

AUGUST 2017

ViewFinder

A FOCUS + Fragile Kids newsletter that frames and focuses life with children who are extraordinary and medically complex



Georgia Grace

By Kristen Rohde

My 7-month-old daughter, Georgia Grace, has Moebius Syndrome. The slogan for Moebius Syndrome is “we smile with our hearts” since many of the children, like Georgia, are physically incapable of smiling due to the absence or underdevelopment of cranial nerves.

Georgia has very limited facial expression, cannot close her eyes, has no oral motor skills (no swallow, suck, cough, etc.), has partially paralyzed vocal cords, and cannot manage her secretions. Georgia is 100% G-tube fed, requires frequent suctioning, and recently got a trach. Georgia is hypertonic in her extremities, but hypotonic in her trunk. We do not yet know Georgia’s cognitive abilities, but she has not hit any true developmental milestones and we do not get much feedback from her. Typically, the prognosis for Moebius is good, but it’s a spectrum and Georgia is on the more severe end. Although every day of the past 7 months has been long and hard, I know we are still at the beginning of our journey and there are still a lot of unknowns.

Georgia is currently at CHOA – Scottish Rite recovering from her tracheostomy. By the end of this extended stay, Georgia will

How to Reach FOCUS



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<http://tinyurl.com/focusgeorgia>



continued on page 6 >

From the Editor...

by Lucy Cusick



My job is tough ...

WHEW! The merger is done and the dust has settled. We love offering equipment grants in addition to camps, family activities, and swim team. The loaned equipment room is almost empty – great to see this equipment going out to ‘new’ homes!

Some of us are still on the journey, just with bigger ‘kids.’ We still struggle, but we know all the acronyms!

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Sometimes I think back on the good ol’ days when I knew the name of every FOCUS kiddo – and their parents’ names, too! We reach more and more families each year, and I gave up trying to remember (or even know!) everyone’s name. As we have grown we also needed to improve our infrastructure: technology, staff, and (of course) budget.

Seems like ‘big business,’ huh? Maybe ... but our (grass) roots still show. FOCUS staff would rather visit families in the hospital or go to Share Group than write grants; Family Camp is more fun than fund raisers, although both make our feet hurt. We still remember the early days of diagnosis, the introduction into this new world, and all the conflicting emotions. Some of us are still on the journey, just with bigger ‘kids.’ We still struggle, but we know all the acronyms!

We want to continue to help as many families as we can with Comfort, Hope, Fun, and Equipment. Our board will continue to evaluate programs – how can we better serve more families, what makes the biggest impact. We’ll write those grants and organize those fund raisers – and tell our stories. And yours.

Thank you for sharing your stories, your children, your journey with us.

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From a Camp Nurse

by Valarie Scales, RN

Hello! I am Valarie Scales – one of the dedicated, long-standing nurses with FOCUS. Here at FOCUS, I take my responsibilities and duties very seriously.



Having a child with exceptional needs is one thing; entrusting him/her to a non-family member requires trust on an entirely different level. As a parent, you want to know that your child will receive the utmost care possible outside of the home environment. I vow that I embrace this sincerely! I know that every day won't be a good day for your camper, but my duty is to make it a safe one. With my selective short term memory, I have a policy to make each day a new one!

