



Comfort. Hope. Fun.

No Longer an Island or ... Finally Exploring Holland

by Angela Langenderfer

My special needs journey began eleven years ago. We look back at that time in our life and feel like the sun was shining down on us: We were happily married, we had a beautiful daughter, our business was thriving and we were expecting our second child. Life couldn't get much better. We never found out the gender of our children before they were born because we liked to be surprised. When the birth team said, "It's a boy!" was a truly joyous moment. Andy was born. He had trouble breathing, but our daughter did as well, so we weren't worried. When he stayed in the NICU that night, I was troubled. The next day we were told he wasn't sick, but he wasn't well. On day three, as they were preparing to release him, the doctor pulled, prodded and looked at Andy over and over with this perplexed and concerned look on her face. She finally told us that they wanted to test him for Down syndrome. In that moment the world shifted on its axis from my perspective. This couldn't be happening to US.

I never really dreamed I was in danger of having a child with special needs. I had no indicators. I was only 32 years old. In college I volunteered at a children's institution for special needs, and I had to quit because it broke my heart. So I felt I could never handle a special needs child ... and here I was facing the unknown future of life in this "special" group.

I didn't want to be a part of this world. A friend sent me the poem "Welcome to Holland" by Emily Perl Kingsley to encourage me. It didn't fulfill its purpose. I DID NOT want to go to Holland. I remember lying in bed crying one night, thinking, "Will the pain ever stop?" I grieved for the loss of the future. We immediately decided to not have more

children even though we always planned to have three children.

We managed with support from friends and family. We had a wonderful Babies Can't Wait Coordinator who helped us find therapists and navigate the system. We heard about FOCUS early. We took advantage of the social events and the swim team, but we didn't get too involved. I still would find myself saying in my head, "This special needs world is not what I want to be a part of." We treated Andy as we did our other children, as much as we could. We didn't get involved with other special needs groups.

Slowly, however, life moved forward. We healed enough to have another child. The moments of pain are now interspersed with overriding joy. We love Andy. He is full of personality. We see how he impacts people in a way he probably never would if he was "normal." It's like travelling with a celebrity; everybody knows him!! And to answer my own question, "Yes. The pain fades." Everyone who meets Andy feels blessed by knowing him.

The FOCUS Fast Fins Swim Team has been a wonderful program for us. We met another parent there who told us about the Special Olympics swim program. We went to our first meet in May, and it was a fabulous experience that really impacted my perspective. I wish I had known about Special Olympics sooner. I started talking to other parents who knew programs I wasn't aware of. Then I thought about the parents I had run into through



(Continued on page 5)



From the Editor

by Lucy Cusick

Several of our articles this month include a lot about family – extended family, friends who are family, and immediate family. This year, in particular, I've heard about several FOCUS siblings – the brothers and sisters of our kiddos with special needs – leaving home to go to college. And since I've 'been there, done that,' I know what a celebration it is – how difficult it is.

We joke at home that many newcomers to FOCUS do not know about Jessica, the younger sister to Josh. Jessica is 27, graduated in 2012 from UGA, worked a few years, and is now at Emory School of Theology, pursuing a Master of Divinity degree and working part-time. She lives on her own and cannot volunteer as often as she did as a teen. Now when Jessica volunteers at FOCUS and we introduce her to someone new to FOCUS, their reaction is often, "You have a daughter?" Josh and I burst out laughing!

As a child, Jessica didn't see a lot of difference in her brother – in fact, when asked by a little girl at the library, "What's wrong with him?" Jessica replied, "Nothing, he just can't walk. I like your nail polish!" In elementary school, she called him "Encyclopedia Josh" because he could spell and define any word she threw his way. She appreciated the 'perks' of disability – going to the front of the line, getting great parking spaces, and having a lift van to use when moving to college! And now, while she's not Josh's best friend, she often is his best cheerleader. She notices when he needs more time to process and gives him time to think. She asks him about the latest roller coaster disaster or Star Wars movie, his favorite topics. At Christmas, birthdays, and after she's traveled (after all SHE has a life!), she gives the best gifts or souvenir, really thinking of him and what he likes. AND she gives him grief when he gets snarky!

