My family during COVID-19

By Ganesh Nayak

It’s [been] months since my 18-year-old son Ishan’s school has been out. Like any family of a kid with special needs, it’s been a challenge taking care of one who needs supervision every minute, while also carving out time for actual work.

His caregivers are down to two, weekday afternoons only. It’s a fairly set routine: after I change him in the morning, set his favorite album of singer Kishore Kumar on endless loop and my wife Sitara feeds him breakfast, he chills in his room for a couple of hours, and then emerges, wanting to be engaged. I take him for a long walk for 1.5 hours, then there are calls with his teacher, para pros, family, et al. Either of us takes him on a long drive in the afternoon. He then slowly dials down and settles back into his room by 6 p.m., and the evening becomes ours. It is physically tiring, moving his 90-pound frame away from stuff he has no business to be in, and distressing when, out of boredom, he bangs his head on the carpeted floor and tries to bawl and shed a tear.

But dealing with all of this becomes that much easier when we dwell on the relativity of circumstances...the weather’s good, the walk is beautiful, we have separate rooms to work in, compared with other families who sometimes have more than one person with special needs or with behavior challenges who may be

continued on page 4 >
Is anyone else feeling like the last five months have been really hard? I feel it more acutely on some days than others. This month, our family is again facing the difficulties of two full-time working parents and one small child for whom virtual learning is not an ideal option. We also decided to throw in a major surgery for my daughter this summer ... I guess because we thought 2020 was not hard enough on its own?! Even though she has spent the last five months with only her parents and endured a very painful surgery, my daughter is still smiling. The enthusiasm our kids have for life is truly awe-inspiring. I also saw so many smiling faces of Camp Hollywood Home Edition campers at events this summer. Our kids remind us that laughter and hugs are vital. They make us remember to celebrate the little things.

Yes, the last five months have been hard. The next five might be hard too, but I resolve to find something to celebrate every day.

From the Editor... by Frances McBrayer

“...”

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The Backpack Lesson

By Heather May

Every year since my boy/girl twins started kindergarten, they’ve picked out a new backpack before the beginning of the school year. Usually something camouflage or ninjas for him; Butterflies, unicorns or some Disney channel character for her. I was happy if they were happy with their choice until middle school was approaching, and backpack shopping suddenly changed.

My typically developing son wanted something that would make him “look cool.” He scoured the internet and stores searching for the perfect one to make his debut into middle school. On the other hand, “looking cool” wasn’t even a thought for his twin sister with special needs. While out shopping, she gravitated to the Paw Patrol backpacks. I steered her away, hoping she could pick something that a 3 year old wouldn’t carry. We agreed upon a “big girl” backpack with drawn pictures of cupcakes, pizzas, fries and other foods she loved all over it.

With 8th grade starting very soon, we started our backpack shopping. EVERY TIME we entered a store, she graveditated to the PJ Masks backpacks (ugh!!) Somewhat I convinced her to pick a polka-dot green one. “Green is your favorite color!” and the PJ Masks one is way too small for you” were my justifications, but my mom guilt set in. I thought about an article I recently read saying it’s 100% OK for Autistic individuals to have an interest in things that may not necessarily be age appropriate, and that sometimes you just have to go with it. If it makes your child happy, then what’s the harm? it said. You probably know where this story ends ... yup, the green polka dot backpack went back and and the PJ Masks backpack is hanging in her room patiently waiting for its first day of school. And guess what? I’m happy that she’s happy with her choice. It’s funny how a little thing like backpack shopping taught this mom a valuable lesson.

Thanks to those who donated to FOCUS on Georgia Gives Day on May 5, 2020 and to those who created and donated through Facebook Fundraisers!

August 2020
cooped up in smaller houses, and may not be able to get out much. They have our gratitude. There’s a low-grade anxiety, not the sort that takes over everything and drowns them out, but the nagging and ribbing type, a constant discordant background hum. Some friends were discussing what plans we have instituted if the virus were to afflict one in our family — which room to quarantine in, those types of questions. Truth is, we don’t have much of a plan. We simply cannot afford to get infected at the same time, for Ishan is helpless. He has to be fed, bathed, clothed, changed. We’ll need a spacesuit like the GI nurse: we think it is a flare and not COVID-19, but … One night both of us woke up around the same time, at 4 a.m. I wordlessly got up to check on Ishan, and reported back: he’s breathing, he’s OK.

