

## Our Little Big Man, Jacob

by Jennifer Tyler

Our little big man is just that – a rambunctious soon-to-be 3 year old who is the size of a 5-6 year old. Thanks to a rare genetic deletion called Sotos Syndrome, Jacob has been off the growth charts since he was a newborn. Jacob's syndrome is an "overgrowth syndrome" which means he grows at a much faster rate than other children. Not only is he very tall, he is developmentally delayed. A terrible combination, really, considering that his weak muscles have to work that much harder to move a giant body! Our son's delays also appear much worse, considering he looks much older than his true age.

One of Jacob's biggest delays, and one that is probably shared by many of us, is speech. Jacob is currently nonverbal, although he can hear and make non-speech sounds. In the past 2 years, we have seen so much progress and success with signing and communication overall. I attribute this success to several things, and I hope that by listing them here, you, reader, may be able to help your little (or big) one communicate.

First, when Jacob was a baby, we started to teach simple communication by playing games that required taking turns (e.g., peek-a-boo). Of course, Jacob didn't really reciprocate except by laughing at us, but that connection would prove useful to getting him to "ask" for more games. Although he could not talk or sign at that age, he eventually learned to put my hands over my face to "ask" for more peek-a-boo. This was the beginning of communication!

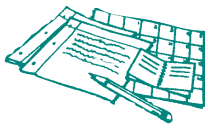
When Jacob was about 6-8 months, we also began trying to teach simple signs like "more" and "all done" at mealtimes. Mealtime was

the perfect time for teaching signs since Jacob was very focused on us and the food we had, and, man, can he eat! As an aside, we quickly learned that a growing boy like Jacob was never "all done" eating, so we really were just working on the "more" sign for the first year. After several months of giving Jacob a bite of food, making the "more" sign with his hands, then another bite, repeat, repeat, repeat, we became frustrated. He did not appear to be picking up the sign at all. Thankfully, we consulted with a friend who encouraged me to stick with it, since even non-delayed babies can take a long time to pick up sign language. We did stick with it, and, sure enough, after months and months of trying, Jacob finally picked up his first sign, "more," and we were off to the races!

Once he picked up his first sign, Jacob picked up additional signs much faster. In fact, he began picking up signs so fast, that I had to continue using Google to find new signs to teach him! Eventually, our speech therapist mentioned a set of DVDs called "Baby Signing Times" which teach sign language. We purchased a few, not confident that a DVD would be able to teach Jacob a sign, but boy, were we wrong. After a few days of watching the DVD, he picked up several signs. You should know that Jacob's "signs" were far from the perfectly modeled hand signals taught in the video; but, the point of teaching sign language is communication, so perfection is not necessary.



*(Continued on page 3)*



## From the Editor

by Lucy Cusick

So ... I'll soon be the mother of a 30-year-old. I know, I know, I don't look that old. RIGHT? But, this means that I can now be a member of the 'older and wiser' club. RIGHT?

Josh (the almost-30-year old, 28-weeker, diagnosed with cerebral palsy at age 1 and seizure disorder at age 3) has had countless hours of therapies, graduated from high school and tried college, had several volunteer jobs, and continues to learn about life-after-high-school. He has used a wheelchair for the better part of his life – he did use a walker for a few years but found sit-down life more functional and more independent as he got older. That said, learning to be independent took a lot of time, and he's more independent at home than he is out in the community.

This synopsis of physical therapy is from memory, so bear with me (I'm old, remember?). From ages 1 to 5, "we" (because we all know that therapy once a week really means "we" should continue therapy in between sessions, right?) worked on tone (stretch, stretch, stretch), strength (because without strength what good is loose tone?), and motivation (because without motivation, you don't really get anywhere!). From ages 5 to 10, we worked on function – moving about school with a walker, staying loose, learning the capitols of the United States, and staying strong. From ages 10 to 15, we moved to using the walker mostly at home, navigating the community with a wheelchair (watch for cars in parking lots, look for the curbcuts, be careful not to follow walking people too closely because they might stop ... and you might not), and working on activities of daily living at home (remodeling a bathroom for more independence, managing in and out of shower/bathtub safely, adding ramps/ways to get in and out of house safely and independently). From 15 to now, we're back to keeping strength, trying to stay loose, and putting more of the responsibility on Josh. (I'm old, remember?)

