



Comfort. Hope. Fun.

Camden

by Holly Elmer

Our precious little boy, Camden, was born on a beautiful fall day, in the afternoon of November 12, 2008. He was my early birthday present! He was born not breathing, though, and was completely blue and lifeless. Not what this first-time mother expected.

Up to that exact point, my pregnancy had been fine. No complications, no problems, no indication that anything could go wrong. But during the birth process, something happened and he suffered a lack of oxygen. When they broke my water, meconium was present so a NICU mobile team was called to be in the delivery room. They immediately took over when Camden was born and resuscitated him. I saw him for a brief moment before they whisked him away to the NICU.

After a few short hours there, Camden was given an initial diagnosis of HIE – Hypoxic Ischemic Encephalopathy. Simply put, he sustained a traumatic brain injury which was caused by his lack of oxygen at birth. While my husband, Wade, and I were still trying to wrap our heads around all that had happened, we were approached by the head NICU doctor and asked to place Camden on a cooling blanket. This was a new procedure and was still in the experimental stages, but would we consider it? It only took a moment before we said yes! Camden was 9 hours old when an Angel Flight ambulance transported him to Emory Midtown, where he stayed for 12 days.

We were told that it would take about a year for us to truly see what Camden's quality of life would be like, that there was no guarantee that the cooling blanket helped, that a brain injury affected each person differently. We had wonderful doctors at Emory, as well as a wonderful neurologist who saw Camden after birth and followed him through the Emory Developmental Clinic. They all gave me

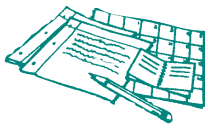
hope that, with therapy and love, Camden's life would be just as wonderful as I'd always dreamed it would be!

Well, those first few years were trying. I knew NO ONE else that had a special needs child, and for those first few months I was in denial about it all anyway. At his six-month check-up, the doctor went through the milestone questions, and I was at a loss. He couldn't do any of them. In fact, he was just at a point where he was rolling onto his side, but not rolling completely over. The doctor mentioned physical therapy, and I finally woke up. It was time to act! So, we did LOTS of therapy. In fact, I tried to make almost everything we did therapy in some way. From playing with toys to stretching muscles and beyond, we were ALWAYS doing some type of therapy. We started with Babies Can't Wait at 8 months, and he continued to progress...but as much as I had hoped and worked for it, Camden never became strong enough to walk. It devastated me to hear the words "wheelchair," but now – it's a way of life. Camden LOVES his chair! It's his independence! We started off with this tiny little manual thing, and now he has a power chair that he drives with his head. Yes, his head! It's amazing to see.

He also has an AAC – an Augmentative and Alternative Communication device. Basically, it's a portable computer that speaks for him. He uses his eyes to make it talk. Yes, his eyes! It's incredible. Up until he received his device (called a Tobii), we communicated with sign language and gestures. Camden could vocalize "yes, no, and mom," but that was about all he could actually say. As a mom, you instinctively know your child – 90% of the time,



(Continued on page 3)



From the Editor

by Lucy Cusick

Have you ever wished you could change places with your child? Wished you could have the surgery, endure the therapy, or take the icky medication?? I think most parents would gladly make the trade.

I recently took a flying leap out of my attic – didn't mean to ... I meant to take the steps ... but I missed and fell 8 feet to the floor. Josh (my son with cerebral palsy) was home and heard the very loud (and unrepeatable) screams. He fetched my cell phone and comforted the traumatized dog while I called my neighbors and cried on the floor.

After a trip to the emergency room where I acquired a cast, a pair of crutches, and a prescription for Percocet, I clunked home to figure out how to manage ten weeks of life on one leg with no driving privileges. And for all the times I wished that I could take Josh's place ... I suddenly realized that instead of taking his place (like in Freaky Friday), I was instead temporarily thrust into Josh's life, living how he lives every single day. Every. Single. Day.

