

DECEMBER 2019

# ViewFinder

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



## Brave. Strong. Heart.

By Melissa O'Dell

Before Ellie was born, our older daughter, Evelyn, spent one night in the hospital. I so clearly remember being sent to the ER at Scottish Rite – waiting on the stretcher as we nervously watched them draw labs and start an IV, all while trying to entertain our toddler and keep her calm.

My husband Brandon went out to Target to grab clothes and toothbrushes for us and we both slept on the little bench in the room. At the time, it was a traumatic night for us. But as we pulled Evelyn along in the red wagon and chased her down with the IV pole (to make sure the IV would stay intact), we saw other families that had been there for a while. I remember thinking that they looked so strong and (ironically) being grateful that our kid was healthy, and a little virus meant we got to go home the next day.

How life has changed since then! Ellie, diagnosed with Down syndrome and a congenital heart defect (AVSD), was born a year later. At three weeks old, Ellie had her first ambulance ride to the hospital and her first admit to the PICU. We were quickly thrown into the world of feeding tubes, oxygen, hospitalizations, and durable medical equipment companies. Ellie spent the next couple of months in and out of the hospital until she had her first open heart surgery at 4 months old. Five open heart surgeries and over 200 days in the hospital later, we have learned how to find strength as a family from a brave little girl.

“How do you do it?” is a common question that we are asked. Honestly, we aren't sure how we get through some days. But, it's the love and support we have from friends and family, and the trust in a loving God who knows each day of our lives.

Ellie's longest stay at the hospital was almost 5 months long (even though we were told to expect a 5 day stay). We were

*continued on page 4 >*

## How to Reach FOCUS



770-234-9111



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# From the Editor...

by Lucy Cusick



Lucy and Josh in 1994 at Lucy's first FOCUS event as Executive Director.

As most of you know, I plan to retire from FOCUS + Fragile Kids in the next few months. We will share news of my successor in the coming weeks and I know you will welcome him or her with open arms.

I'm not saying good-bye just yet, but I am beginning to reminisce about my time at FOCUS.

I wrote this in my first FOCUS newsletter as Executive Director: *The whole premise behind FOCUS is that we have struggles that seem unfair, endless, and ongoing. We also have each other to lean on, learn from, share with. Susan Calhoun, with several other couples began FOCUS with a vision, a vision of families helping each other through tough times, of celebrating with each other through the good times.*

*We must dream to have a vision. I didn't allow myself to dream after Josh was diagnosed....what would I dream? How could I wish this hadn't happened ... I can wish for him that he was healthy and had no disability. Could I wish that for myself, or is that considered selfish? I am finally beginning to dream again, to have a vision of the world I want him to live in. A world that celebrates differences, includes all people, values all lives. We can have that world, but we must dream!*

*My vision for FOCUS is simple.....to give families support necessary to survive and heal and move on to dream again. It's difficult to do alone, we can learn from the experience of others. Our children are our dreams and our vision is our future.*

Josh was 8-years-old when I wrote that – and I was still pretty green about the long-term implications of having a child with a disability. Somehow, I never thought he would ever be a 33-year-old with a disability – I just never looked that far ahead! But, now, I am also 25 years older and I realize just how difficult it is to “survive and heal and move on.” Our children change our lives – our outlook, our perception, our dreams, and our vision.

Surviving took a lot of energy – healing and ‘moving on’ are continual parts of this journey. But I’m thankful I didn’t have to do it alone – you all walked with me, giving me encouragement and sharing experiences. Grateful.

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# A Village of Champions

By Kim Forester

When you become a mother, or a father, the miracle and fragility of life collide in an explosion of love. When you become the parent of a child with special needs, the accompanying fear has a few extra dimensions. There are health concerns, worries over both physical and social development, concerns about acceptance by peers and the community at large, the future ... so many unknowns. And, resting right in the middle of that giant ball of worry is the biggie: "Can I ... how do I ... trust others to care for and educate my child?"

Evelyn is 12 years old and just started middle school. I can clearly remember, in her first few weeks of life, not even trusting my own mother to hold her properly! I couldn't conceive of leaving her alone with anyone except my husband ... and even that was difficult.