And here's what we've learned: tight muscles will likely always be tight when you have cerebral palsy. Stretch daily. (Or not.) You can never be too strong. Workout often. (Or not.) And sometimes you have to consider the needs of the caregiver (that's me, the old one) and learn what they need to help you as you both grow older (and heavier).

The best skill Josh ever learned – and he managed to maintain – is what we call "stand & pivot." Josh can hold onto a grab bar (like in a bathroom), stand up out of his

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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.

wheelchair, take one step sideways, and sit in another chair (or on the toilet). While he sometimes needs assistance, he can hold 75% of his weight, which leaves me with only 25%. When we're in a different set-up, like a hotel or a restaurant bathroom, or even a movie theater with no more accessible seats, stand & pivot is a lifesaver (and a back-saver, too!).

Many FOCUS families deal with kiddos who cannot weight-bear – I hope you have access to a hooyer lift or some kind of system to save your back. Many families deal with kiddos who run and don't walk – I hope you have good arch support for your PF Flyers (another old joke). For those kiddos who need lots of help standing (but who can stand, even with help) – I hope you ask your physical therapist about "stand and pivot." It's the skill that has kept both Josh (and me) independent. ■

# The Day We Became a Family Of a Child Under Stress

By Christa West

**N**evaeh was born March 30, 2012. She had a head full of dark hair, rosy pink lips and was perfect in every way. She was a few days shy of being full term, but with Apgar scores of 9 and 10, we had no concerns. This was not the day we became a family of a child under stress.

At 36 hours, Nevaeh was rushed to the NICU. After blood work and a lumbar puncture, we were told she had bacterial meningitis as a result of Group B strep (even though the initial test was negative). This was not the day.

At 5 weeks old, after an incredible battle with the meningitis and all the things that came with it – seizures, sepsis, and so on – Nevaeh was rushed from the NICU to Egleston for emergency surgery for acquired necrotizing enterocolitis resulting in a loss of 60% of her intestines. This was not the day.

More surgery followed a few days later and again at 11 weeks old for her colostomy reversal. The GI issues became the priority. Having an MRI to see the damage from the meningitis became less critical. The 6 weeks in between were full of highs and lows. She would progress only to relapse again. This was not the day.

When Nevaeh was 4 months old, she finally had the MRI. We were told about the damage to the various parts of her brain and that developmentally she would be delayed both physically and cognitively. The information was vague and there was so much unknown. She also left the NICU within a few days of that MRI and moved to a room on the GI floor. At this time, she had a central line, was TPN dependent 24 hours a day and fed a little through an NG tube as tolerated. This was not the day.

At 5 months old to the day, Nevaeh was discharged to come home. I was overcome with joy and overwhelmed with instructions, follow up appointments, medical supplies, home health nursing, compounded medicines, expensive formula, medically fragile daycare, social workers and more. This was not the day.

At 7 months old, Nevaeh was back in the hospital for the second admission since her discharge. The social worker came by the room to check on us. We talked for a bit about life at home and the frequent hospital visits and stays. She commented to me that this is what life would be like with a chronically ill special

needs child. I swallowed hard in an effort to fight back the tears that were already running down my face. She was the first person to use the term ‘special needs’ with me. I recall saying to her that Nevaeh was not special needs and that clearly she had her mistaken her with another child. Looking back, I realize I was in somewhat of a state of denial of what our reality was. However this WAS the day. This was the day I accepted in my heart and my mind that we were a family with a child under stress.

Today Nevaeh is almost three and a half years old. She is the happiest child I know and blesses us daily. She was diagnosed with cerebral palsy and a seizure disorder when she was 15 months old. Although she will always have short gut, she is no longer TPN or feeding tube dependent. Just 10 months ago she started sitting up independently. She started crawling just 6 weeks ago, and now is starting to use her walker some! She wears glasses for her vision problems and has a communication device on the way for speech. She still has head full of dark hair (now curly!), rosy pink lips, and is still perfect in every way.

