

MAY 2019

ViewFinder

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



A Journey to Independence

By Pam Gross

Recently our son, Jonathan, turned 18 years old. It seemed to happen in the blink of an eye. Don't get me wrong – there have been countless hours of therapies, years of IEP meetings, exhaustive advocacy for resources, and numerous times I second guessed myself that have all added up along the way. But, in addition to those things, were experiences that not only provided opportunities for growth for Jonathan, but also for me. We've met people in our journey who have supported us as individuals, and as a family. We have learned that it truly takes a village to raise a child, especially a child with different needs.

Jonathan was born with Down syndrome to a stay-at-home, helicopter mom. He is our only child, our rainbow child after three miscarriages. So, I was very focused on him, his needs, or, more accurately, what I perceived his needs to be. I argued with Babies Can't Wait to have an intake and assessment done when he was 8 weeks old and had Jonathan's pediatrician write a script for physical therapy (PT) so that he could receive it at 8 weeks of age. He started occupational therapy (OT) when he was nine months old and speech therapy (ST) when he was about 1 year old. He also received a combined session of PT/OT/ST when he was 10 months old in a small group setting with three other children. In the next 2 years, we added aquatic PT, hippotherapy, OT, and music therapy to Jonathan's therapy schedule. Yes, that's 7 therapies a week for a 3-year-old child in case you're counting. I realize that this is not the type of schedule that every parent would or could keep for their child, but it worked well for Jonathan. As we transitioned into the school system, we cut back a few of the private therapies.

When Jonathan was about 4 years old, he was diagnosed with verbal apraxia. I was fine when he was born with Down syndrome, but I was devastated for him to get the apraxia diagnosis. I felt his world would be so much smaller because of his communication difficulties. His opportunities to be successful in the greater

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"... I am a firm believer in providing your child with many different opportunities. You never know what may spark joy with your child ..."

From the Editor...

by Lucy Cusick

By the time this newsletter is printed and mailed, the FOCUS + Fragile Kids staff will be in full camp-mode.

Sad Goodbyes

Since the last newsletter, we've said "good-bye for now" to Keena McCurn, Program Director, and to Elizabeth Snarey, Program Coordinator. We hope to continue to see them at various FOCUS + Fragile Kids events but miss seeing them at the office every day and wish them the best of luck in their new endeavors!



Blythe and Hannah

Sometimes, mail call is the best time of the day. In April, we received the following note, along with a check. *"I can't thank you enough for your tremendous help to my BFFIF (Best Friend Forever In the Family). My cousin Hannah is a part of FOCUS+ Fragile Kids. She is the happiest, brightest, and funniest person I know. For my 11th birthday, I wanted to donate to you; I asked my friends to contribute and we raised over \$200!! Thank you again for your help for Hannah. Love, Blythe Edgar."* Love this sweet girl's love for her cousin!

By the time this newsletter is printed and mailed, the FOCUS + Fragile Kids staff will be in full camp-mode. The first four months of 2019 flew by – here at FOCUS, we've been staycation-ing, share group-ing, respite-ing, camp plan-ing, Six Flag-ing, teen group-ing, swim team-ing, equipment grant-ing, gala-ing, golf-ing, volunteer search-ing and family portal-ing!

The Family Portal is a wonderful addition – easy registration for programs, no more completing long applications year after year. Please take five minutes and set up your Family Portal on our website at www.focus-ga.org ... just six easy steps: (1) Go to www.focus-ga.org (2) Select Family Portal (top right) (3) Scroll all the way to bottom of page and select "Register with Email" (4) Create a Username (you can use your email address) and enter the email address **where you receive the Monday Parent emails** and click "Register" (5) Go to your email and follow the link to set your password. If you don't get a link ... make sure you are using the email address **where you receive the Monday Parent emails!** (6) Go back to www.focus-ga.org, select Family Portal, and enter your user name and password!

