



FOCUS

**Extraordinary Families
★ & Kool Kidz ★**

FOCUS

Volume 28, Number 3

May/June 2011

One Step Forward

By Jeff Key

I decided about two weeks ago I was going to take last Friday as a vacation day. The first week of the NCAA Tournament is one of my favorite times of year, kind of a gateway to Spring. Plus, the forecast was for 80 degrees without a cloud in the sky. I couldn't think of a better time to spend a vacation day.

Hillary and I met for a much-needed lunch together after her Friday meeting at the church, then we went to Bennett's school to pick him up. I always love to pick him up from school, and to see the excitement in his face when he sees me in the parking lot – "Da-deeeeeeeeeee! What are you doing here?!?" It never fails to make my day, if not my week.

After school we headed to chiropractors' appointments for Hillary and Bennett. I took Bennett out of our van and "walked" him into the office the way we typically do – me holding his shoulders with my feet in step with his. I do a lot of the work for him, but it still gets his legs and upper body some exercise.

We were called back to the examination room to wait for the doctor. I sat Bennett in a chair next to mine while Hillary stood. After a few seconds I noticed Bennett scooting forward in his chair and putting his toes on the ground. Before I could react he had both feet on the floor and the back of his thighs resting against the chair, and then he was leaning forward and standing on his own.



He could only hold it for a couple of seconds before he rested back on the chair, but it was pretty obvious his intention.

"Do you want to take a few steps?" Hillary said, reaching out her hands. Bennett can walk a few steps with someone just holding his hands, but it typically happens after therapy when his legs are stimulated. He hadn't had therapy in over a week because of a bout with bronchitis.

"I want to do it myself," he replied.

(Continued on page 6)

Hello, World!

By Heather Miller

When was the last time you woke up with a smile on your face? The last time you greeted the morning with "Hello, World!?" It's a common misconception that heroes have to be powerful and accomplished, strong and formidable. Oftentimes, the person who inspires me the most is my younger cousin, Hannah. She has overcome more struggles in her life than anyone I know and yet she still puts most to shame with her ability to wear a smile every second of the day, even at five in the morning.



I want to go to college to acquire the skills necessary to make a positive difference in my community. Specifically, I wish to gain with my degree the ability to change the lives of children like

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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.



From the Editor

by Lucy Cusick

As always, I was running late ... I dashed into Olde Hickory House in Tucker and quickly found a table so parents wouldn't know I had barely made it there in time! Coffee came and I actually had a minute to realize that I've been going to that Olde Hickory House Share Group once a month (except in the summer) for the past 23 years. Now, that's a lot of biscuits and ginormous pancakes!!

Every month, the participants change a little, the conversation shifts a little, but everyone enjoys the discussion at lot. Often, the parents of younger children have a question, and we parents of older children (note that I DIDN'T say 'we older parents') share our experiences. At today's meeting, we totaled 7 parents, with children ranging in age from 8 to 25. We all had something in common: our kids. We discussed dental appointments, social stories, and siblings; we laughed, and, for once, no one cried.

Share Groups take a break in the summer – we all work hard to lose those biscuits and pancakes! I'll miss 'my' moms (and one dad) because we've become friends; we can say things that would appall others; we can laugh at things that really aren't that funny. It's nice to be a part of a group where everyone understands, no one judges, and to see that others survive.

Yep. We're all in it together. ■

Birthday Club!

March and April were big months for birthday donations to FOCUS!! Mitchell Rowe and Katherine Lucier turned 13 in March, and TJ Anastasio turned 3 in April. Each family requested birthday donations to be made to FOCUS, which we accepted with honor.

So, a big ICE CREAM & CAKE to Mitchell, Katherine, and TJ. We celebrate each of you!!

A complete list of contributions can be found on page 6.



TJ Anastasio



Mitchell Rowe



Katherine Lucier

A Special Needs Family

By Jason Tuttle

I initially wrote this story two years ago to share with my friends and the world, if the world wanted to read it. I've updated it and hope that it helps another family; I am happy to talk to others about my kids or yours! My email is dadofspecialtwo@gmail.com.