I used crutches for 3 long, miserable days before finding a rolling knee walker (best invention since the beach wheelchair). In the rolling knee walker, I can only use one hand (like Josh) since I have to steer with the other (like Josh in his power chair). Things are out of reach, stairs get in the way, small bumps in the floor are Mt. Everest to a wheel, doors are a real pain, and showering is an ordeal.

Luckily, life with Josh has taught me to think outside the box and to be creative. All that I have learned as Josh's mom, I have used several times – when caring for my mom, when helping a friend in the hospital, when breaking my own bones!! When a friend dropped by and asked, "Can I do anything?" I had an immediate answer – PLEASE move the Diet Cokes to the front of the frig, take the basket of clean clothes to my bedroom (no hands when you have crutches!), roll the trashcan to the curb. When a neighbor called and asked, "Going to Kroger, need anything?" YES! Tylenol and dog food. And when one sweet friend realized the cat litterbox was downstairs, she bravely just came and took care of that without asking. And I let her.

One small difference between my situation and Josh's, however ... I'm down for 10 weeks. Josh is in it every day. And he's done it forever. And will do it forever. He rarely complains. He's had multiple surgeries, numerous painful treatments, thousands of therapy sessions, and he still smiles and finds the bright side. So. Would I change places with Josh? You betcha. And, if I could, I sure hope his attitude comes along, too. ■

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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 \$25 for families (waived if necessary) and \$50 for professionals.

Supper & Support at CHOA

FOCUS now offers support groups for the NICU & TICU at CHOA campuses of Scottish Rite and Egleston!! Contact elizabeth@focus-ga.org for more information!



Teen & Young Adult Activities

Monthly teen & young adult activities draw quite a crowd each month! From bowling to field day to a big dance, everyone has a blast!

A Sibling's Perspective

By Annalise Bernardino

When I was three, my youngest sister was born with several heart defects, thrusting me into the world of special needs and a life that began to revolve around therapy and doctor appointments, extended visits with grandparents during hospitalizations, and a seemingly never-ending list of warning signs and precautions. As the severity of my sister's condition increased, interactions with my peers diminished for fear that they might expose my sister to harmful germs. Every invitation I received was met with a familiar question: Has anyone in their household been sick in the past seven days? Any mention of illness meant I wouldn't be able to visit with friends.

I viewed this isolation as a roadblock, a situation not only inserted into my life, but one that became my life. Protecting my sister separated me from my peers and made relationships with my classmates difficult to establish and maintain. I resented the fact that I was born into a family whose daily life was different from the seemingly "normal" lives of my classmates, and I envied my peers' ability to be around others without constant worry of contamination. I longed to attend sleepovers and birthday parties, or invite friends over to my house, without questioning their recent health. I yearned to rid myself of the precautions my mother had set in place and enjoy a life more like that of my classmates, but feared the potential consequences of making my sister ill.

It was not until I entered my freshman year in high school that I began to reach out and actually sympathize with children with special needs and their siblings, rather than resenting the life that illness and special needs had created for our family. I received an email from FOCUS (a support group for families of children with special needs) stating that they were looking for teenagers to help coach their adaptive swim team. After soul-searching and a little convincing from others, I decided to volunteer, since I had experience swimming competitively for years as well as a lifetime of experience living with a sister with medical challenges.

The first day of practice, I was apprehensive about this new opportunity. Questions flooded my brain and I was awash in nervous anticipation, unsure what was going to happen and whether I would like the kids or if they would like me. I wondered if I would be a good coach, considering my experience with children with special needs was limited only to my sister, which is hardly the same as being in charge of multiple swimmers, each with their own challenges. I could not

imagine that I had much to offer, other than recommendations to improve technique, but was willing to give up a Sunday afternoon for a chance to get out of my house. Much to my surprise, I was immediately accepted by the group to whom I had been assigned. These children simply wanted to swim and be part of a team, one of many life experiences I had taken for granted.