If you accomplished the above, you get a cookie!! We hope to see you this summer – at day camp, overnight camp, family camp, or somewhere in-between! Stay in touch through Facebook and Instagram – we know summer is busy, but we're still here!



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Finding Friends at FOCUS

By Christa West

Four years ago, at the annual FOCUS education conference, I sat in a workshop on IEPs, as my daughter would soon be turning 3 and entering our county's special needs pre-k program. I raised my hand and asked a question. Another mom raised her hand and asked a question that I also had on my list of questions. She and I made eye contact and smiled from across the room.

Once the workshop was over we found each other and began talking about our daughters and the mutual fears, concerns, and excitement for special needs pre-k. They were so similar: same diagnosis, their birthdays were just days apart. We shared pictures. They even looked similar! Same glasses, same wheelchair, same gait trainer. There was not enough time, so we quickly exchanged phone numbers and parted ways.

We began texting that evening and throughout the following week. Our girls and our journeys were so similar and yet so different. We planned a trip to the zoo so we could all meet. "The Adventures of Olivia and Nevaeh" began that day. That first meeting was both precious and priceless, and the rest is history. While they are both diagnosed with cerebral palsy, it affects them both very differently. As they continue to grow and develop, the differences are

more apparent, but the bond is ever so strong. Olivia says it best when she tells others, "This is my friend Nevaeh. We both have cerebral palsy. She has the talking kind (as Nevaeh is non-verbal) and I have the walking kind (as Olivia is non-ambulatory)."

The girls have been on various outings together with FOCUS, have had their pictures made together, have celebrated birthdays together, and have had overnight sleepovers.

Living on opposite sides of the city, our families spend time with each other as often as we can. Both Olivia and Nevaeh, as well Janet and I, always pick up right where we left off as though no time has passed! Our friendships are blessings and we are thankful to FOCUS for bringing us together and allowing us to meet.

When are you attending your next FOCUS event? You never know when you'll find a new friend!



Above: Nevaeh and Olivia's first meeting at the Zoo in March 2015. Top of page: March 2019 as they both celebrate turning 7.





FROM THE COVER

A Journey to Independence

community had dwindled. I cried for 2 weeks. We had been using sign language along with his speech therapy to work on his communication skills and that had been helpful, but we needed to do more. The speech therapist evaluated Jonathan for an augmentative and alternative communication device (AAC), and he began learning how to navigate around, forming phrases and sentences. It had opened his world again! Over the years, he has upgraded to using an iPad with the TouchChat app for communicating, but he also continues to work on his articulation using PROMPT with his speech therapist.

Jonathan has come a long way over the years. He once had a lot of sensory related problems which were demonstrated in a variety of ways. He could not tolerate loud noises such as school assemblies in the gym. We had to work on desensitizing him to the noises. He also did not tolerate foods with mixed textures. We had to develop goals with his OT to work on feeding with him in order to overcome his aversions. He went from eating only 3 food items and drinking Pediasure to eating a wide variety of healthy foods. At times, Jonathan was so manipulative it was challenging to tell if problems were more sensory or behavior based. I once consulted a behavior specialist to learn about identifying motivators & appropriate rewards for our child. When I figured out the most effective motivator for Jonathan, he was potty trained in 4 days. Obviously, the little shyster had been playing me for far too long!

But here he is, 18 years later and we are still at it. Jonathan receives OT and ST twice a week each. He is monitored by his PT quarterly to ensure that he stays in good shape; he also works on many Activities of Daily Living (ADL) so he can be as independent as possible. We are so grateful to Jonathan's therapists who have helped him over the years to make so much progress. Darlene, Lauren, Tori, and Merri at Darling Pediatric Therapies have become like family to us!