*She is clothed with strength and dignity. She laughs without fear of the future. – Proverbs 31:25 ■*



## Our Little Big Man, Jacob

(Continued from page 1)

Only our understanding of what he meant was crucial.

Although we have had a lot of success teaching signs, we still yearn to hear him speak. So we continue trying to teach words, and, as frustratingly slow as his progress has been, we still get encouraged every now and again with new sounds and his attempts at words. Soon enough, I know we'll hear the phrase we long to hear: "I love you!" For now though, we are busy shoe shopping (size 12 XXW shoes are not easy to find!) and preparing to send my little big man to preschool this year. ■

## Superheroes

By Angie Haddad

I asked my 14 year-old-son Jordan what he wanted to be for Halloween this year, and he asked to be a superhero. I smiled at him and said, "Honey, you already are."

Jordan (pictured right) was born with Down syndrome, and diagnosed with many other medical issues. At age 5, he was diagnosed with ADHD and Sensory Disorders. At age 7, it was a sleep and anxiety disorder. By age 11, he started having drop seizures and was diagnosed with epilepsy. At age 12, he started choking on food and when scoped, his doctor realized he had severe acid reflux and trouble with digesting food due to a small esophagus. By age 13, he was diagnosed with LGS, Lennox-Gastaut Disorder, a rare form of epilepsy without a cure.

He has had multiple surgeries, multiple medications, multiple therapies. Yet, as I think about all he has had to endure in his short life, I think how amazing he is through all of it.

In my head as I list these medical challenges, my mind wanders, and I think about some of the old catchphrases from Superman cartoons: "More powerful than a locomotive; faster than a speeding bullet; able to leap tall buildings in a single bound..." Hmmm ... how important is it for a person to leap a building or be as powerful as a locomotive?

Perhaps it is time to create some new catch phrases about our kids, the ones who battle each day the most evil villains: rare and often debilitating medical conditions. So, here it goes...More powerful than a MRI; faster than a drop seizure; able to leap into a parent's arms and give the best hugs....it's a bird, it's a plane... it's my child!

I think there are some other superheroes among us, too: parents and loved ones who never stop fighting for their kids; teachers who go into the field of Special Education knowing it may be a tough career path; medical professionals who are dedicated to helping their patients and looking outside the box for new cures and cutting edge treatments. All of you are heroes, for sure.

We may not wear a giant "S" on our chest like Superman does, but I think we know our secret powers. We are formidable opponents to fighting the evils of challenging medical conditions. We do this because we have unconditional love for our kids and want them to be all they can be. Superman may be the Man of Steel, but we all know that love is where real strength comes. ■



## Pampering With a Purpose

By Jen Dicello

Our sweet Jordan passed away 7 1/2 years ago. Her death was unexpected, devastating, and life-altering. When she was first diagnosed, I had no idea how I was supposed to take care of a child with severe disabilities. As a first time mother I had no experience with a typical child, much less a child with special needs. Turned out it didn't matter. God has a way of working all things for His good. I fell in love with her, nurtured her, cried with her, and cared for her every need until the day she was called home. Then I was faced with yet another stark reality. What was I supposed to do with the rest of my life? I had just spent twelve years taking care of Jordan's every need and, although I had another child to raise, it wasn't the same.

Three years later, a good friend invited me to a Mary Kay party. I didn't want to go, but finally agreed. I showed up late, sat on the sidelines and refused to participate. Just to help out my friend, I purchased an eye cream. The Mary Kay Beauty Consultant told me I too would be a great consultant; how could she possibly know that? I barely opened my mouth the entire party and had no any interest in selling the products. Ignoring her, I went about my life... for a week. My friend dragged me to another Mary Kay event; I took some classes to learn about the business. I needed to make a decision, but couldn't imagine how selling makeup and skincare would be as purposeful as taking care of Jordan. As I signed the sales agreement, God whispered to me "*it is finished,*" and I knew my season of grief was over. It was time to move forward. Gulp!