So, when Jessica moved to college, we were all sad. Our 'normal' was leaving us – and with that normal went PTA, high school activities, church youth group and all the friends that went with them. Those activities and friends were a major part of our 'local' social life. I still had many wonderful FOCUS friends, but they lived all over Atlanta – Jessica's activities were the ones in the neighborhood. And I personally missed her terribly – shopping, watching TV, pretending to go to the grocery store and instead slipping away to a movie, and just hanging out. My life had a huge hole, and after leaving her at college the first year, I came home, laid in her bed, and cried. After 30 minutes, I decided I had to get busy to distract myself. So I moved my blow dryer and make-up into her bathroom and felt much better!!

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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

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Jessica 'rounded' our family out – she challenged us throughout her life. She tended to question 'no' and could argue quite effectively by age 2. She showed us what 'normal' means, and it was not always so different from 'special.' She taught me what a 'real problem' was at age 5 (If it doesn't matter in 2 weeks, mommy, it's not a real problem). Her departure for college in 2012 was really her departure from her home. She visits for holidays and dinner occasionally, she still has her 'own' bedroom, but a part of 'normal' is leaving home. While many of our young adults might not leave home to live on their own (a new 'normal' we learned), they can have their own adventures and lives. Regardless, our siblings take with them, and spread to others, that people with special needs have gifts and talents ... and brothers and sisters. ■

Kendall's Testimony

By Keena McCurn

My husband and I are the proud parents of Kendall who is now 5 years old. Kendall has three older siblings who live in Michigan: Jasmine (29), Lacy (17), and Landen (9). Kendall, as the 'baby,' is very much loved and just a little bit spoiled!

Beginning the second trimester of my pregnancy, the doctor diagnosed me with border-line preeclampsia. This meant weekly doctor visits, lots of blood draws, and bed rest for the last month of my pregnancy. My labor was complicated and eventually I had an emergency cesarean section. The moment the doctors removed Kendall, I knew something was wrong. The look on everyone's face, and the silence said it all. I heard no crying from my newborn baby girl and the medical team was quiet. Lacy's eyes were full of worry and sadness. Kendall was not breathing or responding. The NICU rescue response unit rushed in. They finally restored breathing using the Ambu bag. We saw and touched Kendall before the doctors rushed us to separate recovery units. We knew that she was fighting with every ounce of her being - Kendall has been tough as nails since day one.

The pieces began to fall into place. During labor, Kendall suffered a stroke. We later learned that I suffered an arterial hemorrhage, and the entire length of the umbilical cord was clotted. Kendall was diagnosed with HIE (Hypoxic Ischemic Encephalopathy), which is a really long way of saying that she had brain damage due to lack of oxygen.

This first diagnosis was just the beginning. She now has an impressive list of additional diagnoses: cerebral palsy, global developmental delay, seizures, asthma, reactive airway disease, respiratory failure, club feet, auditory neuropathy, cortical visual impairment, and optic nerve atrophy. She has reflux and tends to aspirate. Kendall has a G-tube, Nissen fundoplication, a tracheotomy, and is ventilator dependent.

Over the first couple of years of Kendall's life we spent many days and nights in Children's Healthcare of Atlanta at Scottish Rite. She had approximately ten bouts of pneumonia / respiratory failure, countless ambulance rides, and one three-month hospitalization that resulted in a trach. Since September 2012, however, she has only been hospitalized three times for planned procedures and surgeries: vent wean, bilateral club feet surgery

and bilateral hip surgery. All of this helped us gain three points of clarity:

1. Tracheotomy. Translation: better quality of life and direct access to her airway for better secretion management. This likely keeps her out of the hospital.
2. Auditory Neuropathy. Translation: legally deaf; the inner ear functions normally but the damage to the nerve cells keeps her from hearing.
3. Cortical Visual Impairment. Translation: legally blind; again the damage to the brain cells keeps her from seeing clearly / properly.



Kendall struggled with hearing and sight limitations ... we just did not know to what extent. It was clear to us (and her doctors) that she did not pass the hearing screenings that were done in the hospital and at doctor visits. Loud noises such as the vacuum cleaner did not seem to startle or faze her, but loud, crying classmates at the daycare did upset her, and she clearly responded to and acknowledged our voices! We also knew that she loved music and singing. Talk about confusion and frustration on our end as parents!! How do I tell the audiologist, ENT and others that we know she hears some things? Now, proving it is another ballgame!

The vision challenges presented similar issues. We knew Kendall recognized us and liked lights, story time and shiny things. We also knew she didn't consistently track objects or blink frequently. So once again the unknown left us puzzled, confused and frustrated.