Like therapies, school has provided a solid foundation for Jonathan over the years. I was very excited when Jonathan's teacher approached us last year with the idea of him joining the Junior ROTC (JROTC) program at the high school. Until then, they had not had any students with special needs participating in JROTC. With his teacher's support (she's an AWESOME teacher), Jonathan and 2 other students with special needs began to participate in JROTC. All 3 students are now independently participating in JROTC this year. Additionally, our county (Dawson)

expanded their vocational-rehab program 3 years ago. Although most students don't start jobs outside of the high school until their junior year, Jonathan has started working at Marshalls for a few hours one day a week. I am thrilled that he is gaining experience with more responsibility both inside and outside of his high school.

But Jonathan is not all work and no play! I am a firm believer in providing your child with many different opportunities. You never know what may spark joy with your child. He loves water aerobics class, rides horses, competes in Special Olympics Equestrian State Games, plays Miracle League Baseball, and has found a talent for photography by participating in the Thousand Word project. One of his photos now hangs in the kitchen of actress Melissa Peterman, best known as "Barbara Jean" from the comedy show "Reba." Melissa may be Jonathan's most famous fan, but I remain his biggest fan.

Upon reflection, after 18 years I feel that Jonathan's future is bright. He has had a solid foundation of therapies, school, voc-rehab, and involvement in the greater community. I feel that we are aligning ourselves for his road to independence. It's not going to be easy for this helicopter mom to land and let him launch, but I know the time is near.

Jonathan's occupational therapist helped us understand the need for augmentative and alternative communication (AAC) and Applied Behavior Analysis (ABA). See page 5 for helpful FAQ on both!



**FOCUS + Fragile Kids
Facebook Birthday Club**

Facebook Birthday Fundraisers – We receive 100% of the funds raised on Facebook! And ... if you raise at least \$200, you'll receive a special, FOCUS + Fragile Kids t-shirt as a birthday gift from us!

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Frequently Asked Questions

For new parents or parents with a child with a new diagnosis, the following Q & A provided by Darlene A. Robertson, Darling Pediatric Therapies, may help!

Q: What is ABA?

A: ABA stands for Applied Behavioral Analysis. It's based on the work of B.F. Skinner, a psychologist who focused on operant conditioning, or the study of observable behaviors and the events that cause and reinforce those behaviors. Most occupational therapists (OT) and speech language pathologists (SLP) use the concepts behind ABA to teach, motivate, and shape children's behaviors. There are significant differences in how and when we apply these methods, in how stringently we define the behaviors we expect, in how we select and apply consequences, and in how strongly we believe that the ABA lens is not the only one through which we can view the world.

Q: Will AAC (Augmentative and Alternative Communication) stop my child from speaking?

A: Research shows AAC does not stop speech development. Additionally, evidence shows it may support speech development.

Q: As long as my child talks, is a communication device needed?

A: A child who is not able to communicate effectively is at great risk for cognitive, social, emotional and behavioral problems. AAC can be used to facilitate communication.

Q: Shouldn't speech, even if it is very limited, always be the primary means of communication?

A: Children who have some speech will naturally use it as a primary means of communication. By introducing AAC, we provide a total communication system which includes a range of different communication methods, including speech if possible. Speech and AAC allow the child to communicate with a variety of people, in different environments at different times.

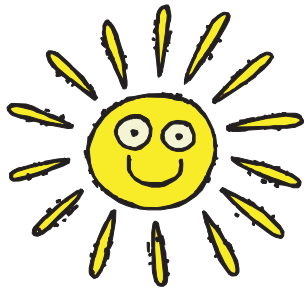


Q: I have no problems understanding my child, so why should I consider AAC?

A: It is great if speech can be a component of your child's communication and used with family. But AAC may be necessary for your child to participate in school, socialize with friends, participate in the community and work towards independence.

Q: When is a young child ready for AAC?

A: Even infants engage in purposeful, communicative behavior well before the development of language. For young children, AAC often means play-based interventions that focus on the development of communication-related skills, intentional communication, or basic functional communication. Speak with your child's SLP.