The host of that first Mary Kay party was the Executive Director of my Unit, Kristin Sharpe. She had a vision of using my story to help children in the community. I considered her suggestion, immediately switched it up. Why not use my business to minister to women in the community? As moms, we are programmed to take care of everyone else before ourselves (even our pets.) Our needs almost always come last. Pampering With A Purpose (PWAP) was painstakingly created to change that!

I have known Lucy since the very first 5 & Under Share Group 16 years ago. I spilled coffee on her carpet that day and didn't tell her until years later. FOCUS was a safe haven for our family, and I witnessed firsthand the toll that a special needs child can take on a family, especially the moms. I could think of no better recipients of free products than the amazing women who care for these children day in and day out!

Fast forward three years. We donated over 600 rollup bags filled with full-size products for moms (and dads and teens!) who are in the hospital with their children. We've pampered moms at various FOCUS events. We've expanded to help other nonprofits. To read more about our campaign and see how we serve others in our community and worldwide, look for us on Facebook and "LIKE" us at [www.facebook.com/mkpamperingwithapurpose](http://www.facebook.com/mkpamperingwithapurpose) or contact me at [dicello4marykay@gmail.com](mailto:dicello4marykay@gmail.com). ■

## 5 Things FOCUS Needs Parents To Do!

### 5. Make Sure You Receive FOCUS Weekly Emails!! Don't get them? Then call or email us at inquiry@focus-ga.org.

(When FOCUS staff sends an individual email to you, it just goes through regular email channels. When we send the weekly emails each Monday, we use a system called Constant Contact. Sometimes email providers think that Constant Contact emails are Promotional or Junk / Spam. If our Constant Contacts are NOT coming to your Inbox, add FOCUS to your Safe Sender list. It's even possible that our emails don't even get THAT far ... Yahoo likes to call us spam even before we get to your Inbox! We don't know how to fix that!)

### 4. Read the Emails. Twice.

(We try VERY hard to make each email as clear as we can ... to give you all the information about a program, how to register, when you'll hear from us after you register, etc. We try to anticipate questions to make life easier for you – of course, you can always call just to talk!)

### 3. Get Involved & Stay In Touch!

(We love getting to know our children and their families! We're here to support you, even if just by listening! Jump in and get involved – enjoy a family activity, let us know if you're in the hospital, come to a workshop – we have something for most everyone!)

### 2. If You Register, Come!

(Now, we know that this life we live is tough – kids get sick, have meltdowns, life happens. But, when you register, we assume you'll be there. For activities like Six Flags Day, we pay for tickets, even if they aren't used. If life happens, let us know. Do your best to protect the date so you can have fun with your FOCUS Friends!)

### 1. Give Back!

(We try really hard NOT to ask parents for help ... but we rarely say NO if you offer! Let us know if you have extra time or would like to help with a fund raiser, label newsletters, ask your company to make a donation, select FOCUS to receive rewards from Kroger or AmazonSmile. A little means a lot at FOCUS!)

## – Upcoming Activities –

Always check the weekly FOCUS emails or the online calendar for upcoming activities! Many programs fill up quickly so don't wait for the newsletter to arrive!

### Workshops & Share Groups – Ongoing! Check the calendar!

### Fall Extra Special Saturday Respite

begins in September and is play time for children ages 1 to 12. Staff includes a nurse, trained caregivers, and volunteers. Children can come to different locations, but not in the same month – no double dipping! Check out the schedule and registration procedure on the website or email questions to [sonca@focus-ga.org](mailto:sonca@focus-ga.org)

### September 20 – FOCUS Day at the Georgia Aquarium is full!

Registration was on-line – please keep your email current with FOCUS!

### September 27 – FOCUS Climbs for Kids at Stone Summit Climbing & Fitness Center

Come climb to the top for FOCUS!

Email [elizabeth@focus-ga.org](mailto:elizabeth@focus-ga.org) for details!

### October 2 – 4 FOCUS Under the Stars 2 at Camp Will-A-Way

We have a waiting list – for more information, email [brian@focus-ga.org](mailto:brian@focus-ga.org)

### October 18 Spin for Kids – Bike for TEAM FOCUS!

The money TEAM FOCUS raises in Spin for Kids supports the programs FOCUS offers at Camp Twin Lakes.

