SEPTEMBER 2018

ViewFinder

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



"... I would like to take this opportunity to personally thank FOCUS for establishing Camp Infinity, for showing me that independence is still possible, even if you have a disability, and for introducing me to Camp Twin Lakes ..."

My Second Family

By Ricardo Aranda

My name is Ricardo Aranda. I have been a participant with FOCUS for 19 years. It all began in the summer of 1999 when I first participated in Camp Hollywood, a day camp sponsored by FOCUS. From there, I began to involve myself more and more. My family went to FOCUS Family Camp and, as I got older, I participated in FOCUS teen and young adult social groups. Then my big opportunity came – in the summer of 2008, at age 17, I applied for FOCUS Camp Infinity, their brand-new, sleep away summer camp for young adults with special needs at Camp Twin Lakes. Like all new things, at first I was apprehensive about going. But through the years, Camp Infinity at Camp Twin Lakes became like a second home and the people like a second family to me.

Therefore, I would like to take this opportunity to personally thank FOCUS for establishing Camp Infinity, for showing me that independence is still

possible, even if you have a disability, and for introducing me to Camp Twin Lakes. I just returned from my 10th year at Camp Infinity. I cannot personally believe that it has been 10 years since that fateful Sunday in July when I got introduced to the people and places that I would end up calling home and family! Thanks to FOCUS for helping



Michelle and Ricardo at Camp Infinity

me grow into the person that I am today.

Camp Infinity and FOCUS not only taught me lessons of socialization and independence that I can use within camp and with my family, they also helped me have more self-confidence and to gain more independence. This confidence led me all the way to Kennesaw State University and my dream of living on a college campus. I am now a senior at Kennesaw State and will graduate in May 2018 with a Sociology

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From the Editor... by Lucy Cusick



Lucy dances at Family Camp

Summer is so busy with the FOCUS + Fragile Kids staff tagteaming at day camps, overnight camp, and Family Camp ... busy and FUN!



at www.focus-ga.org

As fall approaches, share groups, Extra Special Saturday, and workshops will begin ... plus plans for Aquarium and Zoo Days, FOCUS on Moms, and special family days. We are thrilled to be back at 'full staff,' with the addition of Elizabeth Snarey as Parent Coordinator. Be sure to welcome her – and her son, Michael, who might be with her at activities.

This newsletter has a long exchange from Facebook from several families' experience at FOCUS Family Camp in August. Social media is a great way for families to share information and resources, and, now, to raise money! We love being chosen to receive donations in honor of birthdays – see the list of 'birthday club' members on page 7. Every donation – small or large – continues to mean a lot here at FOCUS + Fragile Kids!

And speaking of birthdays, FOCUS just celebrated our 36th year of support. We are proud to have survived some tough financial years, to continue to grow and serve more families, and to walk with so many parents along this journey. Group Hug, FOCUS + Fragile Kids families!!

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Facebook, FOCUS + Fragile Kids, and Family Camp

So, some of us at FOCUS + Fragile Kids are known to stalk around on Facebook – many times we find out about hospitalizations, new babies, tough times, and maybe a few things we really don't want to know! But, we do love cruising around after a FOCUS + Fragile Kids event and seeing all the photos from families! Here's one really fun exchange – names omitted for privacy:

TTH

August 11 at 11:17 PM •

This was our 3rd year we've been blessed to be a part of the FOCUS family camp weekend. A weekend where we get to meet with friends old and new who inspire us. A weekend of fun without stress where acceptance and love is everywhere. A time when we get to meet so many friends that are differently abled, and we love learning from them. There are a couple of new people that I got the pleasure of meeting who left a huge impact on me.

First, a grandmother of a sweet little boy with muscular dystrophy. Her daughter was working this weekend so she brought her grandson. Watching the love for her precious grandson in a wheelchair was simply

beautiful. I got to hold him while she fixed her plate at lunch, and, oh my goodness, he just felt so good to hold. He had very little muscle tone, and it brought back memories of when I first held "A", my daughter with Down syndrome. She just melted onto my body with complete trust from the start. This boy was adorable, sweet, loved and so blessed. I just felt that when I held his little heart up against mine. It made me happy to know he had such a special, strong Grandma to help him and his mother. I enjoyed talking to her so much. Truly reminded me of my mom and how amazing she was especially when A was little. Such a blessing. I know they will have challenges along the way, but I pray for the mother-daughter team to lean on each other to provide this sweet boy with care

throughout his life. I know he has taught them so much even in the short period of time he's been here. Children are such a blessing in that way.