Today Is A Good Day

by Charisma Freeman

So, today is a good day! The birds are chirping, not too cold, no rain, and not a lot of thinking. I don't know about you, but, for me, thinking can get me into sooooo much trouble. My thoughts tend to run away with me, like a child with a wild imagination.

But today I'm not doing that. I'm just being. I'm just here. Where's my son, you ask? Well, of course, he's not here or this day would go much different. He and his Nana went to Chuck E Cheese. She thought I needed a break. She was right.

You see, Cam was diagnosed last week with a rare genetic progressive neurological disorder called KIF1A. It's characterized by spastic paraparesis (weakness or paralysis and spasms), optic nerve atrophy (which leads to blindness), seizures, neuropathy, and a bunch of other good stuff that can worsen over time. You can see why we're not so happy around here right now, Right? There are about 200 people in the entire WORLD with this

disorder. Cam could be so lucky! Not only is it rare, but he's the only one with his own personal mutation. They should call it KIF1A- "Cam the Man" mutation, lol!

So, until March everyone said he had cerebral palsy ... except his neurologist, Dr. Barbara Weissman. She's a doll, by the way! Ultimate girl power! Well, she was on a mission to solve Cam's mystery diagnosis. Five years and three genetic tests later, she did it! So why am I not happier?

Well, for 7 years I've been told, "At least it's not progressive" (doesn't get worse). I've embraced March as cerebral palsy month, sold shirts, and raised awareness, but now he has a different diagnosis. It's

hard to raise awareness for a disease no one knows or cares about. Autism, breast cancer, these things affect more people. Rare genetic disorders ... well, they're rare for a reason. There's no fancy ribbon, day, month or color. So I went from the big powerful, researched CEREBRAL PALSY to little ole KIF1A, a progressive disorder with nothing but doom and gloom to look forward to.

But something powerful happened. I found another family!!! A Facebook group of other KIF1A'ers, most wrongly diagnosed with CP as well. A group of parents and families fighting hard and raising money for a cure. A place we belong with our incorrect diagnosis of CP, spastic paraparesis, seizures, autism, and

neuropathy that never fit nicely in a box. We've found OUR box and in Charisma fashion, I've jumped in head first. Making preparations for the conference in August, scheduling appointments with 3+ more specialists, working on my new baby – a nonprofit for children with KIF1A and other rare disorders.

Because when it's all said and done, I will not be swept to the side or run over. We will fight! We've been fighters since Day 1 when the pediatrician told me, "He's just slow, all boys are slow." Or when the orthopedist told me he was fine at 12 months, or his dad told me I was TRYING to find something wrong with him prior to our divorce. You see, we fight! We will fight the progression,

continued on page 7 >

... Because when it's all said and done, I will not be swept to the side or run over. We will fight! We've been fighters since Day 1 when the pediatrician told me, "He's just slow"...



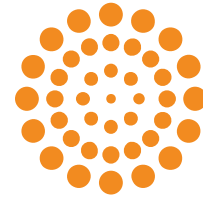


FROM PAGE 6

seizures, chance of blindness, and whatever else this disorder throws at us. We are charting our own path. The heavens have given us a clean slate. We have KIF1A with the "Cam the Man" mutation and in my reality this mutation isn't noticeably progressive as long as we keep working. And trust me, we will keep working!!!

So next time you need a day, remember to make it a GOOD DAY! ❤️❤️❤️

Our little family consists of Cameron, my daughter Nadia, and me. I'm an Adult Geriatric Nurse Practitioner during the day, but my real occupation is a Special Needs Mom. I co-lead the West Georgia FOCUS Share Group that is growing like a wildfire. We started this group with 5 members and grew it to 19 members in just 2 years. We found FOCUS over 5 years ago, and I love this wonderful organization. I'm also a band mom from August to January since Nadia is a Mighty Marching Jaguar. She volunteers at school and at Douglas County Special Olympics. My smallest of jaguars, Cameron, is amazing! Every day, he has a smile on his face that lights up the room! I'm the crier and he's the fighter. He's not aware that he has any weaknesses (or he doesn't care), so he does it all: basketball, baseball, swim, dance, and runs his own personal transportation company in his playroom! Cam and Nadia encourage me every day!