Currently, Evelyn attends school four days a week with a 1:1 nurse, and we have nurses who help us at home part-time. With three younger brothers, it has been necessary to learn to trust that it really does take a village. She is thriving, as is our family...and while our daily life isn't without bumps, things generally work quite nicely.

So, how did we get from there, to here? How do you look at your sweet baby, who is full of life and personality, but can't necessarily tell you what happens when you're not around, and take the leap? Well,

every family must follow its own path, and, for us it was a combination of leading with our hearts and knowing our limitations. I knew with 100% certainty that for our family to be whole and happy (and not just exist in survival mode) that my husband and I could not be the only teachers and caregivers for our daughter. I also knew that Evelyn thoroughly enjoyed the social and educational experiences she had prior to starting school and suspected that with the right structure she would love school as well.

At our first IEP meeting, I was scared and nervous. We had heard so many negative stories, and Evelyn legitimately needed a lot of support to make school a safe and worthwhile place to learn. I decided to walk into that meeting expecting it to go well, expecting to get exactly what she needed, and that is exactly what happened.

In the first couple years, I was still nervous and wary of these teachers and therapists. During early intervention, I knew our therapists so well; I was right there for every minute of therapy - but at school I'd drop Evelyn off, pick her up, and have only a quick note or email from her team, so it took much longer to feel comfortable. I chose to be the room mom almost every year, so that I could get to know the special education staff better. I made an effort to send treats for every holiday and sometimes 'just because.' I figured happy and appreciated teachers and therapists are a good thing. I tried very hard to help them understand, with every interaction, how bright Evelyn is and how important it is to challenge her and treat her well.

*continued on page 4 >*

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FROM THE COVER  
**Brave. Strong. Heart.**

so thankful to have friends that took care of our big girl, family that stayed with us to help, meals from friends and coworkers for months, and friends who came to visit Ellie in the hospital. It was during that long hospital stay that we connected with FOCUS. It was such a big support for us. The hospital can be a lonely place and it was always so nice having a visit from someone who understands. Even though our visitors were usually complete strangers, we had an unexplainable connection.

Ellie would go on to have three more heart surgeries in the next year and a half. We would have never thought this would be her life's path, but it is. And it has become our path. We can't change it, but she has changed us. She's strong and resilient. She is brave and joyful. She pushes through seven hours of therapy a week and (mostly) smiles through it all. Her surgeons stopped her heart five times, and five times it started back up. We have no idea what her future holds, but we try our best to make the most of each day.

Ellie had her mitral valve replaced in June 2019. Since that surgery, she has been doing so much better. She will always be medically complex, but now she is thriving. Ellie's heart now beats strong and every day we are reminded of how a brave little girl has deeply changed the lives of so many around her.

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FROM PAGE 3  
**A Village of Champions**

And you know the funny part? Even if I'd done none of those things, this amazing team of men and women would still have treated her exactly the same. You've all heard the scary school stories, and my heart goes out to you if you've faced a dark or difficult time in school with your child ... but I have a happier story to tell. As the teachers and therapists at Evelyn's school got to know her, first in Pre3, and for these last 9 years, they fell in love with her. They SEE her. They challenge her and they have given her a confidence that I couldn't ... because yes, of course, mommy and daddy believe in you – but WOW look at this entire school community that believes in you too!

Last year, Evelyn accepted a "Yes I Can!" award for accomplishments over the school year. As we were taking pictures, I noticed a couple of people on her team with tears in their eyes, to match my own. We are all so proud of our girl – and what a gift that Evelyn's teachers, therapists, nurses and para-pros love their jobs and their students.

As parents, most of us did not enter this world of special needs by choice, but rather by chance. I feel all the better for it – and Evelyn is an incredibly special blessing in our lives. But I never forget that her team is comprised of people who chose to enter this world, who hope to actively teach, encourage, strengthen and love our children. They may face great challenges and disappointments, and their life's work certainly isn't easy, but they know the secret: when you invest in the heart of a special child, you receive a fullness of joy that surpasses any superficial measures of success. They are a village of champions, and I am so grateful for every one of them.