Working to help the children overcome their limitations, I began to question whether my sister might be feeling the same weight of loneliness and isolation. It was then I realized my perception regarding the extent of my limitations was merely created through my self-centered view. I believed my sister had isolated me from my peers, yet I was the one isolating myself by fixating only on what I had missed rather than what I had experienced. Focusing on the benefits of having a sister with special needs, reinforced through the interactions with my swimmers, I stopped resenting our cautious lifestyle and the limitations it placed on my relationships. Going forward, I realize it is these very experiences that will help me as I pursue my undergraduate studies, and ultimately, a career in counseling those with special needs. ■

Annalise will be pursuing a Psychology degree at The University of Kentucky this fall. From her mom: Annalise's work with FOCUS was a key theme throughout all of her college apps and I thank you for the opportunity you've given her. The attached essay shows just how much the kids have helped shaped who she is and who she hopes to become. Thank you for all that you continue to do for our family.

Camden

(Continued from page 1)

I KNEW what he wanted or was trying to say. And up until his Pre-K teacher told me about the speech device, I had NO IDEA how my child would ultimately talk to me as he grew older. The day we had the meeting to demo the device and have Camden try it out, I cried (I mean, sobbing, ugly cry) to see him use it and actually "speak!!" In fact, he caught on so quickly that the device rep commented on how awesome he was! That's my boy, though. He always exceeds our expectations.

Like at school. He is progressing well and on track with the rest of his 1st grade class. He will most likely tell you "no" when asked if he likes school, but he really loves it! He has what we like to call "personality plus" – he loves a good joke, is sweet as can be, but he will tell you his opinion on something in a heartbeat! He enjoys being around his older brothers and tolerates his little brother. He is a typical 7 year old – he loves Legos, YouTube, and fun. He just started Cub Scouts and is excited about going camping soon. If you overlook his cerebral palsy, he's just

(Continued on page 8)

The Scoop on Poop

By Dr. Jose Garza

What is constipation? Although constipation is a very common problem, there is no one single definition. Normal bowel patterns can vary between individuals and be completely normal. The most complete and used definition is from the ROME III criteria (table I); but the most practical definition is the following: “delay or difficulty in defecation present for 2 or more weeks.”

What causes constipation? In over 90% of children, constipation is named “functional constipation,” which means that it is NOT caused by a known disorder (like Hirschsprung’s disease, for example), and it is multifactorial (more than one reason). In children, constipation usually starts after having a bad experience with hard painful stools which results in withholding behavior. Stools then get retained in the rectum and the large intestine absorbs more water making the stools harder, which reinforces the cycle next time a child has a bowel movement.

What can exacerbate constipation in children with special needs?

- 1) Positioning while defecating: posture is important and if you can’t sit well and increase your belly pressure, emptying the rectum is going to be more complicated and can facilitate impaction.
- 2) Patients with spinal cord injury have changes in the ability to sense stool and in the ability to control sphincters.
- 3) Multiple medications: different medications can have constipation as a side effect.

MYTHS:

Drinking more water will treat constipation. No, this is not true! And while drinking less water than needed will cause constipation, increasing water intake in a child that is already taking enough water will not result in looser stools. The large intestine will just absorb that extra water and stools will not become loose.

Let’s just increase fiber intake and treat constipation. Sadly, fiber is not sufficient by itself. Increasing fiber can result in abdominal pain, flatulence and, if your child has very infrequent stools that are large, painful and clog the toilet, that extra fiber will make “that big one”... BIGGER! Plus, it is not easy to change diet in young kids, especially in those with texture or food aversions.

Constipation is self-limiting. No, in a lot of children, unless we give treatment, it will NOT go away on its own.

So what do we do? We treat it! There appears to be a stigma to treating constipation; families are

H3. CONSTIPATION AND INCONTINENCE

H3a. Functional Constipation

*Diagnostic criteria** Must include **two or more** of the following in a child with a developmental age of at least 4 years with insufficient criteria for diagnosis of IBS:

1. Two or fewer defecations in the toilet per week
2. At least one episode of fecal incontinence per week
3. History of retentive posturing or excessive volitional stool retention
4. History of painful or hard bowel movements
5. Presence of a large fecal mass in the rectum
6. History of large diameter stools which may obstruct the toilet

* Criteria fulfilled at least once per week for at least 2 months prior to diagnosis

Table 1 from the Rome III diagnostic criteria for functional gastrointestinal disorders

usually OK in treating other medical problems with medication, but when it comes to constipation, everyone is afraid their child will become dependent on the medication. I agree that if you don’t need a medication, you should not take one, but if you are having problems with your child’s bowel movements, and it is affecting his and your family’s quality of life, seeking help of a specialist can make him better (and likely happier!).