But Ishan is happiest when both his parents are around, all day, all the time. The countless hugs for his mom, the gratitude for the smallest of things — after a walk or a drive, after cleaning him, are unfailing. And after a long day which leaves us bone-weary and mentally spent, having been ‘with him’ every minute, sometimes he’s all over his dad, with unique sounds of expressing an additional reserve of love for me. He can go for several hours expressing those same sounds only we understand, ‘till he falls asleep. I feel guilt of another kind — that I can never love this boy as much as he loves me, to this obsessive extent.

However it’s slightly different these days — the guilt immediately reminds me of the anxiety which, like the stubborn vampire on the shoulder, is not easy to shrug off in these strange times.

This article was originally published in the Atlanta Journal Constitution on May 28, 2020.

1. Know the difference between the terms and educational standards for Voluntary Remote Learning and Universal Remote Learning:

- Voluntary is when the parent chooses but to accept remote learning, then simply take it one day at a time and focus on what you can reasonably manage — while staying healthy and happy. These tips for remote learning may be useful as you navigate the weeks ahead.
- Universal is when the entire educational system is required to be 100% digital.

2. IEP Meetings to Discuss Distance Learning Plans:

- The school is not smoothly coordinating services or is responding.
- The school is not helping your child supported and share them.

3. Collaborate and Share Information:

- You have tried to contact your child’s providers and they have not responded.
- The school is not smoothly coordinating services or is making promises that are not being followed through.
- Your student is moving between schools.

Tips for Remote Learning During the New School Year

By Christy Calbos of The Calbos Law Firm www.calboslaw.com

In our uncertain times of education, parents are concerned about making the best decision for education. If you are a parent who has decided to utilize remote learning or find yourself with no choice but to accept remote learning, then simply take it one day at a time and focus on what you can reasonably manage — while staying healthy and happy. These tips for remote learning may be useful as you navigate the weeks ahead.

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Propose solutions. Nothing is normal, which means that anything is possible!

- Adaptations and creative solutions may need to be explored with the IEP team to determine how to structure remote learning tasks – perhaps subject by subject – so that your child continues to progress in the general curriculum.

- Speech-language and Occupational therapies can be explored with the IEP team to determine how to structure remote learning tasks – perhaps subject by subject – so that your child continues to progress in the general curriculum.

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4. Communicating Needs to Schools:

- Access to internet and technology and materials for learning – do you have these things? Do you or your child need training to use the technology?

- Student’s attention span and ability to focus

- Student’s behavior

- Student’s special medical needs

- Student’s mental health and self-regulation challenges that require extra supervision or behavior support

- Work schedules and your availability to help your student and meet your own / other family member needs

- Ability to provide a distraction-free environment for your student

- Need for consultation and training for you and your student

- Parent disability or language translation needs

5. Visual Elements:

A visual element is important for kids with developmental disabilities or other special needs. Research shows that visuals are what really support their learning. Verbal instruction alone can be difficult for students to track everything, so the more you can use things visually for their learning, and the more tangible materials you can use for learning, the better you are likely to see your child doing. Ask your child’s teachers and therapists to send you weekly packets of visuals or links to on-screen visuals to support your child.

We saw offices close, schools shut down, stay in place orders issued. What’s a busy family to do? Once again FOCUS to the rescue.

Myles is an active member of the FOCUS teen and young adult group. When I saw the very first email for the FOCUS teen group announcing the first zoom event I thought, “Now how is this going to work?”