And another gentleman I spoke with ... I saw him at the pool. He picked up his son who couldn't walk, carried him around the pool, and up a big flight of stairs to the top of the slide. His son was not small, I would guess he weighed about 90lbs. It definitely wasn't easy for him as I saw him struggle, but he did it. When he got to the top of the stairs, they sat on the bench so he could catch his breath. Then he placed his son on the slide and went to the bottom to retrieve him as he splashed into the pool. The smile on his son's face was pure joy, and watching him really hit me in the heart ... the

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FROM PAGE 3 Facebook, FOCUS + Fragile Kids, and Family Camp

love, the strength, and the will do to anything to see his son smile. It's such a powerful thing to witness.

The families and parents at FOCUS Family Camp always leave an impression on me, a reminder that we all have challenges in life, but the way we handle and push through them is what makes our journey a better one. And many times you find that you're stronger than you thought you were. We spoke to some pretty rock solid people this weekend who have a lot of perspective. I love this camp for that reason and all the joy it brings the families here.

The last night is always a camp-wide talent show. My kiddos decided to dance to Party Rock. Z (6) does not like to dance, but did it to support

his sister. A (8) started off a little nervous but was all in once the music kicked in. It was hilarious to see that they threw in the "floss" dance which I accidentally called the "toothpick" and got laughed at. I'm the uncool mom now, but it's all good. I'm comfortable in my own uncool mom skin. Just wanted to share some photos of some of the fun we had. It was nice to come here and "focus" (pun intended!) on all the good things we have going on around us. Thank you, FOCUS family, for another wonderful camp!

... we all have challenges in life, but the way we handle and push through them is what makes our journey a better one ...

TTH is with LMC and MK August 12 at 5:08 PM

The blessing of an extra chromosome has brought such wonderful friends into our lives. It's our annual tradition to attend FOCUS Family Camp with MK, LMC, and their families. We all crash in a big cabin, and it's so much fun. Once again, we were assigned to Cabin 21. We loved that we had 3 families in Cabin 21 – it represents 3 copies of the 21st chromosome. Maybe we need to tell the FOCUS staff that we want to reserve Cabin 21 every year!

LMC: I love the idea of asking if we can have Cabin 21 permanently! It was a BEAUTIFUL weekend and we loved spending it with all of you! My son, "C", was very sad as we drove back to the A but we promised him that we would be there again and again, year after year, with y'all! As he put it, y'all are "family" and I agree!!!! And, if I ever consider ink. I think I will memorialize our cabin (and life) assignments with "321"! Love you girls and your families! You truly are my family ... whether you want to be or not! I think you are stuck with me!

KA: There is so much to say about my time at FOCUS Family Camp this weekend. This was my first time, and I wasn't sure what to expect. First of all, they take FAMILY very serious! I saw families that included children, parents, grandparents, aunties and uncles. But at the same time everyone treated each other as family. Always willing to help and to encourage.

My grandson "G" and I were newbies, and I guess it showed. But so many people were willing to help out. I felt safe to allow his "flaws" to be on display. For the first time I felt like I belong to a community. TTH was always coming out of nowhere to offer her assistance and her beautiful children were so sweet to G. Then there was a gentleman (can't remember his name!), but he had the most soothing voice. Every time I saw him he would say "if you need anything let me know because I understand and sometimes that's all you need." People who truly understand.

The children at the camp were also amazing! They could just run and play without people teasing them or staring at them. I met a little boy named Cam who had autism, and he took a liking to me. He hugged me and kissed my hand. When G cried he wanted to comfort him.

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FROM THE COVER My Second Family

degree with a cultural diversity concentration. I hope to use my degree to work directly with nonprofits like FOCUS and Camp Twin Lakes.