I am a devoted husband and a loving father. I can not think of anything that makes me happier or brings greater joy. I have two children ... a boy and a girl. My son is 4 years old and my daughter is 2 years old. Both are the light of my life, and I would do anything for them. Both of my children have special needs and have taught me so much. This is our family story.

In 2005, my wife and I celebrated our two year anniversary. We both wanted children and decided the time was right. Jennifer got pregnant just four months later. We were thrilled ... and maybe a little scared. Everything went wonderfully the first 20 weeks.

At the 20-week obstetrician appointment, we could find out the baby's sex. Jennifer wanted to be surprised, but I am a planner and wanted to know!! During the ultrasound, we were amazed at the pictures of our baby; we playfully went back and forth about whether to find out the baby's sex. While we bantered, the tech continued to look and then said that she needed to know because there was an 'issue.' That decided it, and we found out that we were having a boy. The 'issue' was that his left kidney had a blockage or obstruction. The ob-gyn referred us to a perinatologist or high risk pregnancy doctor.

The perinatologist followed Jennifer & Zach carefully and found at week 28 that Zach only had one kidney, and it was obstructed. The doctor also saw signs of neurological issues, finally settling on 'areas of missing white matter' which would eventually be the reason for his developmental delays. Zach also had a thinned corpus colosum and cystic lesions on his cerebellum. We added a pediatric neurosurgeon and neurologist to the list of doctors.

The day Zachary arrived, we rushed to Southern Regional Hospital from Peachtree City during rush hour (good times!) and were immediately admitted. Jennifer's contractions were slowed because the doctor wanted to deliver Zachary by Caesarean section. Zach was 9 pounds, 14-ounces; I had a quick peek at him before he

was whisked to the Neonatal Intensive Care Unit (NICU). The doctor on call diagnosed Zach with a rare condition called Eagle-Barrett Syndrome, also known as 'Prune Belly.' This condition happens in 1 in 40,000 births and has these characteristics: no abdominal muscles, an oddly shaped bladder that will never fully drain, a diminished lung capacity, the inability to 'poop,' undescended testicles which have to be surgically lowered, and the possibility of other kidney issues. The doctors did not know why he had Eagle-Barrett. Zach was transported to Children's Healthcare of Atlanta at Scottish Rite the next morning where he spent the next 10 days in the NICU. We now had eight '-ologists,' almost one per pound!

When Zach was two, we decided to have another child. Many in our family disagreed with this decision, and, while we understood their concerns, we still wanted another baby. When Jennifer got pregnant, we immediately started seeing the perinatologist as a precaution. At 20 weeks, we discovered the baby was a girl. Then came the infamous 28 week appointment.

My daughter had fluid building up around her right lung, only the right lung. The doctors were puzzled, but wanted to remove the fluid so that lung growth was not stunted. They wanted to remove the fluid by amniocentesis, drawing the fluid out with a long needle. I was so against this procedure because of the risk of premature birth. The doctors, however, felt that the risk was worth being able to test the fluid and to help the lungs develop. The amnio was scheduled. At the pre-amnio ultrasound, however, the most miraculous thing happened. The fluid was gone! The doctors could not explain it. Jennifer then went on to have a healthy 10 pound, 3 ounce baby girl. We were known as "the couple with the BIG baby." We had no reason to believe Samantha had any issues.

When Samantha was 8 months old, Zach's occupational therapist came to treat him and an intern was along to observe. The intern asked if she could assess Samantha, just to give her practice. We agreed, and, to our shock, the test scored Samantha as delayed. We didn't believe the test, the OT, or the intern! However, our pediatrician believed them and referred Samantha to a neurologist.

(Continued on page 4)

Coming Up at FOCUS

Always check www.focus-ga.org for details!

May 1: FOCUS Day at Six Flags Over Georgia

Over 900 tickets were pre-sold. Sorry, no more tickets available.

May 7 at 1 pm FAST FINS Intramural Meet Mountain View Aquatics Center

Come cheer on our swimmers and check out our FAST FINS program!

May 15 FOCUS MVPs Take to the Theater! Red Door Playhouse in Roswell

FOCUS MVPs are children who are medically fragile and enjoy smaller events. Email Elizabeth@focus-ga.org for MVP info and ticket information.

June 16 FOCUS Family Night at the Gwinnett Braves!

See enclosed flyer for details.

