

The Story of Kyle

by Tammy Harden Galloway

When I started to write Kyle's story, so many people, emotions, and forgotten details came to mind. As special needs parents can understand, the excitement and joy became fear and anxiety. The usual baby vocabulary was washed away by newfound medical terms, diagnoses and procedures.

When Kyle was born sixteen years ago, he had a weak cry, but his Apgar scores were 8 and 8. The first concern was about his frank breech position which affected his hips. He was whisked away for an orthopedic consult. Other issues then became apparent in those first hours. The first night he would not nurse. Being a first time mom, I assumed it was me. No coaching or positioning assistance from the experts made a difference. When I was released from the hospital, he was admitted to the NICU, taking pumped breastmilk via a NG tube. In the following two weeks, he progressively got worse and was put on oxygen and under a heating lamp.

After three general level chromosome tests and multiple specialists found nothing, he was transferred to Scottish Rite for a muscle biopsy. Over the next two weeks, he gradually began to improve. In an attempt to diagnose him, a neonatologist, who had a hobby of genetics, examined every little detail of my son. From the length of his pinky finger to the swirled hair-growth pattern on his forehead, everything was documented. He ran labs for five possible genetic diagnoses.

Meanwhile, we moved toward bringing Kyle home. My husband and I were taught to place NG tubes by practicing on each other before we did the same on Kyle. For two people with no medical background or training, it was a nerve-

racking experience. But with that under our belts, Kyle was allowed to come home with an apnea monitor and a NG tube.

Some months later, the five genetic labs came back and one was positive for Prader-Willi Syndrome (PWS).

Much of the doctors' knowledge was from medical school and old textbooks. They said monitoring his diet was the key. I learned that was only part of the story – there is so much more to PWS! Officially, PWS is a complex genetic disorder of the 15th chromosome; the most common known genetic cause of life-threatening obesity in children. PWS typically causes low muscle tone, short stature, cognitive disabilities, problem behaviors, and chronic feeling of hunger. (see www.pwsausa.org for more).

Kyle feels hungry all the time, but only requires half the calories of a normal kid. Worse still, he can overeat just once and cause his stomach to rupture, for which there is no treatment. In addition to counting calories, he also has globalized poor muscle tone, anxiety, perseverance, apraxia, delayed processing and learning disabilities. Many of his challenges are made worse by his additional diagnosis of Aspergers.

So, we are diligent in his food access and routine and make sure he eats on a schedule. Routine is key, which helps reduce his anxiety. With



*Kyle (left) at Camp Infinity
with his counselor*

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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.

Ongoing at FOCUS**MVP Events for Medically Fragile Families**

For more information,
 email elizabeth@focus-ga.org.

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for ages 13 to 29**

Please email brian@focus-ga.org for
 information on monthly social outings and
 other events for teens/young adults.

Share Groups, Hospital Visits, and more!

Email lucy@focus-ga.org if you want to
 get involved at FOCUS but can't figure
 out how to start!!

**From the Editor**

by Lucy Cusick

Sometimes, I struggle with what to write here ... I want to be encouraging to new parents – but I also don't want to sugar coat the struggles of parenting a child with special needs. Yes, yes, we're blessed and all that – but somebody needs to own up that this can be a tough job. It's ok to be sad, angry, and scared.

Once in a while, I am reminded of our most important mission at FOCUS. Yep, we offer wonderful programs for children with disabilities and their families. We take our responsibility seriously of keeping kids safe at our programs – from screening all volunteers and staff to counting heads relentlessly at programs. But sometimes, sometimes, it's not about camp or respite or a hospital visit. Sometimes a mommy or daddy might just be sad and need to talk ... or email ... or Facebook chat.

This happened today. I received an email from the mom of a little guy with cerebral palsy (CP), not yet two years old. She's ready to make some FOCUS friends, ready to get involved. We emailed back and forth – I admitted to Facebook stalking her and seeing what a cutie her little guy is. She admitted that she stalked me back and found photos of my 'little one' with CP ... who isn't so little anymore. But she claims he looks happy and that his beard suits him!

During our exchange she admitted to feeling a little 'under water' lately and that even the email conversation helped. Wow – I remember those days – days when therapy seemed endless and the daily routine of all-you-should-do didn't match up with the hours in a day. Days of just wishing someone knew the lingo and that the little one you love so very much didn't have to struggle quite so hard.