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## FOCUS + Fragile Kids Ongoing Activities:

For **Share Groups, Workshops, Hospital Visits, and Family Activities**, contact [jaide@focus-ga.org](mailto:jaide@focus-ga.org)

For **Respite, Day Camps and Overnight Teen & Young Adult Camps**, contact [sarah@focus-ga.org](mailto:sarah@focus-ga.org)

For **Adapted Swim Team, Teen & Young Adult Activities, Family Camps or to volunteer**, contact [audrey@focus-ga.org](mailto:audrey@focus-ga.org)

For information about **Equipment Grants**, contact [devi@focus-ga.org](mailto:devi@focus-ga.org)

*Check our calendar at [www.focus-ga.org](http://www.focus-ga.org) for the most up-to-date information!*



# Miracle

By Tameche Brown

Miracle Brown was born April 28, 2008. She was not due until July, but a head-on motor vehicle collision caused her to appear 3 ½ months early. Our daughter spent 132 days in the hospital fighting for her life.

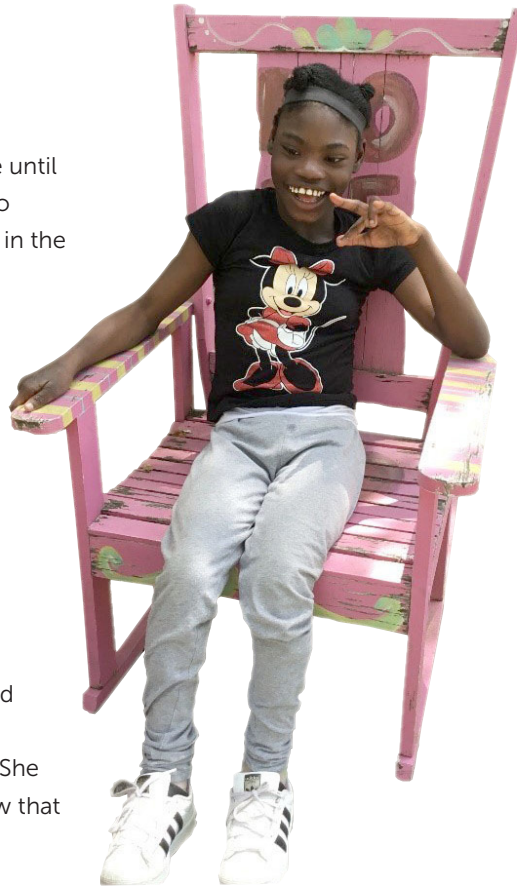
Life changed for our family when we brought our little "Miracle" home. She struggled with most everything – lifting her arms, turning her head, moving her legs. But there was one thing she never missed a beat on, and that was eating!

At age eleven, this hasn't changed. She still loves to eat! She is more independent in her thinking, more confident in her wants and needs, and more consistent with her ATTITUDE if she doesn't want to do something. Although non-verbal with actual words, she uses her iPad or physically shows you what she wants. Did I forget to mention she is a speed racer in her manual wheelchair? She can stop on a dime (although individuals who don't know that often panic as she heads for them)!

As a family, we continue to live on the edge. Miracle also has epilepsy that tends to rear its ugly head at the wrong time. When we are in the ambulance or at Children's Healthcare, I look at our daughter in awe of her constant strength. Over the years, we have learned to ask for help and support. When Miracle was young, I didn't have time for self-care; now I realize that self-care is as necessary as my morning coffee! I recommend finding a therapist who understands your journey; I journal and take advantage of respite when I can. It took 9 years to get there, but we are there.

As Miracle has grown, we have learned the art of "Letting it GO." She is one Free Spirit with a splash of feistiness. Our daughter continues to teach us to keep it moving. She never allows grass to grow under her. As her mother I wouldn't have it any other way. Who wants a boring life? Not me.

We are thankful for our "Miracle" and look forward to our rolling walks and cuddle time.



## FOCUS + Fragile Kids Facebook Fundraisers

*We receive 100% of the funds raised on Facebook!*

Hibbah Ailya  
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# The Game Changer

by Charisma Freeman

The last time I wrote an article for FOCUS, the birds were chirping and my son was at Chuck E. Cheese with my mother. He had just received the diagnosis of KIF1A, a very rare and very new diagnosis.

It's November 2019 and Day 6 after surgery on my right (dominant) shoulder. A neighbor is hammering and the recycle truck is in the cul-de-sac. I sure do miss the chirping birds – their songs are reassuring that everything will be ok. This year has been a whirlwind not just for me and many special needs parents that I know. It's been a year of "what can go wrong will go wrong." A year of testing strengths and relationships. A year of Make It or Break It. A year to determine the strongest vs. the weakest.