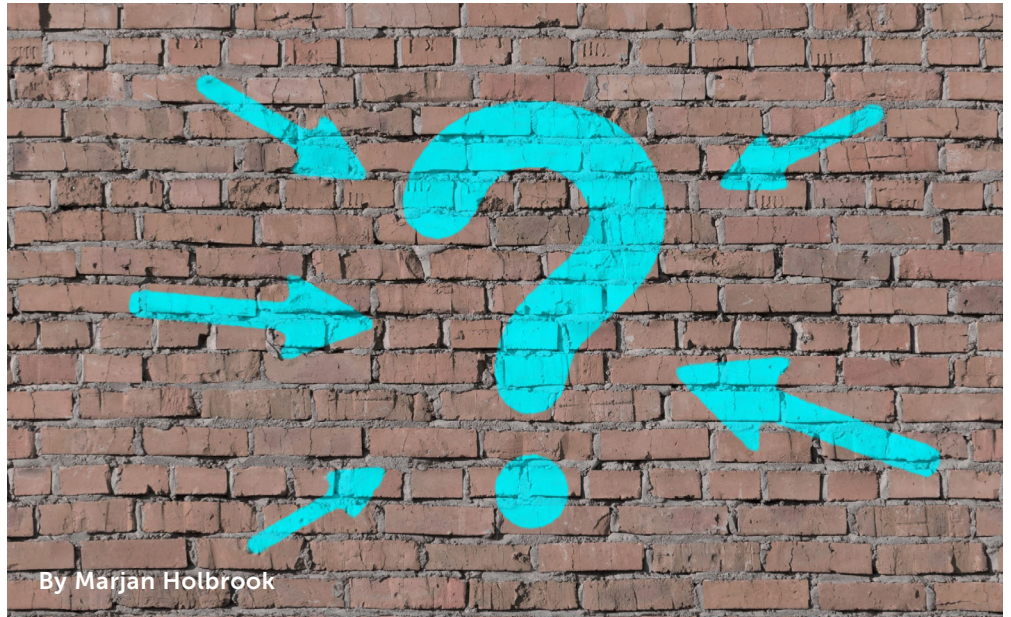
My duties include, but are not limited to, seizure recognition and management, dispensing medications and supplemental feeding support.

I have been with FOCUS for about 5 years now and when I am at Camp Hollywood or respite ... I am home. The children, parents and service animals, and staff are all family to me. It warms my heart to be a part of your kids' growth and development. I thoroughly enjoy their smiles and laughs and try to limit their tears.

Last summer, I practiced my suturing skills as I stitched up a bean bag froggie for one of our campers! My job doesn't end at the medical table, I help with art projects – I look forward to helping paint the legendary picture frames each summer. Those Rice Krispie treats in cooking were quite tasty, and I dance to "tooty ta" after applying a band aid to a small boobo. Music reaches us all in a phenomenal way. Our closing camp song "What I Am" by Will-I-Am allows us to be happy, musical, smart and sometimes even grouchy!

My tour with FOCUS allows me to embrace the reason nursing chose me. I am a nurturer. I think I can speak for all the FOCUS + Fragile Kids nurses and say that we truly love your kids and we pledge to take care of him/her to our utmost ability! Thanks for trusting us with your babies!

What they don't tell you (about parenting a child with special needs)



You will still have to be a decent human being. You get a few more hall passes than everyone else but for the most part you cannot use the difficulties of your life as an excuse to misbehave. This is not always easy, especially not when you know every single person sitting in that IEP meeting deserves to be told, “Bless your Heart.” The rules don’t change just because your life is more complicated than those around you. This is especially important when interacting with volunteers. Be an advocate for your child but remember to always thank the volunteers.

You will not fit in. Do you really think I can talk about where to buy those giant hair bows when all I have been thinking about is my daughter has not pooped in 3 days? There is an incredible community of families who have children like mine. Those people get the poop stories, but we are the minority in the larger community. You will still be a part of everyday conversation with your friends and neighbors but, from time

to time, you will be reminded you are not the same. It’s not all doom and gloom. I love that I don’t always fit in. It has excused me from being a part of drama, keeping up with the Jones, knowing which style of jeans are in this year.

Shared diagnosis does not mean shared interests. Nine years ago, when my daughter was initially diagnosed I thought I would spontaneously become friends with any parent

Do you really think I can talk about where to buy those giant hair bows when all I have been thinking about is my daughter has not pooped in 3 days?

who has a child with the same diagnosis as mine. While it is true a shared diagnosis means a better understanding of what the other person is going through, chemistry and shared interests still play a big role in friendships. I need the guidance and help of the parents who have walked in my shoes but it does not mean I am going to run out and get them all BFF necklaces. You and your child are more than a diagnosis.

There will be people who feel sorry for you and others who will be jealous (gasp) of you. The sorry part is easy to understand, but jealous? Who in the world would be jealous of your state of affairs? Have they seen the pile of laundry on what used to be your couch? The world has changed. Social media has made ordinary people into local and sometimes national stars. People want to be seen and, at times, become envious of anyone who gets the spot light more than they do. How do you change that? Next time you see a parent post pictures of the new equipment or the new trip their child was given,

celebrate with them. Show the world what being happy for someone else looks like.

