that potential. Evelyn's personality, or spirit, really is, in my opinion, her greatest gift – and the people who came into our lives and showed us how to draw that personality out – they are priceless. Evelyn now uses a Dynavox VMax to communicate, as well as some more low-tech switches, and our favorite quick yes/no response – the 'tongue wiggle'. She chooses her outfits for school and her hairstyle each morning, asks about her friends, tells us she loves us, chooses movies and activities, and, well, talks about a lot of other things four year olds talk about. It is difficult to get a full picture of just how much Evelyn knows and understands – but it has been fun trying. She is constantly surprising us with her understanding of the world and her incredible work ethic. Even if she has tried something a thousand times and failed, she will always try again.

Now Evelyn has a little brother, attends a full day of preschool every day, and has playdates with her best friend. She also sometimes has trips



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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.

**Name That Newsletter!**

As a new school year starts, FOCUS begins its 29th year of supporting children with disabilities and their families!! We hope you like our new logo, tagline, and look!!

One project leads to another ... we now need to find the perfect name for the FOCUS newsletter! Send us your ideas; the winner gets free tickets to FOCUS Day at Zoo Atlanta on October 15 for your immediate family!! Send all your ideas to [lucy@focus-ga.org](mailto:lucy@focus-ga.org) with the subject Name That Newsletter!!

Contest opens immediately and closes on September 22!! We'll choose a winner by October 1!! Good luck!!

**From the Editor**

by Lucy Cusick

FOCUS began back in 1983, before the daily use of email, Facebook, and Twitter. We didn't have blogs or Skype, cell phones or text messages. The first FOCUS program was the Share Group, a living room support group where parents gathered to discuss sleepless nights and new therapies, compared notes on the best specialists, and shared tips on toilet training an 8-year-old. While the in-person system took planning and time, we made lifelong friends while muddling through the first few months after diagnosis. We enjoyed playdates, encouraged each other to keep on searching for answers, and drank lots of coffee.

Parents of children with special needs can now give and receive all kinds of support: chat rooms, list serves, Facebook discussions, Twitter, and blogs. We can be 'liked' for standing our ground and speaking our minds. We can complain about doctors, lawyers, traffic, and the President. We can delete those who disagree and encourage those who are on our side.

College students learn to post with care; employers track social media on potential employees; they know to take care in the photos they allow the world to see. A reminder about doctor-bashing, teacher-smashing, and neighbor-trashing might be good for all of us. We should stand up for ourselves and our children, but we might want to consider a more private forum than the Internet. With every status, post, and tweet, we leave a little trail about ourselves ... and our children.

Social media allows immediate support from a large geographical area; we can gather opinions from around the world. We can spout off using big words and bad language. We might feel better, but we paint a little picture of ourselves with each post. The end portrait isn't always good.

This journey is scary and lonely and hard sometimes. Technology connects us with others on this journey. We share our stories, encourage each other, share parenting tips, just like the old-timey, in-person support group. But, our audience is larger, we don't know who is really there, we can't see each other's eyes, and everyone who 'likes' you is not necessarily your friend. Just take care and be careful ... or as my friend says to her children every morning as they leave for school: Just remember, God is watching. And so is Facebook. ■

# Looking Back ...

## Camp Hollywood: Where Everyone's A Star

Camp Hollywood made stars all over metro Atlanta this summer! Offered for one week in ten locations, campers made geysers in a bottle, dragon drool, crocodile cakes and swamp mud cups; decorated lost treasure chests and ant chip clips; played games; and enjoyed daily 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 TEAM (Together Everyone Achieves More!)

enjoyed a fun-filled week at Shirley Blumenthal Park in Marietta. Campers enjoyed sports, pottery, drama, music, and swimming. Camp TEAM focuses on each camper's unique abilities and promotes growth in a traditional outdoor camp environment.

## Camp Infinity: Hang Loose!

Camp Infinity grew to include 47 teens and young adults this August! 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 the sponsors and riders in Spin for Kids for their support of this wonderful week – even in the 95+ temperatures, campers and counselors had a blast and made memories for a lifetime!!



## Under the Stars Family Camp

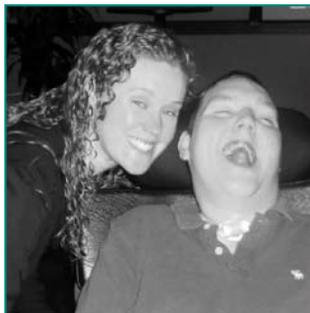
FOCUS families braved rush hour traffic on Friday to travel to Camp Twin Lakes in Rutledge to enjoy Super Hero fun and excitement! Families enjoyed a pool party with a DJ, archery, swimming in the fabulous new pool at Camp Twin Lakes, climbing wall, and arts & crafts (and more!) at the annual Under the Stars weekend. Thanks to the sponsors (see donor list) and riders in Spin for Kids for their support of this fabulous program and to all the volunteers who helped families make memories!



