

FEBRUARY 2018

ViewFinder

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

Happy Birthday, Lacey Faith

By Hillary Key

My Lacey Faith, how are you five? Wasn't it a couple of breaths ago that your NICU nurse so accurately called you fiesty ... one of the many things I love about you.

Here are a couple more,

I love how you are "all in."

When you hear a song you like, you dance.

When I push your chair through a crowd, you wave at everyone like a pageant queen in a parade.

When you see art, a logo, a mural, a sign – you study it.

You love water like a fish.

When you ride a horse for therapy, you don't want to stay in the arena, you want to venture out onto the outside trail.

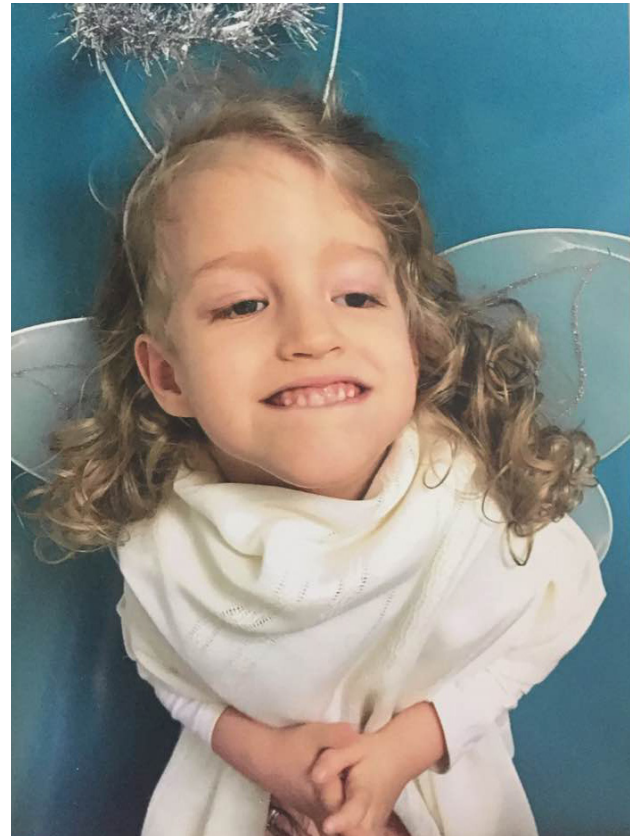
Whatever is happening you want to be all in – in the center of it, doing every part in your own way.

You were not created for the sidelines.

You are all in – all in your Mama's heart.

I love the way you love.

I love the way you squeal and give tight hugs when you see people you love – whether you saw them yesterday or months ago.



I love the way you hug the phone when you FaceTime.

I love that you are your big brother's biggest fan, and a Daddy's girl who welcomes him home with the squealy tight hugs.

I love how you get joy out of giving and sharing.

I love your fiesty spirit though it backfires sometimes.

I love your sense of humor and when you giggle so hard your laugh loses its sound.

I love the way you shine my sunshine girl.

I pray you shine for a long time.

Happy Birthday.

From the Editor...

by Lucy Cusick



FOCUS friends for almost 30 years

So many stories and memories over 35 years of FOCUS, plus the 25 years that Fragile Kids Foundation helped children and families ... and we're still growing!

... as a young mom, having someone to share this journey with, someone who would endlessly listen to me, offer suggestions, or tell me to 'get over it,' was priceless!

About 25 new families contact us each month – EACH MONTH! We love meeting new families and seeing them make a friend who understands the hopes, dreams, tears, and fears of parenting a child with different abilities.

My friends at FOCUS were my lifeline – one had a child just one year older than mine, with a similar premie history. None of us lived close to each other so we spent HOURS on the phone, often late in the evening, after a long day of mommy-dom. We celebrated new skills, laughed at our mistakes, and cried from frustration, exhaustion, or just plain sadness. We rarely talk now – why would we? We have Facebook!! But, as a young mom, having others to share this journey with, people who would endlessly listen to me, offer suggestions, or tell me to “get over it” was priceless.