Your family may not be your real family. Regardless of the names on the ancestry.com report or the names on your marriage certificate, you may find your tribe is a completely different group of people than the ones who share your name. Distance, lack of knowledge, and differences in expectations can break up a relationship. Once you stop fixating on how someone did not meet your expectations it will greatly reduce the amount of sadness and stress you experience. Instead of thinking about how things should look, focus on how you will handle the situation in a positive way. This will make you more effective by putting you in the driver's seat. Someday you will look at your tribe and notice every person reflects who you want to be and how you want to feel.



Coming Up...

... at **FOCUS + Fragile Kids**
Stay up-to-date by liking us on Facebook!

August 11-13
Under the Stars Family Camp (full)

August 26
SummerFest at Monday Night Brewing

September 9
FOCUS on Moms ATL

September 16
FOCUS on Moms West (Villa Rica)

September 17
Aquarium Day

September 23
Fragile Hearts Wine Tasting

September 29-October 1
Under the Stars Family Camp (register quickly!)

October 14
Blue Ridge 250 Motorcycle Ride

Share Groups, FAST Fins Swim Team, Workshops, MVP Activities and Extra Special Saturday respite are gearing up for fall – watch the weekly emails for registration information!



have spent 3 of her 7 months of life in the hospital. I'm fortunate enough to have already been a stay-at-home-mom so I'm able to be at the hospital with her during the day. I'm also fortunate to live nearby so I've made the choice to sleep at home most nights during these longer-term visits. It's saved my sanity and probably my marriage. Although we feel mom-guilt with special needs kids on a whole new level, I know that I likely have the rest of Georgia's life to take care of her, and I'm thankful for the break when I have help. I've agonized over asking for help, but I'm learning to accept it via nursing, or a capable friend

or family member. We are no good to anyone in our family if we burn out, and every day I realize more and more that we have begun a marathon.

My biggest juggling act is balancing Georgia's care while also caring for my son, Owen, who is the happiest, healthiest almost-3-year-old that you'll ever meet. Georgia has had frequent doctors appointments, therapy visits, and inpatient hospital stays that require me to get extra help with my son. I mostly feel like I have to choose which child to spend time with, but just like when I'm with Georgia, I do my best to maximize one-on-one time with Owen. The reality is it's

easier for outsiders to help with Owen, so it's often me staying at home with Georgia while he is taken care of. Again, I remind myself to count my blessings that we have friends and family nearby willing and able to help.

I think one of the greatest gifts my special needs child has given me so far has been perspective. Suddenly, I'm not worried about having the cutest diaper bag because I'm much more concerned with the contents inside of it. Having an immaculate house, perfect wardrobe, and full social calendar are just not possible any more so they can't matter as much. The artificial deadlines I set for potty training or swim lessons for my healthy son don't seem as urgent. My greatest desire is to spend time with my family and to take care of them well.

The biggest lesson I've learned through Georgia so far, is that she needs us to be one-day-at-a-time parents 90% of the time. The other 10% of the time I give myself permission to look ahead, plan ahead to the best of our ability, and worry. I think about what consults

Georgia needs, what therapy goals we're working towards. But 90% – the majority of our time – needs to be spent in the moment. We make the best decisions we can for our children with the information we currently have. As hard as this time is and as anxious as I am to see how Georgia will grow and develop, it is the only time Georgia will ever be my baby. Since joy is so much harder to find in this situation, I don't want to miss a second of it.

I talk a lot about the "competing goals" that we have for Georgia. For example, the tracheostomy was necessary for Georgia to breathe clearly, but won't allow her to vocalize or promote oral motor skills such as swallowing. A hit for her development and speech/feeding therapy, but the higher priority right now has to be her breathing. Since Georgia cannot close her eyes she has light sensitivity, so we end up covering her eyes a lot. I want her to be able to see and experience the world, but we also need to protect her eyes from irritation and dryness.

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We're learning that the first several years for so many special needs and/or medically fragile kids is tackling the medical issues necessary for their survival and just figuring out this new life.

Like many of you, I know that as hard as people try, they don't "get me" or understand what we're going through – how could they? I had to laugh at myself the other night when a kind woman from our church came to bring us dinner. As she was leaving she said sweetly "And don't you worry dear, you don't need to write out a thank you note for this". Honestly, the thought had not even occurred to me to write a thank you note for this. I was completely overwhelmed. Texting is my chosen form of communication. I can barely keep up with showering and brushing my teeth every day, much less writing thank you notes. The road that we are on has felt very lonely and explaining our children can be exhausting. But I am fortunate to have an inner circle of friends who follow our

story closely, a therapist who I can vent to, a supportive and helpful family, and above all a relationship with a good God and perfect heavenly father who I believe knows and loves Georgia and has a plan for her life.