July 10 FOCUS Family Day at Imagine It! The Children's Museum of Atlanta

See enclosed flyer for details.

FOCUS Fund Raisers

Support the programs at FOCUS by attending FOCUS fund raisers ... and bring friends!! All programs at FOCUS are offered at a reduced (or no) cost to families!

August 6 SummerFest at SweetWater Brewery

Celebrate summer with FOCUS! Enjoy brewery tours & tastings, cornhole tournament, and music!
Contact annie@focus-ga.org for more details.

September 24 2nd Annual Run the Farm for FOCUS A 10K, 5K, and 1 Mile Family Walk Cedargate Farms in Newnan

Hosted by Phil & Ann Beegle

Run or walk the trails of beautiful Cedargate Farms and support FOCUS programs!

Sponsors to date include E*TRADE Financial and Chick-fil-A.
Contact lucy@focus-ga.org for sponsor or Run information.

- A Special Needs Family
- (Continued from page 3)

- We took her to Zach's and he ordered a
- CT scan. The scan showed Samantha had
- similar neurological issues as Zach. A
- few months later, Samantha had an MRI
- which showed the same 'areas of thinned
- white matter,' along with a thinned corpus
- collosum.

- Zachary is now 4 and has had multiple
- surgeries and hospitalizations. He is
- high risk for urinary tract and respiratory
- infections. He has seizures and swallowing
- issues. He sees a neurologist, urologist,
- and neurosurgeon; he has physical,
- occupational, speech, hippo- and music
- therapies. He wears ankle foot orthotics
- (AFOs), uses a walker and a wheelchair.
- He is just finishing his second year at the
- Joseph Sams School, an awesome private
- school for children with special needs in
- Fayetteville, GA. He is starting to feed
- himself, make choices, and raise his hand.
- He is a very personable, lovable, little guy
- who is the biggest fighter when it comes to
- overcoming his struggles.

- Samantha, now 2, sees a neurologist
- and receives physical, occupational,
- speech, hippo- and music therapies
- regularly. She says 'momma' and is working
- on 'dada' – music to our ears! She wears
- an orthotic helmet and an eye patch. She
- started having seizures and is now on
- seizure medicine. She wears AFOs, does
- not walk unassisted and will need adapted
- equipment. She also goes to the Joseph
- Sams School and is making such good
- progress there. She is also a very happy,
- determined, and stubborn little girl who
- wants to make her own decisions ... sounds
- like a girl, huh?

- We are crazy busy: driving the kids to
- school, therapies, and 'ologists,' along with
- working and the rest of life. We dread flu
- season; the last two years, Zach has been
- hospitalized for respiratory infections.
- We continue seeing a geneticist to try to
- find answers. We aren't a 'sob' story or a
- 'charity' case; I want to teach our children
- independence, that they can do anything
- they put their minds to. Our kids have
- taught us many life lessons in their short
- lives. They have made us better parents and
- better people. ■



FOCUS and Summer Time!!

Summer Share Groups

FOCUS appreciates the parent volunteers who facilitate support groups throughout the school year. We take a break from Share Groups in the summer since families are on vacation (hopefully!) and children are out of school. However, the FOCUS staff is on-hand to share – give us a call if you want to talk!

Extra Special Saturday

Extra Special Saturday respite takes a break in June, July, & August while kids are having fun at Camp Hollywood and Camp Team. Please take a moment to thank our wonderful caregivers and volunteers at each respite in May. Because of them, FOCUS continues to offer fun for the children – and a break for their parents – in 6 to 8 locations a month!!

Camp TEAM & Camp Hollywood

At the time of printing, some locations of Camp Hollywood still have openings and Camp TEAM is almost full. Complete the applications quickly and MAIL (no faxes!) to FOCUS.

Under the Stars Family Camps

August 12 – 14 at

Camp Twin Lakes, Rutledge

October 1 – 2 at

Camp Twin Lakes, Will-A-Way

Super Heroes are coming to Under the Stars Family Camps! Applications went out by email on April 14. We were overwhelmed with the number of applications that were returned within 48 hours!! Stay tuned for more information!