While I miss the days of sticky kisses and everyone needing my help at the same time, I enjoy my 'kids' as adults now. I watch and admire mommies and daddies who are 'in the trenches' with little ones now – I see them handling diagnoses and surgeries and equipment with the same ease that I did. But, I also remember juggling and balancing and feeling 'under water.' We are grateful that you allow us at FOCUS to paddle alongside and offer you comfort and hope – and then to have fun together! ■

Wearables: The Future of Assistive Technology

By Trey Quinn

As I arrive home after a day at school, I feel a slight vibration on my wrist – a traffic alert. I tell my mom that the traffic to my physical therapy appointment looks bad, and we should probably leave early to make it there on time. After therapy, I feel another vibration on my wrist. It brings data collected on my heart's activity during the session. My therapist must have done something right, because my heart was vigorously active for about thirty minutes. If you have not already guessed, I am wearing something on my wrist. It is a watch but not just an ordinary watch. I am wearing a Moto 360 by Motorola.



At first glance, people might not think twice about the device on my wrist. Moto 360's Rolex-esque design disguises the smart watch as just another circular, stainless steel watch. When the dormant screen comes to life though, it is no longer an ordinary watch. That is when the magic starts to happen.

My Moto 360 allows me to do some simple things normally done on my smartphone right from my wrist. For example, if someone texts me, I can reply to their message just by swiping, tapping a button, and speaking. My reply must be only a few syllables, though, because Google's voice dictation cannot fully understand my impaired speech. It also displays other incoming notifications as well as cards powered by Google with creepily accurate autonomous information to help me through my day. More in depth apps on my watch can let me order and pay for a pizza delivery in under 20 seconds or call a cab to come pick me up. The thing I most use it for is to quickly communicate with my caretakers. If I need my mom for something, I no longer yell across the house. With just a swipe and a tap, my watch sends her a text message telling her I need help. If I ever fall when nobody is around, I can hit a big red panic button. This sends an emergency text message to my mom with my exact location.

While the Moto 360 is my wearable of choice, there are plenty of other wearables that fit everyone's wants, needs, and, most importantly, budgets. I have had the privilege to adorn my wrist with three smart watches over the past few months. I started out with the Pebble smart watch. While the Pebble is relatively low tech with its black and white display and button navigation, it is a great, dependable wearable. It has a super long

battery life of one week, is fully waterproof, and has the biggest selection of apps of any smart watch. Unfortunately for me, my Pebble met a premature end when its pixels randomly started dying. This is a very unusual problem, so please do not let my experience detract from your opinion of Pebble. Also, this is the only option for iPhone owners at the moment. While Apple is set to release its Apple Watch in early 2015, the Apple Watch looks extremely hard for someone with limited fine motor skills to use. The Pebble smart watch has a starting price of \$99.99.

When my Pebble broke, I upgraded to the LG G Watch, which costs \$229.99, but can be found for cheaper. Much like the Moto 360, the G Watch has a color touchscreen, a microphone for voice input, and runs Google's new operating system for wearables, Android Wear. The G Watch features a square plastic body with a silicone watch band. While its silicone band was super comfortable, everything on earth stuck to it. So, when I would wheel myself around school in my wheelchair, all of the dirt off the floors that had gotten on my wheel would get picked up by the band, causing my watch to become super disgusting super fast. I wore that watch two weeks before upgrading once more to my Moto 360.

I have loved my Moto 360 from day one. As I mentioned before, the all-stainless steel body gives it a premium look. Its circular display makes it look classic and, in my opinion, makes Android Wear look more futuristic. The watch band on the black Moto 360, which costs \$249.99, is made of an awesome American made leather that is high quality while being super comfortable and durable. A more expensive model has come out with a stainless steel watch band that costs between \$299.99 and \$329.99. Overall, I love how much attention to detail Motorola put into this watch. For example, its inductive charging dock causes the watch to double as a bedside or desk clock while charging. I also like Motorola's focus on heart health. I cannot trust traditional fitness trackers due to my body's extraneous movement. Since Motorola's fitness apps track data on my heart rate instead of on my body's movement, I can actually take the data seriously. I hope to have my Moto 360 a long time before I have to replace it.



Moto 360

(Continued on page 4)

A Special-Needs Summer

By Kathryn Jackson

One month ago, I spent an evening with a few close friends from church. It was a refreshing time of food, laughter and good conversation. We ended the evening in prayer for one another and it hit me in that moment that I was very-much-anxious about the summer. I confessed my anxiety in prayer and my sweet friends comforted me with their presence while I had a good cry!



Anne at FOCUS
Camp Hollywood

Why does summer create such anxiety in me? One very wise woman commented on my blog recently:

People who don't have a special needs child have no idea what "summers" look like. It's not sleeping in late, lounging around eating meals whenever, etc. but it is constant stress of always making every opportunity a learning experience. Yikes, this is hard and some days almost impossible to accomplish.

She nailed it. So what I've tried to do is walk the fine line between spending every moment working with Anne and letting Anne watch videos all day! I

think the key to this balance is to give the burden to God – let him carry my stress and let him give me the endurance to teach Anne.

It's a daily battle, but I think it's going well so far. Each week has presented a little different schedule and/or challenge providing us with the variety I need to endure. I've also lifted the burden by having a few people come to work/play with Anne each week.