As much time as we spend in medical settings, it should not surprise anyone that we have formed strong, trusting relationships with a great team of doctors, therapists, and nurses. Our family also grew a great support system of family and friends. To any family with a special needs child these are key people to have in your village.

Because of Kendall's hearing and vision diagnoses, we found support groups that brightened our outlook on Kendall's potential, changed our interactions with Kendall and helped expand our daughter's world beyond limits. Enter Georgia Parent Infant Network for Educational Services (GA PINES) and Georgia Sensory Assistance Project (GSAP). These organizations helped us understand her vision and hearing challenges. We were FINALLY able to better wrap our heads around the what,

(Continued on page 5)

Camp Hollywood ... Where Everyone's a Star!

By Karyn Campagnone, FOCUS Parent & Camp Hollywood Coordinator

Zachary peeked out from behind his mother's back as they stood at the registration desk. A volunteer knelt, trying to coax him out to join his camp group. "Come on, Zack," his mom pleaded, "Let's go see the other kids." Zachary looked apprehensive and whined, "I want to go home and hunt letters with you!"

Zachary is just one of the 300 campers who attend FOCUS *Camp Hollywood* during the summer. At a typical camp, these campers would probably not make it past the application requirements; if they did, they might be sent home the first day. Medical needs and developmental disabilities are hard to manage in an ordinary day camp setting, but *Camp Hollywood* is not your ordinary day camp. At *Camp Hollywood*, everyone is a star!

Billy is impatient as he waits for his dad to go over instructions with the camp nurse. He has been a camper at *Camp Hollywood* for over 10 years. During that time, he has grown into a handsome young man, gained independence, and formed bonds with camp friends he may only see at FOCUS activities. Seeing his friend Mary step off the elevator, Billy says a quick goodbye to his dad and rolls off to begin a new year at *Camp Hollywood*.

FOCUS camps accommodate a variety of disabilities, such as cerebral palsy, Down syndrome, and autism. Siblings are welcome to attend camp where they will meet other siblings, or they may just enjoy being at camp with their sibling with disabilities. *Camp Hollywood* might be the only camp that both kids can attend TOGETHER. Joey has cerebral palsy and uses a walker; he has been to *Camp Hollywood* for 4 years. Addie is Joey's little sister and is FINALLY five years old. This year, she marched into camp on Monday and announced that she could "finally come to Hollywood with brother!" These siblings often return as teens and young adults to volunteer!

While every day at *Camp Hollywood* is based on a movie, campers don't waste time watching the movie at camp! Rather, they spend their time rotating through a variety of activities based on that movie. This year, "Star Wars" day ended the week. Campers made light sabers in art and "swamp pudding" in cooking. They explored the layers of earth in science and bowled down storm troopers in recreation. The music therapist filled the building with tunes from the movie and added space-walking movements. Some campers even came to camp dressed as their favorite "Star Wars" character!



FOCUS held the first *Camp Hollywood* 23 years ago. It was a single week at a single location. Since then, *Camp Hollywood* has slowly expanded. Currently, FOCUS runs five weeks of two concurrent week-long camps in donated space at different churches around metro Atlanta. In 2015, FOCUS dedicated one location in Marietta to teen and young adult campers, which is hugely popular.

When asked why, a teen camper who has attended *Camp Hollywood* since she was 7 explained, "I just like not having those little kids around!" FOCUS staff members have become experts at packing and unpacking bins and equipment to ensure each location has all the supplies needed for a fun week.

FOCUS taps into another group of very special people: special educators, music therapists, and nurses, all trained to care for the multiple medical, physical, and behavioral special needs of our campers, are hired each summer as counselors. A few have been with FOCUS since the very first year of *Camp Hollywood*! Counselors modify the activities to accommodate the ability of each child, and every child is encouraged to participate. Assisting counselors are hundreds of teen and youth volunteers! The campers LOVE the attention from these energetic young people – and we hear from many that *Camp Hollywood* is the highlight of their summer!

Camp Hollywood costs about \$350 per child, which is out of the reach of most families strapped with special care costs. Grants, fund raisers, and donations lower the fee to \$150, which is less than a typical kiddo would pay to go to church camp. Further scholarships are available based on the financial needs of the family. Many corporations and foundations have supported *Camp Hollywood* for many years; we are especially grateful for them since donors often want to fund new programs. At 23, *Camp Hollywood* doesn't fit the 'new' bill, but it fits the 'fun' bill! Each year almost 300 campers attend a week of *Camp Hollywood* – parents enjoy the break, children enjoy the fun!

