

APRIL 2020

ViewFinder

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



Get Connected, Stay Connected

By Anne Ladd

Nearly 15 years ago, my husband Paul wrote an article for the FOCUS newsletter about our then young son, Matty, who has a Mitochondrial disease.

At the time of publication, we were several years into our journey as parents of a child with a developmental disability, but we still had many questions and frankly a whole lot of fear for his (and our) future.

So, let me start by saying, 15 years later we are 'okay.' Paul and I are still married; our older son, a well-adjusted, happy adult; Matty has a Comprehensive waiver and many aspects of an "enviable life." How did we get here? Well, we did not get here alone. We got here together. Together with other families, together with school, together with caregivers, and together with FOCUS.

My greatest fear when my son was young, in addition to his healthcare needs, was isolation. I saw it begin to happen as we revealed our baby's disability. Our circumstances made some people uncomfortable or simply sad. We experienced "social distancing" before it was in fashion. And with that, I felt isolation. Although, I didn't want to burden others with our situation, isolation was not going to work for me. So, I decided to broaden our circle. I looked everywhere

for information, took every training for families and went to every workshop and conference I heard about. Some were excellent and some were just alright. But with every action I felt proactive. I built new relationships with families who shared my experience, I learned about special education, I learned to trust others with the care of my son and, we used FOCUS

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**Coming up –
Re-scheduled Programs!**

Watch Facebook & Monday Parent Emails for updates on programs!

From the Editor...

by Lucy Cusick



Lucy coaches Team FOCUS

I know you all think I'm NEVER really leaving FOCUS + Fragile Kids! We've been promising my retirement for the past 6 months – well, it's here!

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at www.focus-ga.org

Frances McBrayer, our new executive director started in mid-February, and we've enjoyed working together for the past 6 weeks. March 31 was my last official day.

One of the hardest things I've ever done was to call FOCUS, after Josh was diagnosed with cerebral palsy at age two. I didn't want to be a member of this 'club.' I didn't want him to have disabilities. I didn't want to admit that I needed help. What a fork in the road for me – because I made that call, I made lifelong friends who have listened, laughed, and supported me. I've shared joys and heartaches. I've eaten about 300 biscuits at Share Groups. I've worked alongside amazing people who love our children and families.

One of the second hardest things I'll ever do is to actually leave. I hope Frances doesn't ask for my key to the office for another month or so. I've received dozens of notes from parents thanking me for all my help; my response is that you all have helped me right back. What will I do in my un-FOCUS-ed life? I won't lie ... it will be challenging to fill the hours that I spent at FOCUS. But I continue to believe, with all my heart, that my leaving is the right thing to do. For the future of FOCUS. For me. Even for our families.

Love Frances like you have loved me. Support our awesome team during these very difficult times. Be generous. Be kind. Know that you will always have my heart.

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From the New Editor

By Frances McBrayer

I am thrilled to be the new executive director of FOCUS + Fragile Kids, though I expected my first month to be different than it has turned out to be! That said, I am grateful to now be able to work for an organization where each family that we serve acutely understands that things often don't go as planned and where I feel such community and support because we know the "real life" that we all live.

I thought that I would be able to meet more of you in person at our program events this spring, but instead I am trying hard to balance work, home school for my five-year-old with cerebral palsy, and all of the other stressors that come amidst a global pandemic. Real life feels a little bit surreal right now, and I know many of you feel the same way.

We are using our creative, problem solving brains at FOCUS as we reimagine programming during this

time when we cannot see each other in person. We are working to bring you daily activities that are appropriate for our kiddos and their needs, and we are holding remote workshops so that we can continue to support and educate each other with the information we need to best care for our children. We would love for you to help us share events and activities on social media so that we can provide support to as many families as we can. We are also reaching out by phone, text, and email

to stay in touch. Please let us know if you need support in other ways, too, while we are apart.