A visit to your child’s pediatrician or GI doctor to discuss options and treatments is always the best course of action! You can help your doctor by bringing a summary of the food your child ate in the last week or so, the medication he/she takes, and the frequency and difficulty of bowel movements. Together, you can ‘get things moving’ and enjoy life a little more! ■

Dr. Garza currently practices at GI CARE FOR KIDS in Atlanta and has presented at the FOCUS Conference for the past two years.

Hunter

By Aaron Klepinger

Our son Hunter has epilepsy, a movement disorder, and extreme developmental delay. He is at a 1-3 month old in cognitive developmental milestones and is therefore non-verbal and dependent for every life skill.

Hunter had an uneventful birth. Four months later we started seeing what we now know were seizures. We took him to the ER at age 6 months and during that stay found out he might not live to adulthood. He's 10 now.

Hunter has taught us so much – especially what's important in life. He's taught us strength, courage, persistence, creativity, and made us reflect heavily on the future. He's made us work harder, both at our jobs and at home, and we're better for it.

As many of you know, there are also a lot of physical challenges to raising a special needs child. One issue we have is where to change Hunter's diaper if we're out on the town with him. We've changed him in the back of the wheelchair van and on therapy tables or floors. He's growing to the point that these changing places may be too small for him. We've also had to re-insert his feeding tube when we pulled it out accidentally or the school did. That used to be a scary thing, worrying about the g-tube site closing if we couldn't get the tube back in.

Special needs parents deal with mental and emotional situations that other parents do not. Hunter gets a good amount of stares. Most of the stares are from children and sometimes the parents ask the staring children to stop staring or to say talk to Hunter or to us about Hunter. Unfortunately, we usually have to wave hello to the child to get them to stop glaring at Hunter. I think many of them are just curious and maybe haven't seen a kid like Hunter before. We just wish their parents would turn Hunter's presence into a learning opportunity for their own child to understand kids that are different than them.

On other occasions, we're reminded of the beauty of humanity. One day at IHOP, a boy at another table said 'hi' to Hunter and asked us all about him. This boy was so concerned about Hunter and his parents talked to that child so kindly and warmly, encouraging him to learn. It's those situations that leave the most lasting and positive impressions.

Sometimes, people just don't know what to say. One time when Hunter was about 3, we went shopping at Wal-Mart. As we were walking around the store with him in his stroller, a woman said, "You should let him walk instead of being in that stroller". I kindly replied that he had epilepsy and was unable to walk. Hopefully, Hunter taught her to ask questions before providing the wrong advice.

There are financial concerns exclusive to special needs parents, too. Who will be able to take care of our disabled child if we're gone? How will



(Continued on page 8)

Coming Up at FOCUS!

Most FOCUS activities are now announced in our weekly emails – we sent an email through Constant Contact every Monday. If you do not receive an email from FOCUS each week, then we either do not have a current/correct email in our system OR our emails are going to your spam folder. Please email inquiry@focus-ga.org if you do NOT receive our emails. We'll try to figure out why!

May 31 to June 3* Camp TEAM day camp at Mercer University

(Camp TEAM currently has a waiting list)

June & July* Camp Hollywood day camps

*Brochures and applications for all day camps were emailed to FOCUS families on February 9. Many locations are now full.

Daddy-Daughter Dance Saturday, June 18, 11:30 am at Mt. Bethel UMC

Watch your emails for details!

Under the Stars Family Camps August 12 – 14 at Camp Twin Lakes Rutledge

September 30 – October 2 at Camp Twin Lakes Will-A-Way

Brochures and applications for family camps were emailed to families on April 26. If you have questions about family camp, please call or email FOCUS!!