On Friday, Zachary is pulling his mother from the elevator at *Camp Hollywood*. He runs up to his waiting counselor and yells, "Today, we are looking for the letter E!" He spends the first five minutes of every new activity looking for the letter E in the classroom and then settles down to do the activity. *Camp Hollywood: Where Everyone's A Star.* ■

My FOCUS Family

By Sara Xiang

FOCUS. FOCUS is the only place where I have ever volunteered – and it's the BEST place I've ever volunteered!! Right when you walk into the doors of any FOCUS event, you are welcomed with a bright happy smile. The amazing staff and volunteers are some of the best people that I know and I now consider them close friends. The kids are the sweetest kids, and I care about them so much.



I discovered this wonderful organization after moving here from Arkansas about 3 years ago. I was starting second semester in 7th grade and was invited to join the Junior Beta Club at my school. I received an email from the head teacher with a list of organizations that needed volunteers. I saw FOCUS on the list and immediately filled the volunteer application out. Little did I know it would be the best decision that I have ever made in my life.

Ever since that email I have helped with the kids at Extra Special Saturday, Camp TEAM, and Camp Hollywood, and many more events. About a year ago, FOCUS emailed the need for a photographer at day camp, so I emailed back that I'd love to try! I am not a professional, but I can take decent photos, I love photography, and have a decent camera. I started taking photos at Camp TEAM and Camp Hollywood last year, then was asked to take photos for the fashion show, Daddy Daughter Dance, MVP events and Snacks with Santa!

Today, I am 15 years old and about to start my sophomore year in high school. I plan on being involved in more FOCUS events – whether as a photographer or helping with the kids. I am so excited! This past summer, I volunteered at five camps and the MVP Luau. I took photos, uploaded them to a laptop and gave them to FOCUS staff. FOCUS was the highlight of my summer – I didn't need a vacation because I had FOCUS

The kids at FOCUS are the best kids ever! They touch my heart in ways that you cannot imagine. They are funny, caring, and loved by the most amazing families who are so sweet and have so much love in them. When a family picks up their child from respite or camp, you can truly see the abundant amount of love and care. The kids can barely contain themselves when their parents come for the closing performance at each week of camp – I admit that I was emotional during the performances! During the school year I think about the kids from respite and cry- not out of sadness, but out of joy!! Each month, I see progress throughout the year – walking tall and proud in their walker, rolling their own wheelchair, talking more. I cry because I think of them as my extended family. Family. That's the word I use to describe FOCUS. It's my family and I am so happy, humbled and honored that FOCUS allowed me to be a part of their big family! I look forward to making more memories! ■

No Longer an Island

(Continued from page 1)

the years who don't know about FOCUS. I have been concerned about the upcoming transition to middle school and wanted to talk to other parents.

The light bulb finally went on for me, "I need to be connected. I need to engage. And I want to help spread the word." I decided that I could no longer be an island. I am happy to report that I am getting involved and connected. I help increase communication to special needs families at PTSA and am a parent coordinator for the Suwanee FOCUS Share Group. My goal is to find out what is available to help other parents connect. If you are a new parent, overwhelmed by this new world, and want to crawl into a hole, I want to say, "I understand. I've been there." It hurts to face the reality that your dreams for your child might not come true. But now I can read the poem "Welcome to Holland," and I agree that the journey can be enjoyable. In fact, we actually WENT to Holland this year, and it truly is lovely. I encourage you to get connected. Take advantage of share groups, respites and the wealth of advice and encouragement from others parents who have had similar experiences. It will make this journey easier and more rewarding for you and your child. ■

Kendall's Testimony

(Continued from page 3)

why and how of Kendall's hearing and vision. Having someone show us how to best teach, relate to, play with, and develop Kendall was a blessing!

