AUGUST 2020

ViewFinder

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

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

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Coming up – Virtual Workshops, Share Groups, Family Activities, and more!

Watch Facebook & Monday Parent Emails for updates on programs!

From the Editor…

by Frances McBrayer

> "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."

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. In August, I want to celebrate FOCUS! Thirty-seven years ago this month, parents started FOCUS because they wanted to find community with each other and to create fun activities for their children. Even though our circumstances and methods have changed in 2020, parents are still telling us that this is what they need – maybe even more so now than ever.

We are committed to helping our FOCUS families make any aspect of life easier right now – even from a distance. Thank you for letting us be a part of this time in your life, and thank you for being a part of FOCUS.

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at www.focus-ga.org

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 gravitated to the PJ Masks backpacks (ugh!). Somehow 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 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!

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 niggling and nibbling 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 those in the movies, or eerily, from the hospital scenes on TV nowadays. Ishan is in a higher-risk category due to his disabilities. We think about it but leave a lot unsaid — it comes in the way of functioning and dealing with the here and now. Again, relativity saves the moment: those kids and adults who are more medically fragile have it worse. They too have our gratitude.

There's the anxiety swirling around our parents in India who are in more-restricted lockdowns. We make daily calls: my 85-year-old mother who lives alone, and Sitara's parents. Advice and instructions go back and forth and are sometimes contentious. It seems like the anxiety is constantly bouncing off each other like sound waves in a hollow; sometimes reverberating, sometimes damping, but not dying out. The immigrant's guilt of not being around them at such a time is tamped down by the comfort that our siblings take care of them.

There's the anxiety from the constant drip-drip-drip of news: the lack of PPE and ventilators in the first weeks, more cases each day, more deaths. And what to say about social media, chiefly Facebook and WhatsApp: conspiracy theories, Islamophobia (in the Indian groups) and Sinophobia (in all groups) run rampant. Yet another atrocious Internet forward: Delete. Snooze. Unfollow. But they're posted by friends and family, who are otherwise helpful and fine people who we like and love. Perhaps they're finding a known target to pin their impotent rage on, in a strange time. We try to refrain from judgment, for Ishan never judges anyone.

Ishan is always teaching us something.

At times, there's a spike in the anxiety, causing it to bubble to the surface. A few weeks ago, Ishan had a Crohn's Disease flare which can be quite painful. In normal times, it passes without undue worry. But this time we were constantly checking his temperature, and it prompted Sitara's call to 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

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.

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

- Voluntary is when the parent opted in for remote learning even though in-person learning is available within the district.
- Universal is when the entire district has decided to have remote learning plans for all students.
- Voluntary remote learners may not be entitled to a fully supportive, appropriate education program (FAPE = free appropriate public education).
- Universal remote learners are entitled to FAPE through their IEP, which means that the IEP team must find creative solutions for remote learning (this could be a combination of digital, nondigital, services at home, at school, parks, community centers, clinics or agencies – and either public school or private staff may be necessary to implement the IEP). *Remote learning is not required to be 100% digital.*

2. IEP Meetings to Discuss Distance Learning Plans:

Universal remote learning services can be provided DIFFERENTLY during closures, but students with disabilities are still entitled to individualization and an appropriate plan. There is no legal requirement currently to hold an IEP meeting to discuss distance learning for Voluntary Remote Learners or Universal Remote Learners, but you have a right to call an IEP meeting if you think it's necessary. When discussing distance learning plans in IEP meetings, please do not waive your child's special education rights. The IEP is a formal legal agreement. IEP meetings can be conducted by phone or video conference. You can tell the team that you plan to record the meeting. Here are some reasons to call an IEP meeting to discuss distance learning plans:

- The services your student needs in order to succeed during distance learning are VERY different from what is provided when school is in session.
- You have tried to contact your student's teachers or 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

3. Collaborate and Share Information:

Focus on your child's individual needs. Don't focus on replicating everything about school at home now. Ask your teachers and therapists how to support your child. Take videos of your child supported and unsupported and share them.

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Tips for Remote Learning

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 materials and also receives instruction on the IEP goals and objectives.
- Speech-language and Occupational therapies can and should be delivered via teletherapy whenever possible, but if your student cannot access the teletherapy modes, then in-person services with face-to-face therapy sessions may be necessary.
- If your child cannot access digital platforms and intensive support is required, write to the IEP team members and ask for a meeting to discuss how to create a remote learning plan for in-person services at home, a clinic, or other location

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.