Myles was skeptical at first. He wasn’t sure he wanted to join the group. By then he had gotten accustomed to entertaining himself by communicating with a few friends on Instagram, surfing the net, and watching videos on YouTube. Little did he know how transforming the experience would be for him. To date, there have been more than 15 virtual teen and young adult events. He’s missed a few, but it was not his doing. One Saturday we knew we would be attending a drive through birthday party for one of his long-time friends. On the drive to the party he reminded me that we wouldn’t be able to stay long because we had to get back home in time for zoom. While there, he kept checking his phone because he didn’t want to be late. We made it home in time and went straight to his room to get set up. I knew then that for Myles the silver lining in these difficult times would be FOCUS teen and young adult group.

While he likes all the virtual events, his favorites are Bingo, Kahoot, scavenger hunt and Karaoke. Audrey and others who host the event have done an amazing job keeping the kids engaged. I’m generally not allowed to check in on him during this virtual hang out because he says this is for him and not me. But outside his door I can hear his laughter, and it warms my heart and calms my fears of what isolation can do.

So, thank you, FOCUS. Once again for Myles, his peers, their parents and for many more, you are the light at the end of the tunnel, the pot of gold at the end of the rainbow, and the wind beneath our wings. And for that we are eternally grateful.

The past 4 months have been challenging to say the least. We’ve had to adjust our daily routine, our diet, and our activities. All have been a big adjustment, but the greatest change has been missing all the activities we as a family, especially Myles, are involved in. Along with school and work we had a hectic but fun schedule. On Monday evenings we did line dancing at Kaiser, Tuesday evenings Darby Dancers and the Emory Metro Duck Swim Team, Wednesday – Thursday we got a break and we were back at it on Saturday and Sunday. Never a dull moment. Then there was COVID-19.
A Look Back at Camp Hollywood Home Edition!

We rolled out the red carpet for our new “Home Edition” of Camp Hollywood. We sought to decrease demands on parents and provide activities to assist with new routines – while maintaining some of the old.

Campers brought Spy Kids, Out of this World Space, Magical Wizard, and Pirate Adventures to their homes. They pulled supplies from their packet and were able to participate in a multitude of sessions each day! Our favorite part of camp this summer was seeing campers during family activities, individual and group sessions.

Reviews:

• All smiles today at camp. Can’t wait for tomorrow. – Kristine I.
• THANK YOU for all everyone did to make the camp experience so much fun. In a sea of cancelled events, Camp Hollywood online was a lifeboat for us this summer break. I am so grateful for you!!! – Angie S.
• Omg.. so fun today at supply pick up. Ty was so tickled by the Parade. Thanks to all that came out and made the effort to make today special for my kiddo. He loved it! – Katherine B.
• Emeline really enjoyed that! “Funnest virtual meet ever.” Thanks! See you next week :) – Amy S.

A BIG thank you to:

• Ms. Lisa, Ms. Belinda, Ms. Cheryl, and Ms. Patricia for all of your work to bring camp sessions into the homes of our campers!
• The George Center for our daily music therapy sessions singing the classics like “Let’s Take a Trip to the Movies” and “What I Am.”
• The volunteers who wrote kind and encouraging messages to our kiddos. We sent out 438 messages from Postcard Pals!
• The Mercer Physical Therapy Students for creating warmups and goodbyes ready for campers to view each day.
• The National Charity League for providing volunteers and for donating parent packets.

FOCUS Ongoing Activities

While all of our programs look a little different for the foreseeable future, we look forward to bringing them back as soon as possible. To learn more about our programs, contact the staff below.

For share groups, workshops, and if your child is in the hospital, contact jaide@focus-ga.org

For camp programs and family activities, contact sarah@focus-ga.org

For teen & young adult monthly activities, and family retreat, contact audrey@focus-ga.org

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

For questions about how programs are continuing during the pandemic, email brian@focus-ga.org.

