

DECEMBER 2018

ViewFinder

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



“... but I think the biggest lesson we have learned in her 5 years with us is that while Meagan has come a long way, we have come a longer way ...”

The 5-Year Lesson

By Molly Gareau

It's hard to believe that it has been a whole 5 years since Meagan was born. But, as they say, time flies when you're having fun. FUN? Probably not the word you would use to describe our last few months, right? We have had some harrowing times recently with Megs and those have not been fun. As a matter of fact, they have been downright scary. However, here we are, safely past her 5th birthday and on to year number 6! And although I wouldn't characterize our last few months as 'fun' with all that has happened, I can't think about Meagan without thinking of fun.

Meagan has come a long way in 5 years. She has started walking this last year, talking more, eating more things, and overall being more curious about life. Those are all big changes, and we are grateful for all of her many positive strides ... but I think the biggest lesson we have learned in her 5 years with us is that while Meagan has come a long way, we have come a longer way! As a family, as parents, and as humans. Meagan has taught us how to have fun and how to love. Priceless lessons we would otherwise have never learned.

When we were gifted Meagan as our child (and yes, she is a gift, as are all our children), there were a lot of questions. There still are, to be honest. As a matter of fact, we probably have more questions now about her future than we did when she was born. As she grows, life gets complicated and so do her challenges. These last few months have been particularly hard because they were the first few times we literally felt helpless and were very scared she may not come home with us. Our girls, for the first time, felt the fear of their sister not being with them. But those experiences have made us realize how strong we are as a family and how much Meagan means to us as a unit. Because Meagan is fun. And our family wouldn't be fun without her.

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From the Editor...

by Lucy Cusick



Claire and Meagan

Many of you look to my editorial for insight as a parent of a now-adult son with cerebral palsy. I often share victories and failures, parenting mistakes, or just plain funny stories. This is not one of those times.

This year has been filled with loss for many FOCUS + Fragile Kids families. We have lost so many children – and parents – in 2018. One after another and another, with no time to grieve individually. At some point, I found myself dreading phone calls, waiting for the next death.

Last week, Meagan (see cover story) made a special delivery to FOCUS + Fragile Kids. For her birthday in September, instead of asking for toys or books or a pony, she asked for gifts to help send kids to camp in memory of her friend Claire. Meagan and Claire have always been friends; born just a few months apart, they shared the same diagnosis and a similar life: touch-and-go stays in the hospital, scary surgeries, and a love of life and fun. Their parents found each other after Claire's, but before Meagan's, birth. In fact, Claire's parents visited Meagan daily after her birth because she was transferred to a different hospital for specialized care, away from her mom. They held and loved her until her mommy could be there to hold and love her.

Claire died suddenly in March; her favorite FOCUS program was FOCUS Camp Hollywood. Meagan connected all those dots so her parents, Molly and Brian, established the Claire Gibbs Memorial Camp Fund. Meagan was very excited to hear about camp and to deliver almost \$2,000 for scholarships!

Our kids truly are special. They bring us together. They teach us to celebrate baby steps and not sweat the stuff that really doesn't matter. We treasure them, and when they leave us, we miss them terribly.

During this season, please remember those who hurt. Be kind. Give light. And maybe a hug.

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Home Alone and Baby Sharks

By an Anonymous FOCUS Mom

Our home is like the house in the popular 80s movie “Home Alone.” It’s decorated for the holidays and booby trapped – but not for the same reasons as the movie where the little boy Kevin accidentally gets left home alone while his family flies off to their holiday destination. Eight-year old Kevin must protect himself from nefarious intruders who break into his house while his parents race home once they realize their mistake.

While the thought of someone trying to get into our house is scary – it’s almost impossible to be honest. Our house is Fort Knox on steroids. The intruder may – and this is a strong may – be able to get in – but like the Eagles’ song “Hotel California” – the intruder could never leave.

For you when you have a young differently-abled child who does not understand stranger danger, literally loves everyone and is a runner – you go to great extremes to keep them inside and safe.

Like – for example – the triple locks on the external doors – each with different

mechanisms requiring adept fine motor skills.

Or the sensors on all the doors AND windows that loudly beep every time they open – just in case someone figures out how to unlock and open the crank-style windows.

Or the security cameras pointed at every entrance of the house in the off chance that our son does get out (which actually did happen once during the holidays when we had company over).

Or the industrial, metal-drilled-into-the-wall- baby gates in almost every room which baffle even the most seasoned OTs.