The Silver Lining of Teen and Young Adult Programs

by Deidra Green

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.**

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.

> To date, there have been more than 15 virtual teen and young adult events.

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!*

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 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 camp
HOLLYWOOD
HOME EDITION
2020

CONTRIBUTIONS

Foundations, Corporations & Organizations

Amazon Smile
Thalia & Michael C. Carlos Fdn
Catholic Foundation of N. Georgia
The Chatlos Foundation
The CHEST Foundation
Greenwich Biosciences
Jackson EMC Fdn
Kulynych Family Foundation II, Inc.
John & Mary Franklin Fdn
Kroger
Liberty Mutual Charitable Gift Fund
May P and Francis L Abreu Charitable Trust
Mt. Bethel UMC
National Charity League, Roswell-Alpharetta
Pamphalon Foundation
Sawnee Electric Membership Fdn
Smith Currie Foundation
The Taylor Family Foundation

Individuals

Susan Anderson & Mark Ledden
Kelly & Ariel Arocho
Sandy & Steve Blagg
Martie & Connrad Bode
Christine & Ken Bolt
Beth Burgess
Judy Byrd
Stephanie & Mark Byrne
Elaine & Jorge Camacho
Helen Carlos & Ron Hilliard
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Emelina Marin
Sue & Dan McBrayer
Elaine & Arthur McClean
April & Chris McGregor
Jessica Miller
Teresa & Butch Miller
Vic Misiewicz
Sheila & Cheldon Montgomery
Heidi & Steven Moore
Paul Murphy & John Withrow
Stacie Nefos
Darlene Olurin
Elba Ortiz
Linda & Bill Oswell
Peter Pappas
Onira Parham
Kathryn Penn/Girl Scout Troup 28427
Brie & Geoff Pollak
Tiffany & Patrick Powell
Jane Puckett
Cheryl Sameit
Kerry & Danny Schnitzlein
Devin Scott
Ginny & Evan Secor
Lauren & John Seidl
Aron Siegelson
Andy & Ann Smith
Suzanne & Curt Smith
William Snoderly
Sharon & Mark Spears
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Luise & Mike Stone
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Ana & Carlos Vazquez
Teresa Vigil
Susie & Tom Williams
Sara Woodbery
Lisa & Harold Wyatt
Dave & Linda Zilles
Susan & Matt Zimmer-Dauphinee

Honorariums & Memorials

In Honor of:
Abraham Vigil by Maria & Ben Vigil
Abraham Vigil by Teresa Vigil
Brian Weiner by Anne Nieberding & Jeff Weiner
Jane Puckett's Birthday by Carey Jackson
Joyce Ryan by Margaret Daniel
Lucy Cusick by Tricia & Jim Lane
Linda McClanahan
Dimitra & Mark Moraitakis
Kenneth & Kiha Jones
Maddie Harrison by Valerie & Steve Harrison
McKenzie Fishback by Christina & Clint Fishback
Nick Medina by Russell & Susan Heitert
Olivia Frey & Family by Steven & Carolyn Frey
Rachel Weiland's Birthday by Marcy & Jerome Konter
"All the students & families I have worked with" by Jessie Moreau
The McBrayer Family by John & Janet Ballard
William Galli by Robert & Kathy Powell
Kathryn Penn's High School Graduation by Amy Penn & Girl Scout Troop 28427
Aidyn Reid, Cancer Survivor by Mr. & Mrs. Doris Reid

In Memory of:
Amanda McGrath by:
John Adams
Debi Barris
Susan Berets
Daniel Boss
Adem Chich
Katie Councill
Friends at GAF R&D
Ed & Cindy Getty
Lynda Grossman
Charles Hogan
Evan Icolari & the Rocker Family
Diane Lange
Martha Livingston
Mr. & Mrs. John Pine
Perkins-Hernandez family
Erica Sherman
Seth Sladek
Susan Smith
Lynn Tejerina
Maureen Wales
Tammy Yang