To our new families at FOCUS + Fragile Kids, please jump right in! If you can't figure out how, email lucy@focus-ga.org. To our more seasoned families, thanks for welcoming new kiddos and their parents – we hope you'll show them the ropes at day camp, family camp and activities, conferences and workshops, and more!

We really are all in this together.

Grateful.

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Eliza

by Christine Perkins

I'm often asked if I knew that Eliza had Down Syndrome before she was born. The answer is no. I opted to not have any invasive tests. This was to be my last pregnancy, and I wanted to enjoy it. Testing would only have ramped up my already raging anxiety. I was going to have three girls under the age of four. Who needed more anxiety?

After I delivered her, they handed me my beautiful baby girl and left the room. I instinctively knew something was off. She was floppy, unresponsive and wouldn't nurse. I asked to see the neonatologist the next day. The neonatologist came in at 7 am and, without waiting for my husband to arrive, glanced at her and threw out words that I'd never heard before: epicanthal folds, trisomy, transpalmar crease and Brushfield spots.

I was reeling. He wouldn't slow down so I could absorb and process this foreign vocabulary. Chromosomal tests were ordered. Then he started talking about heart defects, and I started drowning. I tumbled into a sepia toned rabbit hole where all speech was mumbled. He walked away.

I hated him. I hated him for leaving me alone and for changing all of my dreams in an abrupt conversation. I didn't know how I could tell

my husband. I had to break his heart rather than the doctor. Three days later I saw the same doctor because Eliza was in NICU. I watched his capable hands handle babies so tiny that they didn't look real. I watched him deliver devastating news to a young couple. My perspective changed, and I stopped hating him.

Six days later, we took our beautiful, HEALTHY baby girl home. The world didn't stop. It just changed - in a good way. We have to stop and smell the flowers because she insists upon it! We are now far more aware of what's important in life, and priorities have simply shifted. Is it easy? No, but that's parenting in general. I have days where the state line looks real attractive when I'm driving by myself!



Eliza at FOCUS Day Camp

The Angels Among Us

From a recent talk by Luke Boggs, Sadie's dad



I'm not going to talk about Charlie's Angels, the Blue Angels, or the Hells Angels. I won't be talking about Frank Sinatra's incomparable recordings of "Angel Eyes," one of the finest saloon songs ever written. And I will not even be talking about my favorite fictional angels, including the inimitable and irrepressible Clarence from *It's a Wonderful Life*.

I'm not going to talk about any of those things, I assure you again. But I will say something about angels. Something relatively serious, if I can keep it that way.

Almost every weekday of late, I take our daughter Sadie out to the bus stop at the end of the driveway. Sadie is special, as most of you know. She's a lovely person. And frequently a delight to be around.

But she needs a lot of help, as we all do. And in more obvious ways.

While we're waiting for the bus, I often say a prayer with Sadie. We thank God for the day, we ask Him to watch over Sadie, and we thank Him for the angels, seen and unseen, who look out for Sadie and take care of her and protect her.

Because just as there are angels invisible to us, there are just as surely angels we can see. They don't have wings. They don't shine like xenon high-beams. And they don't live in heaven. Even so, there are angels among us.

Sadie has a lot of these visible angels in her life. Teachers. Para-pros. Therapists. Caregivers. Doctors. And more. And what some of them do is humbling to me to the point of embarrassment and beyond. Because, while we pay Sadie's caregivers, we can't begin to pay them what their work is worth. Sadie's teacher draws a paycheck. But she isn't paid to love Sadie the way she so clearly does.

Angels can also show up fleetingly. And in unexpected places.

Recently, Sadie was having a rough afternoon. We'd gone to the grocery store around the corner, something she normally enjoys. But, this particular afternoon, she was nervous and anxious and ready for the trip to be over. Standing in the checkout line, Sadie made a loud noise. Maybe more than one. And probably jumped up and down a bit. I was focused on trying to calm Sadie down but I could see the lady checking out in front of us bristle.

We wrapped things up and went outside, accompanied by a young woman named Julie. After I'd loaded Sadie in the car and Julie had loaded the groceries in the trunk, she stopped and turned to me. Julie said she knew something about people not always being considerate, particularly with those who are different. You see, Julie walks with a limp. She has cerebral palsy. It doesn't define her. It isn't who she is.