We also found FOCUS. FOCUS is not just a face-less organization, it is family. Being able to spend time with other families that understand our "normal" is paramount. Meeting other families and forming lasting bonds is priceless for us. FOCUS has provided so many formats to gain knowledge and information, to relax and hang out with other moms, and to offer great social activities for Kendall to attend and have fun. Family always makes sure that you have what you need – and on this special needs journey, FOCUS is our Family. Looking back five years later, it still amazes me that Kendall finds the strength and energy to smile and laugh so much. But her smiles and laughs give us strength and hope. ■

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Thanks to Greg Genske for choosing FOCUS for a service project! He collected supplies for Camp Hollywood – pool noodles (made into light sabers at camp) picture frames (painted and decorated by campers for their annual camp photo), general camp supplies (always needed), and over \$400 in donations!

Greg also connected FOCUS with Rebecca Litwin who donated 300 pillowcases for art at Camp Hollywood! Each camper painted a pillowcase – dreams of fun at camp!



Thanks to the Handy Helpers from Mt. Bethel, our Teen & Young Adult Camp Hollywood made memory boxes – such a cool project with lots of ... handy help!

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Looking Back at the Fun!



Six Flags Day

May 3 was sunny and pleasant, perfect for almost 900 FOCUS peeps to enjoy FOCUS Six Flags Day! Everyone reported thrills, chills, and no spills – thanks to Coca-Cola, the Cox Foundation, and FOCUS fund raisers for supporting this annual event!

Camp TEAM (Together Everyone Achieves More)

Mercer University in Atlanta once again welcomed FOCUS Camp TEAM to enjoy a week of camp on their beautiful campus! Campers had a blast – swimming, golfing, Zumba, karate, and dancing to Lil' Vibes.

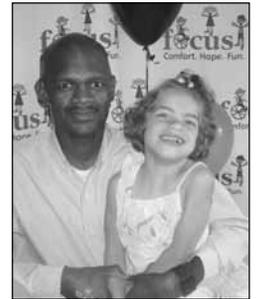


Daddy-Daughter Dance & Dessert "Shake, Rattle, and Roll!"

FOCUS girls wore their best poodle skirts and their favorite dudes wore their loafers to the Daddy-Daughter Dance in June. Whether doing the twist or



enjoying a hot dog and a Coke, they made lots of memories with their special fella. Thanks to DJ Tony Washington who played everyone's favorite songs, the Junior League of Atlanta for volunteering, and Mt. Bethel UMC for opening their doors to FOCUS for this annual event.



FAST Fins Spring Meet

All 8 FOCUS FAST Fins teams showed off their form at the spring meet at Mountain View Aquatic Center in Marietta. Thanks to all the coaches and volunteers who make swim team a ... swimming ... success!!



Thanks to FOCUS parent Nancy Perez and to a biotech company out of Thousand Oaks, California for selecting FOCUS for a project at their annual meeting! They worked together to make blankets and capes for FOCUS to give as gifts to our kiddos who are hospitalized! They had FUN making Comfort and Hope!

(Continued on page 8)



FOCUS Family Camp “Under the Stars” at Camp Twin Lakes in Rutledge in August was a weekend of champions, Olympic style! Over 90 families attended and survived the heat! The pool is always a huge hit, along with the ever popular Art Cabin, bingo,

archery, boating, climbing wall, and hanging out with other FOCUS families at the canteen! Thanks to the excellent FOCUS staff, Camp Twin Lakes program staff, and the many volunteers who help make the weekend so much fun!



Camp Hollywood was offered for 1 week in 10 locations around metro Atlanta. Campers enjoyed art, science, music, recreation, and cooking – activities based on the themes of favorite children’s movies! Thanks to the churches that continue to welcome FOCUS and our wonderful campers: Alpharetta Presbyterian, the Cathedral of St. Philip, Embury Hills United Methodist, Johns Creek United Methodist, First United Methodist of McDonough, McKendree United Methodist, Mt. Bethel United Methodist, and Peachtree City United Methodist, and Summit Baptist.



Camp Infinity “Went for the Gold” this summer! Offered at Camp Twin Lakes in Rutledge, over 50 teens and young adults worked on personal goals while enjoying zip lining, climbing wall, wacky Olympics, horseback riding, and more. Almost 50 counselors volunteered for the week, helping campers make lifelong

memories. The best part of Camp Infinity? **NO PARENTS!**

Summerfest was a celebration of summer, camp, and FOCUS! Thanks to all who sponsored, attended, and donated! Held at Monday Night Brewing, guests enjoyed the live music from Eastside Ramblers, Willy’s Mexicana Grill nachos and burritos, and the annual cornhole tournament! Cheers to FOCUS!



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