Thanks from the Montague Family

I wanted to send a quick letter of appreciation to FOCUS + Fragile Kids and to their sponsors for making the installation of the Stair Lift for our son, Harrison Montague, a possibility.

Harrison has a rare condition called PURA Syndrome which causes him to be severely delayed globally, but also struggles with anywhere from 10 - 50 seizures a day. He is seventeen years old and has a strong desire to be mobile and active. However, now that the seizures have become so common in his life and his muscles seem to be weaker as he grows taller, he has been confined to a wheelchair for the past few years. Once he was confined to the chair, the entire lower level of our home was no longer accessible. Unfortunately, this is where his therapy room and the larger bathroom that could be adapted to be accessible for him are located. It has

been very disheartening knowing that we had all the therapy equipment that could help strengthen his muscles and increase his endurance downstairs, but there was no way to physically get him to it since he is now 5'10" and about 110 pounds. The installation of the Stair Lift is a game changer for all of us! It has made exercising on the equipment in the therapy room a possibility again, as well as encouraged us to work on adapting the larger bathroom that is located downstairs so that he can have a safe place for his personal hygiene. He has already endured multiple oral surgeries due to falls from seizures, some that have taken place in the bathtub. We are thrilled

to have the opportunity to possibly change this and make bath time safe for him again!

We have been with FOCUS for about sixteen years and we can't even imagine what his life (or ours) would have been like without them. We consider FOCUS family and we are so thankful to be a part of such an amazing group of caring and compassionate people.

Please see the picture above of Harrison in his new Stair Lift. He constantly signs "more" when we roll his chair even close to the stairs! Thank you for enriching his life and making things a little easier for us all.

Sincerely,
Traci & Harry Montague

Looking back!



Chili Cookoff



Education Conference



Dinner Dance Gala



Nurses in TICU excited for monthly hot meal & goodies from FOCUS + Fragile Kids, sponsored by Anthem BlueCross BlueShield



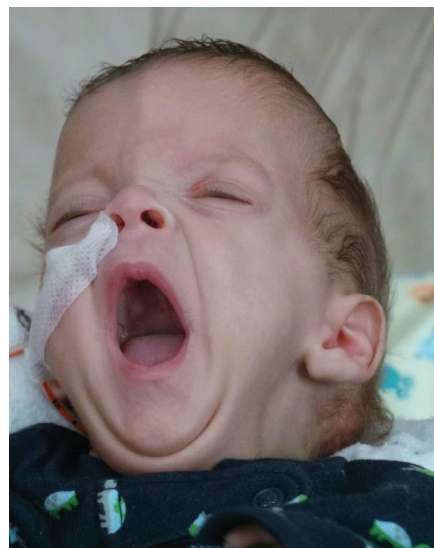
Teen & Young Adult Groups



Spring Break Staycation



Teen & Young Adult Groups



5 YEARS AGO TODAY

by Larissa Olivieri

It's been 5 years since the day I brought you home.

It's been 5 years since that happy and scary day, That for 4 months I have prayed, and now you are where you belong.

It's been 5 years that I don't sleep for a whole night, that I can literally hold you so tight. And I can finally kiss you Good Night.

It's been 5 years that I can sing your favorite song, That I didn't know your outcome; And I am so proud of the boy you become.

It's been 5 years, without machines and wires, without beeps and alarms. And you can fall asleep every night in my arms.

It's been 5 years, with a lots ups and downs, hospital visits and hospital gowns. And you always turn yourself around.

It's been 5 years, with some late and few milestones, but with a strength that only you own, and that Happiness you've always shown.

It's been 5 years, that I have been every day by your side, that we laugh till we cried and your World and Dreams became mine.

It's been 5 years and much more to come.