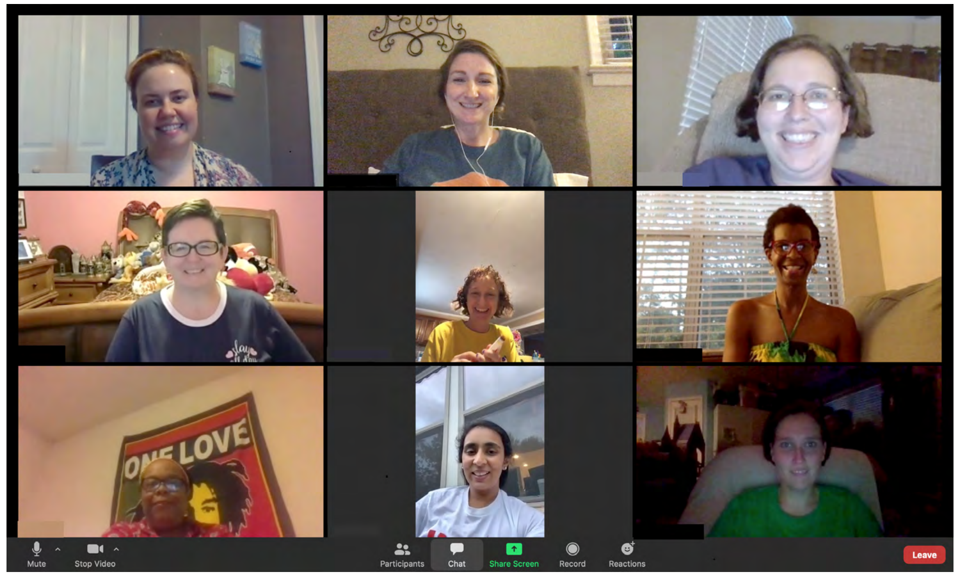
Maybell McDowell by:
Mary & Fox Crabtree
Georgia Marsh
Jeanette & Edward Rogers

Todd Copenhaver by:
Friends at Allscripts Classics
Valerie & Steve Harrison
Patrice Kesler
Luticia Spearman
Cindy & Bill Stephens

Ronnie Knapp by IBM
Barry Waldman by Susie & Tom Williams
Claire Gibbs by Sherry Hart
Francine Davis Sommerfeld by Ellen & David Herold
Gordon Lewis by Doreen & Burt Wittenberg
Kim Treppunti by Barbara & Matt Battiato
Liam Vilensky by Rachel Wittenberg & Asher Vilensky
Lucy Rockett by Leslie Taylor
Pat Jurgenson by Doreen & Burt Wittenberg
Helen Rebecca Gilmer & her wonderful caregiver, Mrs. Bailey, by Susie Williams & Lynn Pogue
Dr. William Meyers by Barb & Gary Eklund
Jeanne Colette Hanley by Ashley Smith
Feras Hamde 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 share 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, Jaide – both of whom consistently attend the Friday share group – 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 IEPs in the context of virtual learning, traveling during COVID-19, concerns about a child's developmental progress and possible testing avenues, and simply asking one another how the week has been, is so incredibly refreshing.

> The fellowship, the honesty, the laughter, and even discussing the "hard stuff" is what I look forward to every week.

Being the parent of a child with significant (dis)abilities is not a role that I signed up for. It was bestowed upon me, and I try to both perform and embody my role with grace. I foster a home and lifestyle centered on inclusion and find ways to involve my son in everything that we do, to the extent possible. I have an incredibly supportive family – my parents and my sister have been pillars of strength for me, especially in the last 4 years. I have a tight and extremely supportive network of friends, both locally and in Canada where I am from. Though I am not lonely in an absolute sense, I find that this particular parenting journey itself is lonely. A few months ago, while in the grocery store with my children, a father (whose son had special needs), after having noticed my son, approached me and asked if I am aware of FOCUS. I told him yes, then we had a short chat in which he told me, "It's a tough life." I did not even get this man's name, but I have thought of his words very often. Those four words encapsulate so much. So much. I would like to add to it, however. My revised interpretation of his words are, "It's a tough life. With the right people, however, it can be a beautifully tough life." My family, my friends, my children's teachers, my son's therapists, the local special needs organizations, and now this FOCUS Friday night share group – Thank you for making this 'tough life' ever the more beautiful.

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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.**

Ride for Team FOCUS on October 4th! Join the team at **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/** or contact Frances@focus-ga.org

How to Reach FOCUS

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