Or the baby locks strategically placed on the interior doors.

And then there are the booby traps.

Our son is obsessed (like so many others) with baby sharks. So in my infinite wisdom I thought, “Wouldn’t 100 miniature, hard plastic sharks with sharp fins be great to use as math counters?” Nope. Nope. Nope. The brightly colored baby sharks make stepping on Legos feel like a pleasant foot massage. And, of course, all 100 are usually scattered throughout the house. After endlessly picking up and stepping on said sharks, you give up, always wear shoes,

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Home Alone and Baby Sharks

and figure they're now an extra layer of security.

And then, of course, everyone knows that sharks need water. Our son just also happens to be obsessed with dumping water on the tile floors near his sharks. Dodge the sharks – slip on the water. Either way – no one is getting far without some kind of injury.

And then there's our very special service dog who truly believes she's a lap dog. She loves everyone – like our son – and will literally push over any intruder with her 90-pound body as she looks for attention. Seriously.

And last but not least – after spending 9 years on-call 24/7 with our son who has medically

diagnosed severe insomnia, I don't miss a sound. Any change in breathing heard through the baby monitor in our son's room – despite sound machines and fans – this momma bear is up faster than Olympic sprinters (well, until I step on a baby shark).

So this holiday season as we prepare to celebrate with our

family and friends, we celebrate the many ways in which our differently-abled son has made our home an adventure and one not for the faint of heart or feet.

(This super mom assures us at FOCUS + Fragile Kids that the family has an escape plan that includes leaping over baby sharks in a single bound and that their daughter has ninja unlocking skills in case of a fire!)

... So in my infinite wisdom I thought, "Wouldn't 100 miniature, hard plastic sharks with sharp fins be great to use as math counters?" ...

FOCUS + Fragile Kids Ongoing Activities:

For **Share Groups, Workshops, Hospital Visits, and Medically Fragile MVP** events, contact elizabeths@focus-ga.org

For **Respite, Day Camps, Overnight Teen & Young Adult Camps, and Family Activities**, contact sarah@focus-ga.org

For **Adapted Swim Team, Teen & Young Adult Activities, Family Camps or to volunteer**, contact brian@focus-ga.org

For information about **Equipment Grants**, contact angie@focus-ga.org

Check our calendar at www.focus-ga.org for the most up-to-date information!



My First FOCUS + Fragile Kids Saturday Respite Childcare

From the Perspective of Michael Campbell, 10

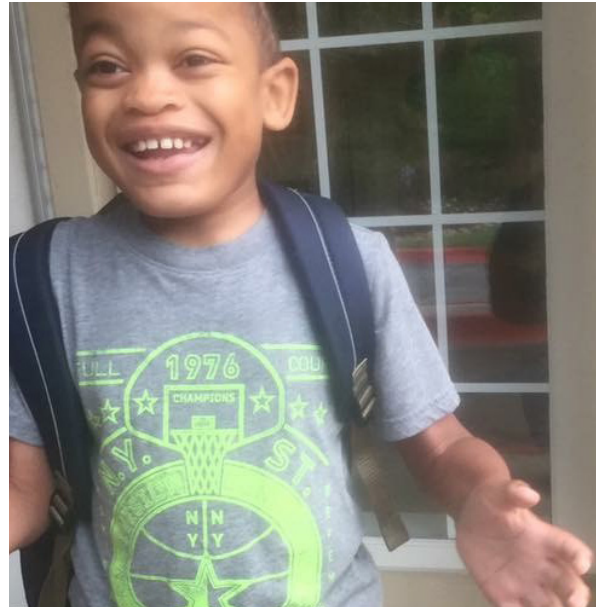
Hi! My name is Michael, and I got to go to FOCUS + Fragile Kids Respite in October for the first time. I've never been to anything like this before, and, boy, was it fun!

When we first got there, my mommy was able to follow the "FOCUS + Fragile Kids signs" in the parking lot that told her exactly where we needed to go. When we came in the doors, some nice people in red shirts greeted us and found my name on their list. I didn't have to take any medicine that day, but a really pretty nurse was there putting everyone else's meds in a locked box with secret instructions.

One of the people in a red shirt – somebody called them "staff" – took us to a classroom. I met kids there who would soon be my new friends, and I found toys and trucks to play with! I like to put things in my mouth, so the people in the red shirts kept their eyes on me to make sure I didn't eat anything that wasn't my lunch.