# I Wanted a Sister, But Got So Much More

by Sarah Steele

I distinctly remember the day my brother Matthew was born. I was in first grade and had been called to the front office. As I approached the door, I saw my dad standing there. He picked me up and said "Mom had a boy." I'll admit, I was a little disappointed, because I already had a brother. I really wanted a sister.



Matthew has been the most joyful influence in our lives and has made us all more aware and caring individuals. I started volunteering at a special needs summer camp when I was in junior high school. From then on, I have continued to be involved with many different organizations to help special needs children.

When I moved to Atlanta, I was fortunate to find FOCUS and become involved. If it weren't for my brother, I don't think I'd be as caring,

compassionate and interested in the world around me. My parents, and brother John, can say the same.

Later that day, we went to the hospital to visit Mom and Matthew. I held him and was excited about the new baby in our family. After the hospital visit, things changed, and quickly. Matthew didn't come home as most babies do. Mom and Dad were running back and forth between home and the hospital. Matthew went into a coma for weeks and the brain damage was irreversible. He nearly died in those first few days. We learned that he had a genetic defect that doctors didn't know about until after he was born, which caused the coma, thus brain damage.

Once Matthew was able to come home, I remember him crying a lot. It seemed like he was always upset. Mom always told us that she thought the world was too much for him. Looking back now, who can blame him? As the weeks and months went by he encountered different surgeries and hospital trips, which became a normal routine over the years. Thankfully, we lived in Cincinnati, and the hospital was one of the best. Matthew doesn't walk or talk, but you definitely know how he feels about whatever is going on around him.

I remember playing with my brother one day while Mom was in the other room. I was 8 or so and eating chocolate Teddy Grahams. I was talking to him and playing with my dolls. I decided to give him one of my Teddy Grahams. Matthew was on a special diet due to his genetic defect, so it was an unexpected treat. As Mom came back in the room she thought the Teddy Graham was part of his liver coming up, and understandably freaked out. I was just trying to share, I told her! To this day, it's something we laugh about.

As I got older, I realized my family life was different than my friends. We couldn't pick up and leave as easily, didn't go on a weekend get away, had one parent at home and one out with us cheering at our sporting events (particularly swim team, which are all weekend events). People were curious, but to us it was our normal. I also started to realize how much of a blessing Matthew was.

There were and continue to be many hard times for our family – but we wouldn't trade a single moment of it.

I moved to Atlanta five years ago, after college. It was a difficult decision leaving the family in Ohio, but I speak with them everyday. Matthew knows that I'm still around - he listens to me on the phone and loves when I come home for a visit!

I'm so happy I was able to find an organization like FOCUS to stay involved. I jumped in with the FAST Fins swim team as soon as I heard about it. I love helping with the swim program because it's the sport that I love so much and working with special needs children is also the most rewarding experience for me. It's a win-win!

Overall, it's hard for me to articulate what it is like growing up with a sibling that has special needs, but what I can say is I wouldn't change Matthew or our family's life with him for anything. Matthew is now 21 years old. For someone who wasn't supposed to live past the age of two, I think he's a miracle himself. We can all learn something from each special child. They bring so much joy in this world.

There are always going to be stressful times, but Matthew is the most amazing sibling I could have ever ask for, even if he wasn't the sister I had wanted. I am a better person because of him. Most importantly, he has taught me to believe in myself, stay strong and to see the world as a better place. ■

## Kool Kidz Closet

Gently Used Toys & Clothes for Children  
Village Terrace Shopping Center  
2500 Old Alabama Road in Roswell

**Open every Tues., Wed., Fri., and Sat.**

**10 am to 2 pm**

**for shopping and donations!**

## Extra Special Saturday Respite – Fall 2011

New registration option for registering your child/ children for Extra Special Saturday Respite!! To register your child, email [karen@focus-ga.org](mailto: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. Call 770-234-9111, select extension 4. "I would like to register Betty and Jack Smith for respite at Mt. Bethel Daycare on

September 17 and December 3 and be on the waiting list for October 15 and November 5. Betty is 5 years old and has cerebral palsy; Jack is 3 years old and has no extra needs. I can be reached at 770-000-0000 if you need to call me about this reservation."