My wish for the future is to "pay it forward" and help other parents and families in the same situation as mine was 19 years ago. I am so thankful for FOCUS and its programs that helped me become the man I am today. May God continue to bless all of you and the work you do for years to come.

Coming Up...

... at FOCUS + Fragile Kids Registration for all activities are by email. Do you get our Monday emails? (If not, email lucy@focus-ga.org)

September 15 FOCUS on Moms

September 23 Aquarium Day

October 5 – 7 FOCUS Family Camp 2

October 13 Blue Ridge 250 Motorcycle Ride Fund Raiser http://www.blueridge250.org/

October 20 BooBQue for All Families!

October 21 Spin for Kids – Ride for TEAM FOCUS!

October 27-28 OctoberFest for Teens & Young Adults

October 27 FAST Fins Swim Meet

November 11 FOCUS on FASHION is back by popular demand!

November 17 Zoo Atlanta Day

Questions about any of these activities? Email lucy@focus-ga.org and she will forward to the staffer-in-charge!



Create Your Own Classroom

By Jasmine Mack

My son Caleb was diagnosed with autism on March 27, 2018 at age 2. I was devastated, heartbroken, and distraught when my husband and I received the diagnosis. I was so scared and filled with grief ... and questions.

After a few months of living in a fog, going through several therapists, and a roller-coaster of financial and emotional loops, I finally feel like my family is happy and our home is peaceful. Being a mother of two toddlers, especially one with special needs, is so lonely at times. However, the good truly outweighs the bad, and I thank God every day for my family.

Caleb attended a Montessori School for six months, but this past June, I decided to create my own classroom at home. I work closely with Caleb's therapists to create the structure and schedule that works best for him and for my 17-month-old daughter. I realize everyone does not have the luxury to be home with their children, but we decided to give it a try. I found specialized teaching curriculum and materials for ASD children on www.difflearn.com and found great toys on Amazon.

I love seeing my children learn and develop together. I am also amazed with the strength and patience that I have gained! One day, I hope to return to my career, but, for now, home is where I need to be!!

Editor's Note: FOCUS + Fragile Kids now has a new Facebook Group called @FOCUS + Fragile Kids Homeschool Group.



Welcome to FOCUS + Fragile Kids!



Elizabeth Snarey has joined the staff of FOCUS + Fragile Kids as the new Parent Support Coordinator.

Elizabeth recently received her Master of Social Work and completed a year-long fellowship program, Georgia Leadership Education in Neurodevelopmental Disabilities (GaLEND). In addition, Elizabeth is the mother of Michael (MPS II, Hunter syndrome) and a FOCUS mom. When not in the office, Elizabeth can be found eating pizza with Michael, advocating for inclusion, and spending time with people she loves.

From Elizabeth: "I look forward to serving FOCUS families and journeying alongside each of you!"



CONTRIBUTIONS

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Amazon Smile Atlanta Rotary Youth Service Fund Cobb County Friendship Club Cobb EMC Community Foundation DeKalb School Employees Foundation E*Trade Friedman Family Philanthropic Fund Heritage Community Foundation John & Mary Franklin Foundation Kiwanis Club of Suwanee Kroger Kulynych Family Foundation II. Inc. Mobility Works National Charity League, Roswell-Alpharetta Resurgens Charitable Foundation SunTrust United Wav The Holly Lane Foundation The Roderick S., Flossie R. & Helen M. Galloway Foundation United Way Chattahoochee Vallev United Way of Central & NE Connecticut

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FOCUS + Fragile Kids Facebook Birthday Club Doug Beasley Connie Coyne-Grady Charisma Freeman Brad Gibbs Authurine Johnson Lisa Lucier

The Claire Gibbs Scholarship Fund has been established in memory of Claire, a Camp Hollywood camper and an all-around MVP here at FOCUS + Fragile Kids. We are grateful to continue to offer scholarships to our programs in memory of sweet Claire Bear.

SHOUT-OUT to Our Staff & Volunteers!