While I got used to my new space, my nervous mommy was able to talk to the people in the red shirts. I wear diapers, and she was worried about me being changed. They told her that I wouldn't be changed by just one person, but that there would be two people in the room to change me! This was really cool because I like lots of attention!

Mommy was giving away all my secrets – she told my teachers that I was a "runner." But, Mommy noticed that the people in red shirts always stood in front of the door to remind me to stay inside! I think she liked that! Mommy was also worried about my behavior. Sometimes I like to use my hands to get attention. Turns out, there were lots of other grown people there in shirts that said "Mercer Physical Therapy." They helped me find toys to keep my hands to myself and to keep me busy.



Once Mommy was relaxed, she left me there to play and learn with my new friends. We spent time in the toy room, gym, and outside! The playground was so much fun, and it was fenced in, so I didn't wander away. But I didn't want to because I had new friends and fun things to do!

When I ate my lunch, the nurse helped kids who don't eat with their mouths to get their food directly into their bellies! How cool is that?

Guess what we did after lunch? Listened to music and played musical games! (I heard someone call it "music therapy.") We got to sing and dance to new songs. I have a hard time holding things on my own, but one of those special Mercer people cupped her hands over mine so that I could play the maracas. It was so much fun – I love making noise!

This thing called respite is much more fun than school, and my Mommy said she could get used to having a breather. I don't really know what that means, but I can't wait until my next adventure at FOCUS respite! Maybe you can talk your parents into letting you come too!

Interested in more information about Extra Special Saturday Respite? Email sarah@focus-ga.org.



We are so grateful for the grant we received from FOCUS + Fragile Kids to help towards the lift for our van. The lift is in, and it is working beautifully! Thank you so much for helping us navigate this process. And please thank everyone who has donated money to help us get to this point.

This is really a dream come true for us. I can remember years ago going to CHOA/ Scottish Rite and seeing other families getting in and out of their accessible vans and wishing I could have something like that. At the time Stockton was younger and still light enough to lift in and out of his manual wheelchair and into our Suburban. That was doable for many years. But as he has grown, that scenario became difficult. Not only has he gotten bigger and heavier, so have his wheelchairs! We began pulling his Permobil K3 on a trailer. Going out became so stressful. We transferred him in and out of the chair and into our van which became dangerous as he hit 125

pounds! And rainy days were the worst – we had to cover the chair with a tarp and hope that it would stay dry. I found myself keeping him home because it was so hard to load the wheelchair.

Fast forward to now! The past few days with our new lift have been AMAZING!! Every day life is so much easier. No more worries about dropping him on a transfer or hurting Dad’s back. This has been such a blessing to our family. It is also a conversation piece with his peers. They have enjoyed watching him get in and out of the van with the lift.

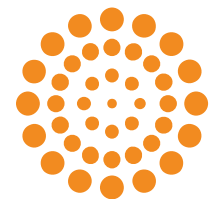
We are excited about driving up to the mountains in a

few weeks to see the leaves change. It will be so wonderful to be able take a quick day trip and stop for lunch somewhere without having to worry about the difficult transfers and hauling the chair on a trailer. Doctor appointments will also be so much more manageable. Before the lift I would have to find someone to go to doctor appointments with me, to help load the wheelchair. Friends and family would have to take a day off work or school. I am actually excited about our next doctor’s appointment and having the freedom to take him without any help!

I wish I were a better writer and could more fully express what this means to our family. We

feel so blessed to have received this funding to help with the lift. We are so thankful that God has given us the “problem” of a growing boy who has outgrown being lifted by Daddy as we are very aware that many special needs children do not make it to this point.

Thank you so much for your generosity!



FROM THE COVER
The 5-Year Lesson

In Meagan's 5 short years, she has taught us how to laugh in serious situations. She has taught us how to think freely without reservation. She has taught us how to ask questions, answer without a filter, and say what's on our mind. Meagan has taught us humor, compassion, and friendship. Most of all, Meagan has taught us how to love unconditionally. She has taught us judgement-free, unfiltered, pure unconditional love. Of all Meagan's accomplishments, I think this is the most important.