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

*Register soon since locations fill up quickly!!*

### Acworth at Summit Baptist Church 4310 Moon Station Lane

*(You may register for two months,  
choose wait list for two months)*

- September 10, 10 am to 2 pm
- October 15, 10 am to 2 pm
- November 5, 10 am to 2 pm
- December 3, 10 am to 2 pm

### Alpharetta at Alpharetta Presbyterian Church 180 Academy Street

*(You may register for two months,  
choose wait list for two months)*

- September 17, 10 am to 2 pm
- October 22, 10 am to 2 pm
- November 19, 10 am to 2 pm
- December 17, 10 am to 2 pm

### Chamblee at Embry Hills United Methodist Church 3304 Henderson Mill Road

*(You may register for two months,  
choose wait list for one month)*

- September 10, 10 am to 2 pm
- October 15, 10 am to 2 pm
- November 5, 10 am to 2 pm
- No December ESS

### Cumming at Christ the King Lutheran 1125 Bettis-Tribble Gap Road

*(You may register for all dates.)*

- No September ESS
- October 1, 10 am to 2 pm
- November 5, 10 am to 2 pm
- December 3, 10 am to 2 pm

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

*(You may register for two months,  
choose wait list for two months)*

- September 17, 10 am to 2 pm
- October 15, 10 am to 2 pm
- November 5, 10 am to 2 pm
- December 3, 10 am to 2 pm

### Newnan at Cornerstone United Methodist Church 2956 Sharpsburg McCullum Road

*(You may register for all dates.)*

- September 10, 10 am to 2 pm
- No October ESS
- November 19, 10 am to 2 pm
- December 17, 10 am to 2 pm

### Evelyn

*(Continued from page 1)*

to the ER, or sleepy days, or times when she is just too grouchy to cooperate. Life seems to have a nice rhythm; Evelyn is relatively healthy and very happy, her little brother's terrible twos aren't so terrible, and we usually know what to do when a problem arises – or at least who to call. Evelyn is and will always manage to surprise us – whether it's a new skill or an unexpected hospital stay – but we do our best to rise to the occasion.

I have said many times that while I wish Evelyn didn't face the struggles she faces, I am thankful every day for having the opportunity to be her mommy. She has given me perspective, patience, and shown me that we are far stronger than we ever would have imagined. It is an interesting life, dancing between the ordinary and the extraordinary, but slowly we are learning the steps. ■

# 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.

## Corporate/Foundation

Cobb County Friendship Club  
DeKalb School Employees Foundation  
Fragile Kids for Camp Hollywood  
IBM Employee Services Center  
The James M. Cox Foundation for Camp Hollywood  
Pepsico Foundation Matching Gifts Program  
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## Individual Contributions

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Diane & Derek Tabor  
Brooke Tiner

*Thanks to the Princeton Mill Sharks in Marietta for hosting a Swim-a-Thon and raising over \$1500 for FOCUS Fast Fins!*

## Memorials

In memory of F. Lamar Clark by Nori & Joe Clark

## Honorarium

In honor of Nick Kostopoulos by Christine Kendall  
In honor of Samantha Leiter by Kelley Moore  
In honor of Stacy Georges "Your Respite" by Karen and Alan Knieter

## 2<sup>nd</sup> Annual SummerFest 2011 at Sweetwater Brewery

### Thank you to our sponsors:

Englert & Associates  
Graphics Central  
Jeyaram & Associates  
Premier Children's Therapy Center  
John & Lauren Seidl  
Tin Shed Creative  
Willy's Mexicana Grill

### And a special THANKS to our DJ:

Jason Bruorton

### In-Kind Sponsors of Under the Stars

Coca-Cola  
Heroes Alliance  
Tony Washington, DJ  
Songs for Kids Foundation



# Jake the Rooster

Every year at Under the Stars Family Camp at Camp Twin Lakes, Rutledge, FOCUS families gather for an evening of talent!! This year, the emcees included Bat Girl, Super Stephi, Spider Girl, and Captain Spaghetti (Lane Howard, her daughter Stephi, and friends Wendy and Jamie). These super heroes introduced each act, encouraged a few shy performers, and entertained when technical difficulty occurred. While each performer is special to FOCUS, one brought everyone to their feet, clapping and cheering, with a little tear in each eye.

We share with you "Jake the Rooster," starring Rocky Ghosh assisted by his parents Shivi and Prasun.