As I lay here, I don't really know if I am the strongest or the weakest. However, I think since I've made it to November, I'll consider it a win! The big news is ... I am taking 2020 by storm. I am relinquishing these labels, these alphabet acronyms, and these hospitals that we can't seem to stay out of. In 2020, I don't know CHOA and you don't know me ... except for that one adenoidectomy and tonsillectomy that Cam needs!

In 2020, we are bigger and better. We will not wallow in self-pity. We will not be the

"epitome of the poor special needs" family. We will be the "I can't believe that family is doing so much stuff" family. "Did you see their Facebook page" family. "They make me tired they do so much" family.

Because honestly in 2019 we have been the "I wouldn't want to be them" family!

I can sit here and tell you how hard it's been, but you've lived

your own story: enduring multiple hospitalizations and surgeries, rehabilitations, allergic reactions, fighting with the school system, crying in the bathroom at night so you don't wake the kids, trying to work full-time while being in the hospital with your kid, celebrating the 16-year-old getting her license, managing my own necessary surgery. Yep, we've been there. We wrote the book and then

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... Therefore, ladies and gentlemen of the special needs world, as your official spokesperson for the next 30 seconds, I declare 2020 "The Game Changer!"...



FROM PAGE 6

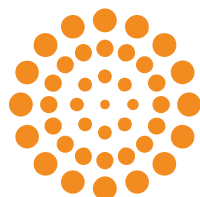
rewrote it, in case you didn't read the first edition! But I am very much insistent on not taking that book with me into 2020. People think I'm insane when I say this, and that's okay. I think we all have to be a little insane in our world because being normal in this world is crazy.

We just want a bit of 'normal' on our 2020 vision board. Some vision boards have a house with roses and a yacht in the tropics. My 2019 vision board consists of only ONE (LONG) hospitalization, a trip to Six Flags, and a trip to Disney (where I'm screaming at the inclusion specialist – don't judge me). I want a yacht on next year's vision board; I'll skip the roses – too many bees. My 2020 vision board looks like this: an airplane, a flag of Spain, our family laughing, my son enjoying ice cream, a grass skirt, and a cruise ship! Travels in 2019 were hijacked by surgeries and illnesses. We might get a second flu shot in 2020 to cover any new flu bugs that appear.

Therefore, ladies and gentlemen of the special needs world, as your official spokesperson for the next 30 seconds, I declare 2020 "The Game Changer!"

Run to Michael's or Dollar General and grab a fluorescent poster board. Put your dreams on there now! Don't wait until the end of December like the regular people because nothing about us is regular! We are extraordinary, and, as extraordinary people, we plan! We will drive to an Extra Special Saturday respite this year and we will use that time for a lunch date. We will take a day off work to go to Share Group (West GA Share Group rocks, ya'll.) Spa day anyone? We're going on that trip whether it's local, national or international, 3 days or 10 days. If you want to see the Grand Canyon, then plan to go! Not ready to plan a big trip? Then try a new food, but just check the ingredients for allergens first.

Add to those vision boards and don't be afraid! Dream a little or dream big – just dream! When you have those vision boards ready, please send me some pictures so I know what to put on mine! LOL, JK. Maybe.



## A New Sweet Ride for Kamryn!

Thanks to the Coweta-Fayette Trust, the Mark & Marcia Miller Foundation, and FOCUS + Fragile Kids, this sweet girl came home after a month in the hospital to her new Convaid Trekker! As you can see, she's feeling better and happy in her new ride!

# Looking back!

**Just the Highlights** – It's been a minute since our last printed newsletter – here are just a few highlights!



Camp Hollywood



Family Camp 2



Zoo Day



Family Camp



Six Flags Day



Camp TEAM





FOCUS on Moms



Daddy Daughter Dance



BooBQue



Hospital Visits



Teen & Young Adult Activities



Extra Special Saturday Respite

# CONTRIBUTIONS

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Edward Goldstein  
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Scott Ballard by Robert & Trena  
Hargreaves  
Susie Williams by Anne Marie &  
Michael McBrearity  
Bob Bruce by Ruth & Paul Parker  
Mackenzie Cassidy's Birthday by  
Kim & Carl Cassidy & friends