I so appreciate the warm welcome that I have received from the staff, the families that I have met, and especially from Lucy. FOCUS would not be where it is today without her leadership, and I am grateful that she is still "around" to support us as we move into our next chapter. I am so looking forward to what is to come!



FOCUS + Fragile Kids Facebook Fundraisers

Thanks for these birthday or other Facebook fundraisers!

Alexis Crawford
Josh Cusick
Ruby Fields
Bob Little in honor of George

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FROM THE COVER
**Get Connected,
Stay Connected**

respite, family camp and Camp Hollywood!

As I began to find answers (or at least who to ask), I knew I wanted to help other families by sharing my knowledge and experience. In 2005, I began working in Gwinnett County Public Schools as a parent mentor. The Ga Parent Mentor Partnership (GaPMP) is an initiative of the Ga Department of Education (DOE) whose mission it is to build effective family, school, and community partnerships that lead to greater achievement for students with disabilities. I went to help others but guess what? My circle began to further widen, and I got to know even more people with a shared experience. I met people with whom I may never have crossed paths. People different than me in many ways and yet we are bound by our common interest and passion for people with disabilities. I connected on a personal level, I connected on a professional level. My life got richer because of these connections.

Then we began to realize how critical connections would be for Matty, especially when he transitioned from school to adult life. We wanted Matty to have an “enviable life,” a life that any of us would want, a life characterized by dignity.* So once again Paul and I got busy building Matty’s circle. We went to every activity we could find, dances, drum circles, bingo, bowling, parties,

swimming, Sunday school. If it was accessible and fun, we went. Matty really enjoyed some and some were just alright. But his circle began to get larger.

In 2017, it was time for my son to transition from school. For years we planned, but when the day finally arrived, our plans did not go as we thought they would. We thought, “How could a family who had so earnestly prepared be in this situation?” Well, our plans had to change but our preparation is what made the difference. When the yellow bus stopped coming, it was the

connections that allowed us to pivot. We had friends who had gone through the process before us; we had nurtured our relationships with caregivers who partnered with us and connected us to additional caregivers; Matty’s social connections had provided the continuity of relationships after school ended; and, our connection to FOCUS brought us the Young Adult group for Matty and the G.O.T. (Get Old Together) group for me. Yes, FOCUS still plays a significant role for our family.

Today, our life is still complex, but we are okay. And you

will be okay too, but you need connections. Whatever age your child is, it’s never too early or too late to make connections.

Here are a few suggestions for you:

1. Make friends with other families that have your shared experience so you can talk about your unique challenges. But also nurture those relationships you have outside of “disability world” because, face it, sometimes you need to think and talk about something unrelated to disability.

FOCUS + Fragile Kids Ongoing Activities:

For **Share Groups, Workshops, Hospital Visits, and Family Activities**, contact jaide@focus-ga.org

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

For **Adapted Swim Team, Teen & Young Adult Monthly Activities, and Family Camps**, contact audrey@focus-ga.org

To volunteer for any or all programs, contact brian@focus-ga.org

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

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



2. Learn about special education and participate in the learning opportunities your child's school district offers. Visit www.parentmentors.org to see if there is a parent mentor in your school district and make the connection.
3. Network with other families to find caregivers and have those caregivers help you make connections with other caregivers.
4. Survey what your community has to offer to give your child an "enviable life" ... the library, parks and recreation, farmers markets, faith communities. Let the leaders in the community know what your family needs. And, of course, you are already connected to FOCUS (at least by the newsletter) so take advantage of the abundant programming that it offers.

In 2013, I moved from being a parent mentor to working as Family Engagement Specialist at the GaDOE. It was not my original career path, but life is not predictable. However, there is one certain thing, which I learned from the GaPMP ... Together, we can! Get connected today.