Another highlight of our summer is that I've scheduled two camps for Anne which provide respite for me! Her first camp is this week, and her second camp is at the end of the summer. I'm so thankful for organizations like FOCUS and the Walton Foundation for providing accessible camps for kids like my Anne!

But I think the best thing about this summer is that Anne is thriving! Her seizures and irritability have diminished resulting in her being delightful and fun. I love my time with Anne! We are working on potty training and reading. She is doing well on both goals – staying dry and reading longer sentences.

This past week, I met the same friends who comforted me in my anxiety a month ago. Their first question was, "How's the summer going?" It was such a relief that I was able to say, "Great!" God has supplied our every need. He always does. I don't know why I ever worry ;) ■

Kathryn wrote this blog post in July 2014. Read more by Kathryn at her blog www.kathrynjackson.com.

Wearables

(Continued from page 3)

Smart watches are great, but for people who do not have use of their hands, these watches may not be practical. That is where Motorola's new Moto Hint



Moto Hint

comes in. The Moto Hint is a small bluetooth earbud that allows users to control their phones using their voice. With an Android device, especially with the Moto X smart phone, users can activate the Hint just by saying a trigger phrase. With an iPhone, you must tap the side of the earbud to activate Siri. Once you activate the Hint, you can control your phone just by speaking commands. The only problem I see with this device is its three hour battery life. While the Hint comes with a nice battery case, taking the device in and out of the charger multiple times a day would be an extra task for a caretaker. Even with this handicap, the Moto Hint could still change some people's lives dramatically. The Hint costs around \$149.99.

While these wearables are pretty good already, they are only going to get better over time. In the future, I envision wearables doing more advanced things like opening a door as someone walks (or rolls) up to it or automatically summoning an elevator in the same fashion. As of right now, modifications can be made to one's house to allow someone living there to do things like controlling the lights from their wearable. Overall, the future looks bright for assistive technology and wearables. For now, these are the best wearable devices available for purchase. ■

Trey Quinn is 15 years old with athetoid cerebral palsy. He is a freshman at Cambridge High School, and lives in Milton with his parents, his Canine Assistant, Whit, and two cats. Trey has one sister who attends UGA, studying to become a veterinarian. At school Trey is active in Future Business Leaders of America (FBLA) and the computer science department. He loves music and anything techie. When asked what chores he does at home, he answers, "Tech support!" Trey has a great sense of humor and a competitive spirit, and he loves to play wheelchair sports.

Information You Can USE!

GEORGIA MEDICAID COVERS DIAPERS!

Georgia Medicaid is now purchasing diapers, diaper liners, and chux pads (but not wipes) for children ages 4 – 21 with an eligible diagnosis of documented disabilities and a diagnosis of incontinence of bowel and/or bladder. Here's the drill:

1. Call one of the suppliers (listed below).
2. Supplier will set up a profile. You must provide your child's Medicaid number and name/contact info for child's primary care physician (PCP).
3. Supplier will contact PCP for prescription and letter of medical necessity (LOMN). This must be documented in your child's records.
4. Supplier will confirm Medicaid status and submit a request to Medicaid for authorization. This might take 30 to 60 days.
5. Once approved the supplier will send samples to parent for a 'best fit' and 'most effective' product.
6. Diapers will be delivered to your home!
7. Parent will order by phone or online every month from the supplier.
8. Authorizations are for 6 months. Supplier will re-authorize.

A few exceptions: If the child is receiving in-home nursing services, the child is not eligible. Parents should contact their Nursing Agency. The Nursing Agency can contact Medicaid to see if they can be reimbursed if they provide incontinent care products to the child. Again, this is the responsibility of the Nursing Agency who is providing services. If the child receives services from CMS, the parent must order the diapers from the supplier. CMS does not order diapers.

Suppliers:	Uromed	1-800-841-1233
	S2 Medical	1-888-799-3767
	Advanced Medical Group	1-877-645-5170

ARE YOU HIPPI?

Some resources feel like a best-kept secret! Georgia has a program for Medicaid members called HIPPI (Health Insurance Premium Payment). If your child has Medicaid, then he/she is a "Medicaid member" and can apply for HIPPI. From a parent on the FOCUS Facebook page: Once an individual has been approved for Medicaid, you may then apply for HIPPI. A calculation is made to determine if it is more cost effective for the state to give the child a separate insurance policy or just reimburse the family for the premiums it pays through its employer. For us, it is cheaper to reimburse us each month for the ENTIRE FAMILY'S premiums through my husband's employer than it would be to pay for a separate policy for just my one child. I submit paystubs each month. They are processed in about a week and a check is mailed to me. Easy and a super perk! Here is the website: <http://dch.georgia.gov/health-insurance-premium-payment-program-hippi> ■

The Story of Kyle

(Continued from page 1)

food locked, we have avoided obesity, which was the focus of the original doctors. He has learned to count calories and to make good choices when allowed to pick his own meals. That said, he, in an anxious moment, and with the opportunity, might eat unsupervised food.