Still, I grieve. It does not mean I love Georgia any less, but I grieve for her struggle and for the babyhood I pictured her having. I grieve over the medical probability that I may never see Georgia smile and I may

never know what her voice sounds like. I grieve over this year that has been spent much differently than we imagined and the heartaches it has

brought to our family. With every poke and procedure, I wish I could trade places with Georgia Grace and pray that God will give her comfort, ease her pain, and give her an easier life. I know Georgia has a Heavenly Father who created, loves, and knows her; who gives and takes away, and remains sovereign through every joy and pain. I find peace in knowing that Georgia is not a surprise to God – her challenges and her victories are known to Him and a part of who God created her to be.



**Kristen &
Georgia Grace**

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Kids Golf Classic!*



Zoe

by Katie McKoy



Twelve years ago when Zoe was born, her Apgar scores were 1 and 4. She had a grade 3 intraventricular hemorrhage at birth and subsequent GI issues, respiratory issues, and seizures. We heard a lot about what she would never be able to do when she grew up (if she even made it to her 1st birthday) from a lot of people who are more educated and smarter than us. It was a scary time.

Twelve years ago, I became something I never thought I would become and was thrown into a world I never knew existed. I became a special needs parent. Zoe would have a lot more medical diagnoses and equipment in the years that would follow. But one thing would never change. She was Zoe and she was the one in charge of this journey.

Little by little, with the help of family, friends, other special needs parents, therapists, different doctors, nurses, teachers,

paraprofessionals, and many others, we now have a 12 year old young lady who is exceeding everyone's expectations. Yes, she has her limitations and issues, but she is an amazing young lady who brightens the day of everyone around her. I wouldn't trade her for the world. The world would be a better place if we were a bit more like Zoe.

My point in sharing this is to send a message to those who are in the early years of this journey: never give up on your kid. Keep swimming. Refuse to take "no" for an answer. Keep pushing. Don't be afraid to make mistakes. Let your child lead as much as possible. Listen to them even if they can't talk. They

will show you the way more often than not. Trust your gut and intuition. Focus on your child's quality of life. More often than not, your kid will surprise you. And no matter what, I promise you that it will be ok even if life and your situation is not 100% fine. You got this and are a good parent.

Never give up on your kid. Keep swimming. Refuse to take "no" for an answer. Keep pushing. Don't be afraid to make mistakes. Let your child lead as much as possible.

Volunteers & Part-Time Staff at FOCUS + Fragile Kids

FOCUS + Fragile Kids staff and volunteers are incredible people – from nurses, caregivers and music therapists at Extra Special Saturday and day camp to coaches at swim team. They are dependable, loving, and responsible – we could not manage the programs we have without these amazing folks.

We also greatly depend greatly on volunteers at FOCUS + Fragile Kids – for the extra hands, energy, and youth. Our kiddos love the attention from these young people, and their willingness to give up their time amazes us! Usually, we do not assign specific children to volunteers; instead we assign volunteers to a group. It's always fun to watch them gravitate towards a particular child - the best pairs happen on their own!

Big FOCUS + Fragile Kids group hug to all those who support our children and their families!! Thank you!



"These are great kids with great enthusiasm for learning, playing and for life. I have learned a lot just by being around them and also appreciate without wasting even the smallest blessings. I would definitely continue working and volunteering at FOCUS and recommend this rewarding experience to my friends and family."

"Standing at the door at Six Flags was a particularly profound experience for me because rather than 5 families, I saw almost 200, each individually trying to provide for their children who need a little more care than most. It dawned on me then just how difficult it is to be in such a situation. I am so, so glad that they are able to turn to FOCUS for support and care, and I had so much fun being a part of that."

"Working with the children and families through FOCUS was one of the reasons why I decided I wanted to become an occupational therapist. First, working at the Saturday respite opened my eyes to how rewarding it can be to work with kids with disabilities. Then, working at Camp Hollywood showed me a way that I can help them – adapting activities to fit a kid's individual needs and giving them experiences they may not have had otherwise."



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Looking Back at the FUN!