**To learn more about an "enviable life," watch this video <https://www.youtube.com/watch?v=RsqpGycJedg&feature=youtu.be> or Google Ann Turnbull An Envable and Dignified Life*



Swim Sundays

By Sallie Dekutowski

Sunday evenings are one of my favorite times of the week. While others are wrapping up weekend activities or preparing for school or work the next day, I head to the pool. As a volunteer for the FOCUS + Fragile Kids Fast Fins program for over 13 years, I love seeing the swimmers improve their strokes, compete in swim meets, and enjoy being part of a team. This program enables me to combine two of my favorite interests – swimming and people with special needs. I have watched so many swimmers start off as young children with beginner skills, needing a coach helping them participate in the swim meet. Then, I have the privilege of seeing them grow into young adults mastering competitive strokes, participating independently at the end-of-season meet, and joining their summer and school swim teams. We have such a great group of enthusiastic and knowledgeable coaches, supportive and encouraging parents, and excited and engaged swimmers.

I am so proud to be a part of this FOCUS + Fragile Kids program. I get more out of my volunteering than the swimmers! During the work week, I am a partner in a CPA firm helping the healthcare industry. But on Sunday evenings, I am "Coach Sallie," and I could not imagine a better way to spend my time. It is so rewarding and gets me ready for the week ahead!

Coach Sallie has coached FAST Fins for over 13 years and is well-loved by current and past swimmers. We are grateful to her and to the other 20 coaches that volunteer for FAST Fins. We can't wait til next season!

How to Reach FOCUS

-  770-234-9111
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-  inquiry@focus-ga.org
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a very special person who has had such a positive effect on so many people and lives.
*"Not everything that is faced can be changed,
but nothing can be changed until it is faced."*
– Lucille Ball

Thanks for your friendship, leadership,
commitment and courage over these many years.

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Our Fierce Leader –
Thank you for all
the years of great
**LEADERSHIP,
DEDICATION
& LOVE**
Now, onto the
next chapter ...



Fundraising at FOCUS + Fragile Kids

**Golf Classic Postponed
to October 27, 2020**

at The Manor.

Contact Frances@focus-ga.org
for more information.

**Family Fun Ride scheduled
for April 14 has been cancelled
for 2020.**

**SummerFest is ON for
Saturday, August 15** at
Monday Night Garage.
Go to www.focus-ga.org for
information.

**Ride for Team FOCUS in Spin for
Kids on October 4.**

More information to come.

***Thanks to those who donated
through FOCUS on Georgia
Gives Day and who purchased
items in our online auction!***



My dear Michael

For the past week, you've gotten up every morning and brought me your shoes. You say "bus," "door," and "outside." You look at me with your big beautiful eyes and sign "please" with your perfect curled hands. I guide you back to your room and try to show you the toys that have been in the toy box for years, hoping you'll show interest. But you don't. You and I both know you love being near people, and you LOVE being outside. You love having the freedom to run a few feet ahead of me, almost as if you're going to run away — only to turn back and smile so I know you won't go too far.

I know you are confused as to why your routine has changed. I tried to explain to you today what was going on, but you told me to "go play" (and because I know you, I know what that means). My beautiful boy, life is the way it is right now because I'm trying to protect you and others. I want so badly for you to be able to have the chance to live as long as possible. I want so badly for your friends, people we love, and even people we don't know to have the chance to live long, beautiful lives.

You cried today.

I cried today.

This is hard.

But even in the difficulty, I am so grateful you're here.

Sending lots of love and hugs to everyone during these uncertain times,

Mom

Looking back!



Education Conference



Teens & Young Adults



Brunch with Santa



Valentine Dance



OctoberFest



Holiday Party

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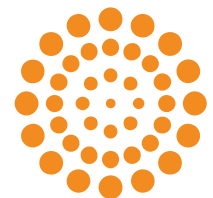
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Thank you, Lucy Cusick,
for your 25 years of
selfless dedication
and service to
FOCUS + Fragile Kids!
You will be missed!



With Love,
The Carlos Family