Because just as there are angels invisible to us, there are just as surely angels we can see. They don't have wings. They don't shine like xenon high-beams. And they don't live in heaven. Even so, there are angels among us.



Coming Up...

*... at FOCUS + Fragile Kids
Stay up-to-date by liking us
on Facebook!*

Watch your emails from FOCUS + Fragile Kids!

Events are announced in our weekly emails – usually on Monday! If you do not receive an email from FOCUS each week, then we either do not have a current/correct email in our system OR our emails are going to your spam folder. Please email inquiry@focus-ga.org if you do NOT receive our emails. We'll try to figure out why!

February 10
Annual Education Conference

February 11
Family Valentine Dance

March 17
St. Patrick's Day Family Party

May 7
Family Day at Six Flags

May 29 to June 1
Camp TEAM at Mercer University

June & July
Camp Hollywood

PLUS –
Workshops & New Family Fun Activities

35th Annual
FOR THE LOVE OF CHILDREN GALA
February 24, 2018

Honorees:
Lynn Fleetwood Dukes, Jim Shevlin,
Athanosios Verras, MD

FORE FOCUS + FRAGILE KIDS GOLF CLASSIC
April 23, 2018

Tournament Chairpersons:
Curt & Trevor Smith
Przemek Szczepanik
Dan Dubowski

*For more information about either event,
please contact Jill@focus-ga.org*

But she's seen and no doubt heard some less than charitable reactions from others.

She saw how the lady shopper reacted to Sadie, even if Sadie didn't. And she didn't let the moment pass.

"Your daughter," she said, "is a miracle."

Yes, she is. And, just as surely, Julie is an angel.

A few weeks ago, Laura and I took Sadie trick-or-treating. She was dressed as a lion – her choice – but refused to wear the part over her head. Also her choice. Along the way, many of the homeowners paused a moment to give Sadie a special bit of attention or an extra piece of candy.

At one house, half-a-dozen couples were gathered around a fire. The kids were expected to come around the fire and get candy from each of the ladies. When Sadie hesitated, the women all got up and came over to us, putting candy in Sadie's bag and complimenting her on her lion costume. They could see Sadie was special, and they didn't want to challenge her with making the standard round-the-campfire tour.

A little while later, I could tell Sadie was getting tired. And

we were almost back to my sister's house. We passed a few houses and came to one that was particularly festive, with arched lights over the walk and tombstones and other decorations. One last stop, I thought.

We walked up on the porch, knocked on the door and waited. Over to the left, a full ashtray sat on a small table. A mostly empty plastic soda bottle held a few more cigarette butts. The door opened and a man came out. Immediately, he greeted Sadie by name – I wondered if he had a camera somewhere on the porch and had heard me talking with her. Sadie said "trick or treat" and "Happy Halloween" and the man gave her a generous handful of candy.

He asked if Sadie was okay with people touching her. Yes, I said. He placed his hand gently on the top of head. "God bless you, Sadie," he whispered. And, like that, we were done trick or treating.

We're grateful for the angels among us, the seen and unseen.

Strategies: Finding What Works

By Lidiya Valentine-Welch

We've all been there. Days where everything is spinning out of control and all our "tricks" don't seem to work. It is very easy to become frustrated with the day to day stresses of parenting a child with special needs. Our ten-year-old daughter, Nalina, has autism and every day presents its own set of challenges. Finding strategies to manage the day-to-day, as my husband would say, has been like throwing spaghetti on the wall to see if it will stick. Well, some noodles did stick and here are some things that have worked for us.

1. Seeing is understanding

Asking Nalina to "go with the flow" is equivalent to speaking a foreign language. Nalina needs to "see" what's going to happen next or there's a total meltdown on the horizon. Visual schedules in our house are like clothing. We don't do anything without them! There's a visual schedule for morning and afternoon routines to help manage her anxiety about future happenings. And, we

take them to-go, too. Creating on-the-go visual schedules are helpful because she can hold it. That way she doesn't have to ask "what's next."

2. Feed me Seymour

It's hard to believe that any child's appetite is bigger than our daughter's. Her metabolism is high and a lot of times, her irritability comes from just being hungry. Thankfully, Nalina is not a picky eater and she loves vegetables.