**The setting:** Rocky as Jake the Rooster is at FOCUS Under the Stars Family Camp on his adapted bike. Mom Shivi narrates from stage left and cannot be seen. Dad Prasun assists Jake with the microphone.

**Narrator:** Jake had a very special job in FOCUS To wake everyone up in the morning Jake would crow and crow as loud as he could

**Rocky:** Cock-a-doodle-do, cock-a-doodle-do!

**Narrator:** He was a very proud rooster and FOCUS families depended on him to start their day One morning as the sun was coming up

**Rocky:** Cough, cough, cough

**Narrator:** Oh no! Sounds like Jake had lost his crow!  
No one woke up in time – DISASTER!  
Cook could not make breakfast!  
Lucy could not wake her team up!  
Joy could not go for her morning walk!

What is a rooster with no crow?  
Jake ran away as fast as he could on his trike.

**Narrator:** But the next morning, Jake had an idea!!  
He rode quickly back to FOCUS Camp on his trike  
And touched the screen of his iPad to say:

**Rocky:** [played] "Cock-a-doodle-doo!"

And the crowd went wild!!

## Coming Up at FOCUS

### Under the Stars Family Weekend

**October 1 – 2 at Camp Twin Lakes Will-A-Way**

Have No Fear, FOCUS is Here!! We have a Super Hero weekend planned for our second family camp this year!! Forty more families will enjoy a weekend of family fun – and we still have a waiting list!

### Moms Day Off!!

**Saturday, October 22, 2011  
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](mailto:elizabeth@focus-ga.org)

### FAST Fins IntraSquad Swim Meet

**Saturday, October 29, 2011**

The swim team season is underway – we have seven locations and almost 70 swimmers!! Come cheer on our swimmers at the swim meet at Mountain View Aquatic Center. Call FOCUS for more details.

### MVP Boo-B-Que

**Saturday, October 29, 2011**

We invite our medically fragile children and their families to the 3<sup>rd</sup> annual FOCUS Boo-b-que at Holy Cross Catholic Church, sponsored by Knights of Columbus. Contact [elizabeth@focus-ga.org](mailto:elizabeth@focus-ga.org) for details.

### 7<sup>th</sup> Annual

**Extreme Home Modification Tour**

**Saturday, November 5, 2011**

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

### 12<sup>th</sup> Annual FOCUS on Fashion

**Sunday, November 6 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 [lucy@focus-ga.org](mailto:lucy@focus-ga.org) if you're interested!

### Teen / Young Adult Activities

Contact [annie-focus-ga.org](mailto:annie-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.

### 10<sup>th</sup> Annual FOCUS Day at Zoo Atlanta

**Saturday, October 15, 2011**

**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 October 15, rain or shine.
- Make a day of it! Go to [www.zooatlanta.org](http://www.zooatlanta.org) for zoo hours!
- October is the perfect time to visit the zoo - cool enough for the animals to appear, warm enough to be comfortable.
- Families with Zoo membership can attend for only \$5 per person (3 and over) to defray the cost of the catered meal.
- To purchase Zoo tickets, you must send by September 22 this completed form, your check, and a SELF-ADDRESSED, STAMPED #10 ENVELOPE to:  
FOCUS Zoo Day  
3825 Presidential Parkway, Suite 103  
Atlanta, GA 30340

Name of FOCUS child attending & date of birth

\_\_\_\_\_

Name(s) 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 = \$ \_\_\_\_\_

# Fun and Fund Raising at FOCUS!

Mark your calendars NOW for these FUN fund raisers!  
Info on all fund raisers at [www.focus-ga.org](http://www.focus-ga.org)



## Run the Farm for FOCUS A 5K and 10K Trail Run 1 Mile Family Walk

**Saturday, September 24, 2011**  
**Cedargate Farms**  
**848 Copeland Road Newnan**

Run or walk the trails of beautiful Cedargate Farms and support FOCUS programs! This inaugural event is sponsored by E\*TRADE Financial.

For more information, go to [www.focus-ga.org](http://www.focus-ga.org) or email [runthefarm@focus-ga.org](mailto:runthefarm@focus-ga.org)

## Spin for Kids Saturday & Sunday October 22 & 23, 2011

Join Camp Twin Lakes and its Partners for a fundraising bike ride! Ride for or donate to Team FOCUS and support FOCUS programs Under the Stars and Camp Infinity! Go to [www.focus-ga.org](http://www.focus-ga.org) and select Spin for Kids. 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 2011 donated \$1 ... Team FOCUS would raise an extra \$1,000!!!! Contact [lucy@focus-ga.org](mailto:lucy@focus-ga.org) for details!!



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