Saturday, August 20, 2016 7th Annual SummerFest At Monday Night Brewing

More information coming by email.

Sunday, September 18, 2016 3rd Annual Climb for Kids

Stone Summit Climbing & Fitness Center
3701 Presidential Pkwy, Atlanta 30340

More information coming by email.

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Looking Back at the Fun ...



FOCUS recognized Lauren & John Seidl, Dr. Jim Fortenberry, and Diane Slothouber as the 2016 Comfort, Hope, Fun Honorees at the 33rd "For the Love of Children" Gala on February 27.



Guests enjoyed bidding on silent and live auction items, dancing, and a lovely

dinner. Special thanks to our honorees for filling up the ballroom and to host and emcee Tom Sullivan (www.tomonair.com). See gala sponsors and donors to the left.



FOCUS Education Conference

FOCUS parents enjoyed a day of information and networking at the 29th annual FOCUS Conference. Thanks to Dunwoody UMC for hosting, Chick-fil-A for donating lunch, and the speakers and exhibitors for sharing their time and knowledge.



FOCUS Conference at Clayton State

FOCUS parents enjoyed a day of MORE information and networking at Clayton State! Parents from south Atlanta love NOT navigating through the city! FOCUS on the GO!

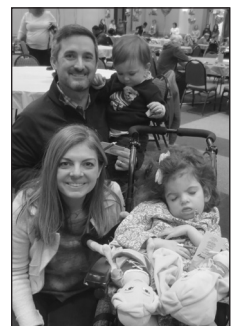


MVP Valentine's Day Party

The 10th annual MVP Valentine's with Character was a SWEET afternoon!

Children enjoyed dress-up, arts & crafts, photos, and autographs

AND dancing with Disney Princesses!! A special thanks to the Greek Orthodox Cathedral for the use of the beautiful ballroom, the Philoptochos Ladies Auxiliary for providing the delicious desserts, and the Junior League of Atlanta for volunteering.



Hunter

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the child’s healthcare needs be met if they no longer have mom and dad’s insurance? Today, how am I going to pay for all the diapers and therapies and medical visits? How am I going to pay for transportation to haul him around in this wheelchair when I can no longer fit it or lift it into my vehicle? We’ve faced all these. Most of these questions had difficult answers.

Through all the challenges, Hunter taught us to accept whatever outcome life gives us and make the best of it. He is our first child and we had found no root cause for his diagnosis, so initially we were scared to have more kids. We wondered, “Will our second child be healthy? I’m not sure I can handle another disabled child.” When we looked at Hunter, we thought how much we love him and how having a 2nd special needs child would be much like having one special needs child. In the past 4 years, Hunter has gained two happy and healthy brothers who love him so much. And now Hunter is teaching them! ■

Camden

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a regular kid who happens to have problems moving his muscles. And while we may see and think that our special needs kiddos have such obstacles to overcome, the role of being a special needs parent is just as tough. Everyone’s journey is different, and navigating the maze of therapies, paperwork, etc. can be overwhelming. I am so grateful that we have FOCUS to help us through it all! I only wish that I’d known about them sooner. They came into our lives at the perfect time, though. It was actually ME who needed them more than Camden, and I honestly believe I’m the one that’s benefitted the most so far. I don’t know what I’d do without the monthly share group! We have a wonderful group of parents that I now call friends, and I look forward to our meeting every month. I’ve learned SO MUCH from them! I’ve also been to the education conference to learn more about issues that are currently affecting Camden. And I’ve met so many other parents who “get it,” which is wonderful! Camden had never been to “camp” until Camp Hollywood, and he enjoyed it so much that he looks forward to it every year now! Our family has also enjoyed several outings, including the Christmas party and a trip to LEGOLAND. These outings have been wonderful for Camden, because he doesn’t like crowds and the loud noise that comes with them.

FOCUS truly lives up to their motto of “Comfort. Hope. Fun!” We are so glad to be a part of such an amazing organization. I know they’ll be there to help us through whatever the future may hold! And thankfully, this Mama’s sanity will still be intact – well, until the next IEP anyway. ■

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