Preparing healthy snacks to have ready after school and when we are on the go is essential. Plus, it cuts down on unnecessary stops when going out which ultimately interferes with the schedule. So, we head off being hangry and unsure.

3. Unplug

Technology is great, and in a lot of ways, we can't completely live without it. However, too much time in front of the television or with the iPad can cause sensory overload. Nalina can get fixated on a certain character from a show or want to repeatedly watch a movie. And when the TV or device is turned off, the tantrum begins. For a long time, she would have massive meltdowns over wanting to watch her favorite movie every day after school. Then I created "Movie-Fridays." Sounds simple enough and it worked. Literally, Friday is the only approved movie day of the week and Monday – Thursday is dedicated to therapies, homework, and sleep.

4. Oh Where Oh Where Did My Nalina Go?

One of the scariest new developments is Nalina's tendency to elope. I will never forget the first time she ran off in the store and headed out the door. I had my other two kids

ages eight and four. I couldn't leave the other two to run after her. So, we all ran. Talking to her about the dangers of running off didn't help. One day, we were in Walmart and I told her that if she didn't run off that she could listen to her music on my phone. Amazingly, she didn't leave the basket's side. After that, I made a small \$20 investment in wireless headphones which I paired with my iPhone. Our deal is that Nalina can listen to her favorite music on the headphones if she remains beside me. If she starts to wander off, the music goes off. It's worked very well.

Every day brings its own set of unique obstacles. Every child is different and these strategies may not work for everyone. As parents, we are always searching for a variety of approaches. For the moment, these are working for us, and the best aspect is that strategies are not a one size fits all. They can be altered, adjusted, and improved, but know that we must think ahead and have a plan for most situations.

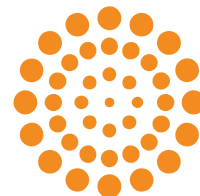


Welcome to Sarah Wigton!

FOCUS + Fragile Kids welcomes Sarah Wigton to our staff as a program coordinator. Sarah is a 2013 UGA Graduate with experience in camp, childcare, classroom facilitation, and adapted recreation. She will direct day camps, overnight camps, and respite programs – and in her spare time, help with volunteers and family programs.

From Sarah:

I actually met FOCUS a few years ago, as a program staff member for Camp Twin Lakes. It was near the end of the summer, camp was winding down; then Camp Infinity arrived and started a summer camp party like no other! Some of my favorite memories from that summer were from Camp Infinity: the chuckles from a camper at a counselor's antics, the smile of a camper flying faster than their maximum wheelchair speed on the zip line, and the incredible talent show where the one and only "Elvis" made a personal appearance. Now a few years down the road, I'm thrilled to be a program coordinator to continue the party! I am honored to work alongside the FOCUS staff to provide comfort, hope, and fun to our kiddos and families.



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Blue Ridge 250 Motorcycle

Ride: Thanks to Sam Shaw, Ben Cheatwood, and all the riders and donors! Great event for FOCUS + Fragile Kids!

Thanks to those who provided Holiday Help for FOCUS + Fragile Kids families:

Cooper Carry, FAA, Kindred Healthcare, Ray's on the River, St. Elias, Santa Eddy, and West Georgia Elves.

Looking Back at the FUN!



Breakfast with Santa



Gobble Day



Swim Team



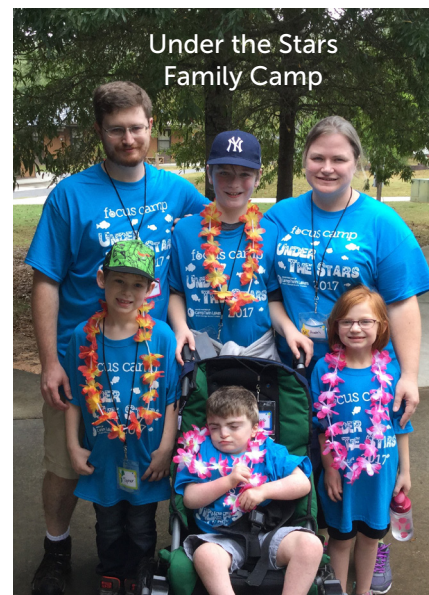
OctoberFest



Boo-b-que



Teens & Young Adults



Under the Stars Family Camp

Why Get Involved at FOCUS + Fragile Kids?