Email [lucy@focus-ga.org](mailto:lucy@focus-ga.org) for details!

### October 24 – MVP Boo-B-Que

Medically fragile children and their families are invited to the 7<sup>th</sup> annual Boo-B-Que at Holy Cross Catholic Church, sponsored by the Knights of Columbus. Contact [elizabeth@focus-ga.org](mailto:elizabeth@focus-ga.org) for details.

### October 24 – FAST Fins Intrasquad Swim Meet

The fall season is underway – eight teams are working hard at practice. Come cheer our swimmers on at the Mountain View Aquatic Center in Marietta. Call FOCUS for more info.

### October 25 (tentative) Moms Day Off on Lake Lanier

Watch email for final date and information.

### November 7 – FOCUS Day at Zoo Atlanta

Information and registration will go out by email!

### November 8 – FOCUS on Fashion

Calling all models! Walk the catwalk for FOCUS!

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 In honor of Jordan Haddad and  
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 In honor of Janice & Bob Russell's  
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 In honor of Cameron Langwick-  
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# Looking Back at the Fun ...

## Under the Stars



FOCUS Family Camp went "Under the Stars" at Camp Twin Lakes in Rutledge in August! Over 90 families attended – our biggest number ever, thanks to the new cabins Camp Twin Lakes added this past year! Families enjoyed the art cabin, pool, archery, boating, climbing wall and just hanging out with other families! Thanks to the excellent FOCUS staff, the fabulous program staff at Camp Twin Lakes, and to the many wonderful volunteers who help make the weekend so much fun!



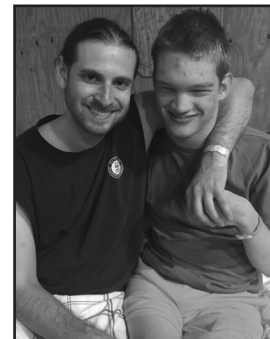
## Welcome to FOCUS!

We're thrilled to welcome Sonca Pham to the FOCUS family and the office! Sonca is a senior at Kennesaw State University and has worked with FOCUS as a camp counselor at Camp Hollywood, Camp TEAM, and Camp Infinity for the past two years. She quickly grew to love our kiddos and their families and is now coordinating Extra Special Saturday respite this fall. You'll also see her helping at other events so give her a big FOCUS hug when you see her!



Sonca (center) with two Camp Infinity campers

### Camp Infinity



Camp Infinity was a BLAST 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 – and THEY had fun, too!



### SummerFest ...

... was a celebration of summer, camp, and FOCUS! Thanks to all who sponsored, attended, and donated! Guests enjoyed the fabulous music from DJ Rockin' Wheels, Willy's Mexicana Grill nachos and burritos, cool treats from SnoBayou, and the annual cornhole tournament! Cheers to FOCUS!



### 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! A new addition this year was designating one week just for teens and young adults – an emphasis on health and exercise, with a side of rock and roll! Thanks to the churches that continue to welcome FOCUS and our wonderful campers: Alpharetta Presbyterian, the Cathedral of St. Philip, Embry 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.



### FOCUS on Moms

FOCUS on Moms was another great day! Moms enjoyed a day of a little Comfort, a lot of Hope, and a heap of Fun! From massages to share groups to yoga, moms were pampered, spoiled, and appreciated! Thanks to First Christian Church of Atlanta for hosting, the Junior League of Atlanta for volunteering, and all the speakers who shared their expertise and talent!



# Many Thanks from FOCUS!

We thank a lot of people at FOCUS – donors, sponsors, volunteers, and more. But, there’s a group of folks that we may have NEVER thanked properly: our program staff. They work part-time at various FOCUS programs like Camp Hollywood, Camp TEAM, Extra Special Saturday Respite, FAST Fins, and Camp Infinity. They all have ‘day jobs,’ and they work for FOCUS because they love our kids! Because of their dedication, FOCUS is able to offer activities that are fun and safe. Many of them have been with FOCUS for almost 20 years – we likely have photos of them all, but there’s only room to print a few. So – big group hug to all of our counselors, caregivers, coaches, and music therapists!! We love ya!!



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