## Memorials

In memory of:  
John Just by:  
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Gary Huber  
Vince Hutnak  
Jeanne Just  
Thomas Roth  
Albert Deibert by Barbara &  
Matt Battiato  
Claire Gibbs by Girl Scouts of  
Greater Atlanta Troop 17055  
Ann M Taylor by Sharon Rivera  
Bernadette Sauter by Sandra  
Chamberlain  
Dan Pilson by Gayle &  
Larry Carlson  
Jennifer Smallman's Birthday  
by Carol & Ralph Smallman  
Jim Moran by Barbara & Matt  
Battiato  
Karen Greenfield by Alexander  
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Darrin Cott by Susie & Tom  
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Rae Bickwit by Susie &  
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Rachel Trotti by Martha & Marion  
Trotti  
Ralph Ruocco by:  
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Noah Anderson & Luke Albano  
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Zachary Chambless by Laila Flores  
Cervantes  
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## 19th Annual FOCUS + Fragile Kids Golf Classic

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Sectigo  
Simeio Solutions  
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### Beach Towel Challenge

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Larry Chambless  
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Lisa Lucier  
Kirsten Langwick Temples  
Ruth Norman  
Andrea Warren

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# Coming Up at FOCUS

## Are you getting our Monday emails?

Our Monday afternoon emails tell you all about our wonderful upcoming activities and give you a chance to sign up online. If you're not getting them, call the office at 770-234-9111 or send an email to [brian@focus-ga.org](mailto:brian@focus-ga.org).

## Set Up Your Family Portal TODAY!

It's simple to set up your Family Portal:

- Go to [www.focus-ga.org](http://www.focus-ga.org)
- Select Family Portal (top right)
- Scroll all the way down to bottom of page and select "Register with Email"
- Create a Username (you can use your email address if you want) and enter the email address where you are receiving this email. Click "Register"
- Go to your email and follow the link to set your password.
- Go back to Family Portal and login with your username/email and the password you just created.

You cannot change your address (or add children!) on the Family Portal! Email [brian@focus-ga.org](mailto:brian@focus-ga.org) to do either of these!

## Celebrate / Love Lucy! at Our Annual Gala

On March 14, 2020 at the Thalia N. Carlos Center at 2500 Clairmont Road, we'll be celebrating 36 years of FOCUS + Fragile Kids and 25 years of leadership under retiring Executive Director Lucy Cusick. For more information on how you can be a part of the celebration, go to <https://focus-ga.org/how-you-can-help-focus/fund-raisers/dinner-dance-silent-auction/> or call Joy at 770-234-9111 or email [joy@focus-ga.org](mailto:joy@focus-ga.org).

## FOCUS + Fragile Kids Golf Classic

Tee it up FORE FOCUS on Tuesday, April 28, 2020 at the Manor Golf & Country Club in Milton. For more information, go to <https://focus-ga.org/how-you-can-help-focus/fund-raisers/golf-classic/> or call Lucy at 770-234-9111 or email [lucy@focus-ga.org](mailto:lucy@focus-ga.org).



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### Annual Membership Contribution

Please make checks payable to FOCUS + Fragile Kids or complete the credit card information and mail to:

**FOCUS + Fragile Kids** • 3825 Presidential Parkway, Suite 103 • Atlanta, GA 30340

#### Yes! I would like to contribute to FOCUS:

- Family Membership .....\$25.00
- Church Membership .....\$25.00
- Help another family.....\$25.00
- Professional Membership
- Friend of FOCUS – I would like to support FOCUS
- One newsletter.....\$50.00
- with a gift of .....\$\_\_\_\_\_
- 5 copies of each newsletter .....\$100.00
- I cannot contribute at this time, but wish to continue to receive the newsletter.
- I no longer wish to receive the newsletter.

(Please write your name below as it is printed on the last newsletter label and mail to the address above.)

Name \_\_\_\_\_ Phone \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

#### CREDIT CARD INFORMATION:

Name as it appears on card \_\_\_\_\_

Billing Address \_\_\_\_\_ City \_\_\_\_\_ Zip \_\_\_\_\_

Credit card number \_\_\_\_\_ Exp. \_\_\_\_\_ Sec. code \_\_\_\_\_

Signature \_\_\_\_\_