Be sure to check out our weekly parent email for real-time updates on activities and how to register!
CONTRIBUTIONS

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Lisa & Harold Wyatt
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Susan & Matt Zimmer- Dauphinne

Honorariums & Memorials
In Honor of
Abraham Vigli by Maria & Ben Vigli
Abraham Vigli by Teresa Vigli
Bryan Weil-Alphonse
Janet Wiedling & Joval Wieder<br> & Jeffrey Weir
Jane Puckett's Birthday by Carey Jackson
Joyce Ryan by Margaret Daniel
Lucy Cusick by
Tricia & Jim Lane
Linda McClanahan
Dimiria & Mark Malaisak
Kerri & Kth Jonas
Madeline Harrington by Valerie & Steve Harrington
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Olivia Frey & Family by Steven & Carolyn Frey
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"All the students & families I have worked with" by Jessie Moreau
The McBayr FAMILY by John & Janet Bakalara
William Galli by Robert & Kathy Powell
Wendy Penn's High School Graduation by Amy Penny & Girl Scout Troup 28427
Adyn Reid, Cancer Survivor by Mr. & Mrs. Doris Reid
In Memory of
Amanda McGraw by
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Kim Trepontini by Barbara & Matthew Wittenstein
Glen & Jenny Wittenstein
Liam Vlinskiy by Rachel Wittenberg & Asher Vlinskiy
Lucy Rockett by Leslie Taylor
Pat Jurgenson by Doreen & Burt Wittenberg
Haley Poblick Gilm & her wonderful caregiver, Mrs. Rowling, by Susie Williams & Lynn Pogue
Dr. William Meyers by Barb & Gary Estland
Jeanne Collette Hanley by Ashley Smith
Feris Hamdy by Kelly Stuart

A new Friday night tradition
by Camille Sutton-Brown

A Friday night for me 10 years ago looked very different than the way it does now. Instead of preparing for an evening out with friends, I now settle onto my couch at 8pm to prepare for an evening in with – well, with people I have never met in person! Instead of talking about superficial topics as we dance the night away, we now shed our facades of ‘being okay’ and express our vulnerabilities about what we are currently struggling with.

The experiential knowledge that we all bring to the Friday night Share Group is beyond what any textbook or self-help book could ever approximate. We represent a range of ages – both ourselves as well as our ‘special needs parenting age’ (ie. how long we have been parenting a child with special needs), a range of diagnoses for our children, a range of parenting styles, a range of professional backgrounds, a range of pretty much everything. These differences, I believe, contribute greatly to the effectiveness of the group, because we each offer various perspectives about how to address a certain situation.

The most important thing that I appreciate, is that even though various viewpoints are shared, they are done so in a respectful manner and without judgment. I applaud the FOCUS director, Frances, and Program Coordinator, Jane – both of whom consistently attend the Friday group share – for creating and maintaining such a culture of safe space.

Though we connect in a virtual space, the connection manifests in a comforting, almost physical, manner. The fellowship, the honesty, the laughter, and even discussing the ‘hard stuff’ is what I look forward to every week. In the midst of this pandemic, such forms of connection are ever more important – for everybody. For us, in particular, to have a supportive group of parents who can discuss navigating IEP’s in the context of virtual learning, traveling of whom consistently attend the Friday group share – for creating and maintaining such a culture of safe space.

The fellowship, the honesty, the laughter, and even discussing the ‘hard stuff’ is what I look forward to every week.
Fundraising at FOCUS

SummerFest has been cancelled on August 15th, but we are going to have a Virtual Birthday Party in August! FOCUS is turning 37, and we would love for you to donate an extra $37 as a birthday gift that will celebrate and benefit thousands of families of children with disabilities! [https://focus-ga.org/birthday](https://focus-ga.org/birthday).

**Ride for Team FOCUS on October 4th!** Join the team at [https://p2p.onecause.com/spinforkids2020/team/team-focus](https://p2p.onecause.com/spinforkids2020/team/team-focus)

**Our Golf Classic will take place on October 27, 2020 at The Manor Golf and Country Club.** We are looking for sponsorships! More information at [https://focus-ga.org/how-you-can-help-focus/fund-raisers/golf-classic/](https://focus-ga.org/how-you-can-help-focus/fund-raisers/golf-classic/) or contact Frances@focus-ga.org

How to Reach FOCUS

- 770-234-9111
- [www.focus-ga.org](http://www.focus-ga.org)
- inquiry@focus-ga.org
- @focusga