It's been 5 years since the day I brought you home.

Lars was born prematurely at 27 weeks and spent 114 days in the NICU. Lars has Hydrocephalus and Cerebral Palsy and has been a FOCUS KID since age 2. Lars loves FOCUS HALLOWEEN Parties and CAMP HOLLYWOOD, and his mom Larissa Olivieri is a member of our Parent Advisory Council. Lars is also the Miracle Kid Spokesperson for Children's Healthcare of Atlanta.



Robotics



Valentine Dance

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Susan Vigil
Alex Roth by Marianne & Joe Roth
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Rita Marokko
Breanna Barber by Veronica &
Harold Still
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Kaitlin Hong by Dena & Tom Hong
Katherine Lucier by Kathleen &
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Katie Norris by Dina Norris &
Stephen Young
Kevin Cleveland by Cheryl &
Dallas Galli
Kirk & Scott Lawton by Celia &
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Lucy & Josh Cusick by Beth
Carscallen
Lucy & Josh Cusick by Lolita
Watson
Lucy Cusick by Betsy Primm
Mackenzie Cassidy by Kim & Carl
Cassidy
Marcia Coursin by Ronald &
Sharon Zimmerman
Matthew Ladd by Lizabeth
Mahaffey
Michael Campbell by Deltavier Frye
Mitchell Rowe's Birthday by Sharon
& Kenneth Rowe
Josephine Moltoed's Birthday by
Barbara & Matt Battiatto
Martinez's Anniversary by Barbara &
Matt Battiatto
Patty Vastakis by Elaine & Anthony
Stratis
Phyllis Muttone by Barbara & Matt
Battiatto
Ricky Raschke by Linda & Rick
Raschke
Rose & Michael Haber by Wayne
Huntsinger & Martin Haber
Rose & Michael Haber by Rita
Marokko
Sam Shaw by Mark Kronenfeld
Sarah Davidson by Joshua Mikel
Scott Ballard by Mark Panfel
Shevlin Family by Barbara Wittick
Susie Williams by Miriam Gottfried
Teddy Haber by Rita Marokko
Tom McMurrian by Jim Clark
Trevor Smith by Andrea Bowles
Vicki & Ron Canakaris by Susie &
Tom Williams



Victoria Brown & Family by Anna Miller
 Martin Haber & Wayne Huntsinger by Rita Marokko
 Wyatt Stryker by Alicia & Joe Stryker

Memorials

In memory of:
 Ann Carter by Margie, Chris & Sarah Maurer
 Brad Robertson by Barbara & Matt Battiato
 Camille Bass by Justin Ford
 Catherine Walski by Sharon Rivera
 Claire Gibbs by Randy Dewitt
 Claire Gibbs by the Hauser Family Foundation
 Claire Gibbs by Brad & Amy Gibbs
 Claire Young by Sharon Rivera
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 Liam Vilensky by Doreen & Burt Wittenberg
 Moe Dominguez by Kathy Schoen
 Natalie by Beth & Bill Tumlin
 Virginia Debele Reeve by Frank, Celia, Kirk & Scott Lawton
 Zachary Chambless by Susan & Brooks Patterson

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 Hope Brandt Beissel
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 Jennifer Catherine
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 Karen and Tim Davis
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 Michael Fischer
 Shannon Goodman
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 Ofelia & Randal Mandock
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Coming Up at FOCUS

June 8 • 12:30-2pm
 Daddy Daughter Dance at Mt. Bethel UMC, Marietta

May 28 to July 12
 Day Camps! Multiple Locations!

August 17 • 7-10pm
 SummerFest at Tucker Brewing Company

August 9-11
 Family Camp 1 at Camp Twin Lakes Rutledge

October 4-6
 Family Camp 2 at Camp Twin Lakes Will-A-Way

Information and registration for all activities are announced in our Monday Parent email! Don't receive it?
 Contact lucy@focus-ga.org

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