As a parent, we always talk about unconditional love. We love our kids no matter what. Of course we do. But we are also human and we still have tiny stigmas that come along with that. Not Meagan. She is free of those reservations we struggle to ignore. I have seen her hug someone after they were mean to her – she being totally unaware of the 'mean' but just sensing the person needed a hug. I have seen her rub her sisters' heads when they were sick even though she might be having an off day. I have seen her snuggle her dad when he's tired. I have seen her give kisses to her baby sister when she's crying. Meagan doesn't sit around and analyze whether someone needs love ... she just gives it. Without judgement. Without hesitation. Meagan really is love, to the truest definition.

We were blessed this year to have many friends be able to attend Meagan's birthday celebration. We probably had close to 100 people at the house throughout the day. The afternoon was filled with laughter, celebration and fun. Meagan was beaming when everyone sang her "Happy Birthday" and loved seeing all her friends. She spent the evening Facetiming her extended family far away and loved talking to her grandparents and aunts, uncles, and cousins.



It was quite a celebration for a 5-year-old! But, as we already know, she isn't your typical 5-year-old. She is loved by many.

Life is serious. It is very serious. And, we do have to treat many situations with such gravity as they cross our path. Still fresh in my mind is sitting in the ambulance in Virginia holding Meagan's limp hand as the EMS tried to get her to breathe again ... or cradling her on the side of the road covered in vomit as she seized and desperately looking for the ambulance to find us. These are the very serious things that we have lived through with Megs. However, even in those desperate times, all I could think about was missing my fun little girl ... her smiles, her sweet nature, and her love. Even in serious situations, Meagan had helped me to think about the positive. She showed me why we trudge through all the serious – because the fun times are what make it all worth it.

I am so excited to see what the next 5 years hold for sweet Meagan. Surely there will be more difficulty ahead. But we know that, right? I just hope we can get through it all with as much poise and love as she has helped us manifest up until this point. The world has enough darkness. I'm so thankful Meagan is here to keep spreading her light. Her beautiful judgement-free light of love.

Looking back, I now see that it's not Meagan who has come a long way in 5 years ... but really the rest of us, who have been lucky enough to encounter Meagan's love, if even for a moment. We have so much more to learn from her little soul, and I cannot wait to open my heart to those lessons. I hope you will, too.

Looking back at the FUN!

Do you look at these photos and wonder how to get involved?? Here's how: **READ** our Monday Parent Emails! **EVERY WEEK!** That's how we announce and how you register for programs!

JUMP IN! Don't know anyone? You will, after your first activity! **PROMISE!**





CONTRIBUTIONS

Corporate/Foundation/Groups

Amazon Smile
Anthem for TICU program
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Colorado 500 for Family Fun Ride
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In honor of Bret Weiland by Rebecca Selber
In honor of Doris Melnychuk by Barbara & Matt Battiato, Sharon, Michelle & Mike Rivera
In honor of Eli Carrillo by Genevieve Carrillo
In honor of Elizabeth Amodio by Holly & Carl Amodio
In honor of Ira Rachelson’s birthday by Rose & Michael Haber
In honor of David Herold, Welcome Home, by Rose & Michael Haber
In honor of Lucy Cusick by Elaine & David Harris
In honor of Matthew Grossman by Luise & Mike Stone
In honor of Nick Kostopoulos by Angela & Nick Economy
In honor of Noelle Ford by Joyce & Ron Crowe
In honor of Susie Williams by Pamela & Charlie Williams
In honor of The Seidl Family by Maria Kochiras
In honor of Joni Pelta’s birthday by:
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Nancy Rudy
In honor of Michael Haber’s birthday by:
Sharon & Stuart Cott
Myrna & Paul Cott

In honor of Teddy Haber’s 100th birthday by:
Barbara Katinsky
Ellen & David Herold
Susie & Tom Williams

Memorials

In memory of my sister Alice by Eugenia Costarides
In memory of Barbara McGoff by Sharon Rivera
In memory of Joe Tatum by the Greenwood Acres Civic Association
In memory of Julie Klee by Susan & Doug Klee
In memory of Dolores Carlon by Elinore Wynne
In memory of Michael Moir by Betsy & Jeff Fester
In memory of Melinda Quinn by Betsy & Jeff Fester
In memory of Robert Russell by Christine & Robert Byrne
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for the Liam Vilensky Camp
Scholarship Fund by:
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Thanks to all who created Giving Tuesday and Birthday
Fundraisers on Facebook! In 2018, we've raised over \$10,000
on Facebook, thanks to so many of our families and friends!

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Fashion Show



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For the Love of Children Gala*

April 9, 2019

FORE FOCUS Golf Classic*

**Email lucy@focus-ga.org for more information*

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