The FOCUS + Fragile Kids year-round staff are ah-mazing! They work during the week to prepare for an event, then they manage the event on the weekend – from scheduling to schlepping supplies, the FOCUS + Fragile Kids team pays attention to every detail to make sure each activity is organized and as easy (as possible) for parents!

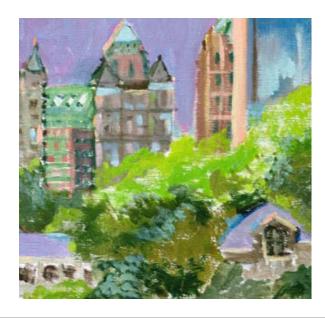
Our part-time staff – from nurses and caregivers to counselors and swim coaches – give their weekends and summers from their 'day job' to help our kiddos and families have fun (and stay safe!). They are teachers, paraprofessionals, and retired medical professionals who have a heart for our children.

And our volunteers are the extra hands, energy, and youth needed to give the extra attention to our children! From a few hours on a weekend to a few hours EVERY weekend, to an entire week at FOCUS Camp Infinity, these young people continue to amaze us with their big hearts and willingness to serve.



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Save the Date!

Friday, September 21 at 6 pm, "The Artsome Four" exhibit will open at the Rectory, 17 College Street, Norcross, GA with a reception to meet the artists. This fabulous art sale will remain open through October 26. It is free and open to the public.

Thes "Artsome Four" will display works of 4 professional women artists: Jane Carroll, Mozelle Funderburk, Linda Hanks and Sherry Needle who have been painting together for a number of years. We are most grateful they chose FOCUS + Fragile Kids to receive a portion of the proceeds.

The exhibit is accessible by calling either 678-421-2048, 678-421-2049, or 678-421-2025 when staff is on duty Monday – Sunday.

FROM PAGE 5 Facebook, FOCUS + Fragile Kids, and Family Camp

The staff went above and beyond to make sure we could just enjoy the weekend. I loved my time there and I can't wait to come back next summer. It was such a blessing!!!!!

Our camp photo in the picture frame G helped paint. Some would notice his lopsided sunglasses. I notice a little boy being his very own version of perfect.





JMH with ZH August 10 at 3:01 PM •

Our family LOVES FOCUS Family Camp – we've been coming for many years! Here's our favorite photo – from left to right, we are each wearing a shirt to represent each year we have attended FOCUS camp together!

CP by email

I wanted to say that it was a pleasure meeting you this past weekend. Erik had a wonderful time and returned to his Day Program today with lots of photos and stories to tell his friends. FOCUS provides such great events for the participants and we really appreciate it. I was truly able to relax and not worry about Erik's presentation to others this past weekend. It was quite an experience for both of us!

Erik insisted that we visit the donkeys after each meal – he always took them apples. I asked him where he was getting the apples and he told me the "lunch basket." I had to send Rob out to buy more apples for the dining staff because he insisted on feeding them each time he ate. At the end of our trip, he told them goodbye and said "you are so cute" – they responded with a bray and he got really excited that they told him good-bye also. Erik is normally very good around animals, but this experience with these donkeys were something a little more special. Thank you and the FOCUS team for all that you do for us!



Erik feeding the donkeys

Looking Back at the FUN!

















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 - http://tinyurl.com/focusgeorgia



Wish FOCUS + Fragile Kids a Happy #36!

Celebrate #36 with a \$36 donation to FOCUS + Fragile Kids! This newsletter reaches almost 9,000 households by mail or email: families, friends, professionals, volunteers. If HALF of these households gave a \$36 birthday gift to FOCUS + Fragile Kids, we could plan 2019 with a big sigh of relief and a lot of Comfort, Hope, Fun & Equipment! https://www.givedirect.org/ donate/?cid=8063 or Mail a Check to FOCUS + Fragile Kids: 3825 Presidential Pkwy, #103, Atlanta, GA 30340.

We know many of our families cannot manage a donation – would you consider choosing FOCUS to receive rewards through AmazonSmile (listed as Families of Children Under Stress); Kroger (#MM138) or by having a lemonade stand or birthday fund raiser on Facebook (see page 7.)