(So your family can learn, have fun, and make memories, too!)

From Jenny Edgar, mom to Hannah and Joseph:

FOCUS has been a lifeline for my family and me for over 9 years. We joined FOCUS when my daughter Hannah, who is 10 and has cerebral palsy and several other diagnoses, was just a baby. FOCUS has been there for us in so many ways. My share group has been a source of information, laughter, and a shoulder to cry on for many years. When Hannah is in the hospital, I can count on FOCUS to show up with chocolate and a hug when I'm about to have a breakdown. We are also a Fragile Kids family. In 2013, I received a grant from the Fragile Kids Foundation to help us get

an adapted van. That van is my most prized possession; without it I would never be able to take Hannah anywhere. She is much too big for car seats and I cannot lift her in and out of a car. But, because of that grant, I push her chair up the ramp, strap it down and I'm on my way.....often to an event organized by the newly merged FOCUS + Fragile Kids: day camps, parties, and affordable family outings!

I think the best thing about FOCUS + Fragile Kids is the friends we have made. Other FOCUS + Fragile Kids parents 'get me' and understand my life. Hannah has also made friends! Some are kids with similar needs as hers – they see

each other at FOCUS + Fragile Kids events and communicate with each other in a way that is special and unique to them. Hannah also has made a lasting friendship with a typically developing friend she met at FOCUS + Fragile Kids day camp. It warms my heart to see those two girls together. Someone once described having a special needs child as the club no one wants to be in. It is certainly not an easy club, but FOCUS + Fragile Kids makes it bearable and sometimes really fun! My family is truly blessed by FOCUS + Fragile Kids.

From Katherine Lucier,

18 years old: FOCUS is a community of individuals that understands the true meaning of the word acceptance. Acceptance means acknowledging a person's strengths while not disparaging their weaknesses. For me, this means that I belong to a community of people who respect me for who I am and you not only know me because

I am disabled. I first joined FOCUS when I was 4 years old. Since then I have participated in many events not the least of which includes Camp Infinity, a camp for teens and young adults. Camp allows me to take chances and to try things that I normally would not try, like zip lining. A normal able bodied person would think "She's disabled. There is no way she would be able to do this." I overcame the challenge and zip line every summer at camp. FOCUS has been going strong for many years and I am grateful for their acceptance and the camp adventures!



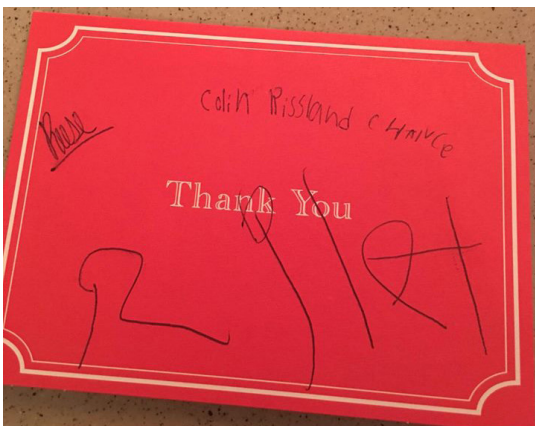


3825 Presidential Parkway
Suite 103
Atlanta, GA 30340
770.234.9111

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Shout Out to the Rissland Kids:

On the way home from a recent FOCUS + Fragile Kids program, the four Rissland kiddos (Riley, Reese, Chance, and Collin) talked about the fun they had. One of the twins became emotional and wanted to know why kids have disabilities. His older brother has disabilities, but that afternoon really struck a cord. They decided they wanted to give back – so each gave \$5 from their piggy banks to FOCUS. From the Risslands: Thank you for all you do for our families – we are forever grateful!



How to Reach FOCUS

-  770-234-9111
-  www.focus-ga.org
-  inquiry@focus-ga.org
-  <http://tinyurl.com/focusgeorgia>