Hello, World

(Continued from page 1)

Hannah. At birth, Hannah was diagnosed with a disorder that impacted both her physical and mental development. Hannah became mobile at a much slower rate than others her age; she began with a walker and leg braces and after years of physical therapy was able to finally walk independently. Today, Hannah runs, swims, and dances. Since observing Hannah's transformation and being exposed to numerous others' through my extensive participation with FOCUS, a local organization that offers support to families with disabled children, I have known physical therapy as my calling. It has become clear to me that the compassion, determination and patience I have been blessed with will be best utilized aiding similar children in their quest to gain more independence.

I remember the first time that I was invited to one of Hannah's physical therapy sessions: her mother and I were seated behind a one-way window, listening with headphones to the dialogue on the other side. Struck by the array of brightly colored balls, slides and cushions, I experienced at the young age of eight the first introduction to my destined career. I'll never forget Hannah's benevolent doctor or the cheerful patients I met that day. Another group of people I know I'll never forget are the children at FOCUS - their lightheartedness, bravery and incredible senses of humor are all reasons why I want to turn helping them into my career.

Over the ten years that I have been so fond of physical therapy as my profession, I admit that I have had my doubts. At times, I have lost faith that I possess the perseverance required of a physical therapy student. What helped to convince me otherwise was the beginning of my junior year of high school. After adjusting the rigor of my classes, I was finally in a position to allow myself to reach my full potential as a student and realize my true capabilities. The beginning of junior year also roused my interest in college and shortly I discovered my current college of choice. From this newfound passion for my academics emerged the confidence that had been lost and I again made the decision to pursue physical therapy - without hesitation. With the opportunity to refine and expand my knowledge and experience, I fully intend to be a positive, active force in the community of disabled children. With my college degree, I intend to devote myself entirely to ensuring that these children wake up every morning with a smile on their face. ■

Heather is a senior in high school and has been accepted to North Georgia College & State University. She plans to be a physical therapist. This essay is one of her college entrance essays.

Stone Mountain Chorus Spring Concert "Love Is In the Air"

Saturday, June 4 at 3 pm

Mountain Park United Methodist

1405 Rockbridge Road, Stone Mountain

To purchase tickets at a group rate of \$10 each, call or email lucy@focus-ga.org. FOCUS receives a portion of the ticket sales.

The concerts are always beautiful and fun!!

Join us for a wonderful afternoon!

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

Alpharetta First UMC Womens
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Huddleston Elementary School
IBM Employee Services Center
Kiwanis Club of Suwanee
MissionFish Payables

Individual Contributions & Newsletter Renewals

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Memorials

In memory of Brandon Scott by
Sheryl Chapman
In memory of Dr. Annette
Bernard's father by Doreen
& Burt Wittenberg
In memory of Amy Bristow by
the SID and Haven
Classrooms at Simpson
Middle School

Honorarium

In honor of Amari Smith by
Nita Stephens
In honor of Jane Wells' Birthday
by Nancy Chewning
In honor of Angie Weiland by
Rob Storm
In honor of Bret Weiland by
Hannah Davis
In honor of Victoria Brown
& her family by Mr. & Mrs.
Michael Miller

In honor of Tristan "T.J." Anastasio's
3rd Birthday by
Wendy Artman
John Chamblee
Duane Dauphin
Phil & Mary Davis
Richard & Rochelle Elmore
Amanda Hegwood
Monica & Kevin Otto
Amy Sbarra
Jennifer Smither
Tammy Stancel
Susan Tanner

In honor of Katherine Lucier's 13th
Birthday by
JoAnne & Doyle Bailey
Scott Corey
Susan Crawford
Alice & Charles Dennard
East Cobb Pediatrics
Brenda Estes
Cynthia & John Ethridge
Lisa & Matthew Frooman
Joan & Art Gifford
John Glover
Susan Groszkiewicz
Renee & Alan Hildebrand
Dot & George Hillegass
Ellen & Danile Hillegass
Kathleen & Harry Hotchkiss
Karen Hughes
Terry & Dick Ingwersen
Edwina & Tom Johnson
Anna Mettler
Diana & Dan Pilson
Larry Rusher
Marcia & John Shurley
Cynthia & Borden Taylor
Martha Willis

In honor of Mitchell Rowe's 13th
Birthday,
by Friends & Family

FOCUS Teen & Young Adult Group Splits!