I can honestly say that many a sleepless night was spent worrying about things that never happened. Yet other, unexpected issues replaced them. With advancements in the medical field, what to expect and what we are experiencing is changing rapidly. Now we face this syndrome with other PWS families we have met from around the world, thanks to the Internet and social media, where we share our challenges, successes, and knowledge. No one knows better than someone who is experiencing it firsthand.

Living in a large metropolitan area like Atlanta, we were fortunate to find help early on our journey as part of Kyle's group therapy at Scottish Rite. We became involved at LEKOTEK where we borrowed toys that helped Kyle in physical, speech and occupational therapies. He enjoyed several years with that program.

As he grew older, his needs changed and soon he was able to attend FOCUS' summer day camp, Camp Hollywood, at a church in our community. It was great to have such a loving, supportive, safe place for him to spend some time making crafts and getting to know others with disabilities. He likes to help those with more physical challenges and really shines when he gets a chance to be the caregiver.

Now, Kyle has progressed to the FOCUS Teen and Young Adult Group which meets once a month on Saturdays. This has allowed him to develop long lasting relationships with others, seeing them monthly at FOCUS groups. Kyle spent his first night away from our family at FOCUS' OctoberFest in 2013. It was a huge step for us and gave him such a feeling of independence. We never imagined he would be able to experience being away from home in a camp setting. He did so well with October Fest, he was able to attend FOCUS overnight summer camp, Camp Infinity – another new and exciting activity! He watched his sister go to camp and was so excited to have his own camp, too! That one experience has done more toward his happiness and growth than anything else.

With all these great FOCUS programs, Kyle has been able to grow and mature. From day camp to overnight camp (with no parents!), FOCUS has been there, providing him with opportunities and providing me with peace of mind. ■

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Looking Back ...

FOCUS Education Conference



FOCUS families enjoyed a day of information and networking at the 28th 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.



Super Sunday Skating Party

Super Sunday Skating Party at Skate Zone in Morrow was a rolling good time!

MVP Valentine's Day with Character



The 9th annual MVP Valentine's With Character was a fabulous afternoon! Children enjoyed dress-up, arts and crafts, photos and autographs with princesses from Fleetwood Dance Theater and superheroes from Hero Alliance, and stories by the charming "Queen Glitter." A special thanks to the Greek Orthodox Cathedral for the use of the beautiful ballroom, the Philoptochos Ladies Auxiliary for providing the delicious desserts, Marie Reynolds for her face-painting ability, and the Junior League of Atlanta for volunteering.

"For the Love of Children"



"For the Love of Children," the 32nd gala, which recognized Dr. Frank Berenson and celebrated FOCUS, was enchanting! Guests enjoyed bidding in the live and silent auctions, dancing to music selected by EEP Events, and generally having fun! Special thanks to host and emcee Tom Sullivan (www.tomonair.com). See page 6 for a list of sponsors and donors.

Volunteer at FOCUS!

Volunteers are critical to FOCUS programs! If you are interested in volunteering, please check out our website at www.focus-ga.org for the age requirements or email volunteer@focus-ga.org.

Coming Up at FOCUS!

Always check the calendar at www.focus-ga.org for the details of all programs!

May 3, 2015

FOCUS Day at Six Flags Over Georgia
Registration information will be sent by email on March 18. Call FOCUS if you need a paper registration form.

May 26 – 29*

Camp TEAM day camp
at Mercer University

June 20

Daddy-Daughter Dessert & Dance

June & July*

Camp Hollywood day camps

*Brochures and applications for all day camps were emailed to FOCUS families on February 6. If you need a paper application, please call FOCUS right away!

UNDER THE STARS FAMILY CAMPS

August 7-9**

Under the Stars Family Camp 1
at Camp Twin Lakes Rutledge

October 2-4**

Under the Stars Family Camp 2
at Camp Twin Lakes Will-A-Way

**Brochure and application for family camps will be emailed to FOCUS families on April 16. If you need a paper application, please call FOCUS.

To register for all FOCUS events, PLEASE read the emails & directions carefully! This ensures that your family will be able to participate – and saves FOCUS staff time!

New at FOCUS

FRIDAYS AT FOCUS!

Join other FOCUS parents to learn (and laugh!) for 2 to 3 hour workshops on various informational (and fun!) topics. Topics are announced by email. You must RSVP for Fridays at FOCUS by emailing elizabeth@focus-ga.org or calling 770-234-9111 ... be sure to let us know which date you want to attend!

FORE FOCUS!

at Bear's Best
in Suwanee
Tuesday, May 12th
Tee off at 9:00 am

For more information,
contact
lucy@focus-ga.org



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