The FOCUS Teen & Young Adult Group is so popular that we have divided into two groups: FOCUS Teen Group for ages 13 – 17 and FOCUS Young Adult Group for ages 18 – 29. For both groups, the ratio is 1:8. Participants must stay with the group, have no disruptive behaviors, toilet independently or schedule toilet visits around group time, and not require on-site medical care.

Email annie@focus-ga.org for information on upcoming events.

One Step Forward

(Continued from page 1)

Hillary and I shot a quick look at each other, and then she said, "OK, do it."

He lifted off the chair with balance that you rarely see him exhibit. After standing for a second, his left leg bent at the knee ever so slightly to give him the weight shift he needed to move his right foot. His right foot lifted and in a flash moved about two inches forward.

At eleven years, one month and nineteen days, we witnessed Bennett's first step.

Bennett has travelled many miles and climbed many mountains to get to this point, and there are no doubt many miles and many mountains to go.

But that one step covered a heck of a lot of miles in itself. ■

Jeff and Hillary Key are proud parents of Bennett, 11, and keep friends and family updated on his progress at their blog A View from Roswell (www.viewfromroswell.com).

FOCUS at the



2500 Buford Drive • Lawrenceville, GA 30043
Thursday, June 16th • 7:05pm

TICKETS:

- ★ Tickets must be purchased from FOCUS in advance, using the order form below.
- ★ Tickets are \$6.00 per person. Children 2 & under are free, but will not have a seat.
- ★ This special offer is for existing FOCUS families only. We are offering tickets only to FOCUS children with disabilities, their parents, and their siblings under age 21 living in the same home.
- ★ Please indicate on the registration form below how many wheelchair seats your family will need.
- ★ These tickets can only be used on Thursday, June 16th.
- ★ Deadline for registration and all money due by Wednesday, June 1.
- ★ Your family will receive tickets in the mail before the event. ***You must include a self-addressed, stamped envelope to receive your tickets.***

PARKING:

- ★ Coolray Field has very convenient parking adjacent to the stadium.
- ★ Parking is \$5.00 per car.
- ★ If you need a handicapped parking space, please make sure to indicate on the registration form.

FOOD:

- ★ This event will not include any food and outside food is not permitted in the park. However, there is plenty of 'baseball food' available at the park to purchase!

For more detailed information about the Gwinnett Braves and Coolray Field, including directions, please visit www.GwinnettBraves.com

FOCUS at the Gwinnett Braves Registration Form:

Names of all ADULTS attending:

Names AND birthdates of all children attending:

Street Address: _____

City: _____ Zip: _____ County: _____

Phone Number: _____ Email: _____

Number of Tickets _____ x \$6 = _____ Number of wheelchair seats needed: _____

Does your family need a handicapped parking space? _____

Enclosed is my check for \$ _____ *Please make separate checks for each FOCUS event.*

Please return FORM, PAYMENT, and SELF-ADDRESSED, STAMPED ENVELOPE by June 1 to:
3825 Presidential Parkway, Suite 103 Atlanta, GA 30340

AJ

By Patricia Jones



Anthony "AJ" Jones is a 13-year old College Park resident, and a student at the Joseph Sams School in Fayetteville, GA. He is the second youngest child of six. When he was 6 months old, AJ was diagnosed with cerebral palsy. Doctors told us early on that his mental and physical development would be impaired, and that he would never walk,

talk or do 'normal' functions of a typical child his age.

On March 28, 2011, AJ served as a page, alongside his sister Brittney, for State Senator Donzella James (35th District). With the assistance of Sen. James' assistant, AJ was able to deliver information to various Georgia state senators. He stood on the state senate floor with all the other pages and actively participated in the process during the 2011 legislative session.

Although being a page is one of AJ's most noted accomplishments, he is also an active participant in the Special Olympics and the Boy Scouts; he is also a Jr. Knight at Most Blessed Sacrament Catholic Church .

A lover of all music, AJ plans to join the youth choir at his church where his vocal talents can be heard. AJ is a young man who is loved and adored by his family and friends.



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!

FOCUS is a nonprofit organization that provides emotional, informational and physical support to families of children with disabilities or ongoing medical conditions.

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