

OCTOBER 2017

ViewFinder

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



How FOCUS Made Our Lives a Roller Coaster!

By Lisa Perner

Our son Colin is 22. He is a happy, funny, loving young man who has touched so many lives.



Colin has Down syndrome and polyglandular autoimmune syndrome, type II. This means he has at least 3 glandular issues. In Colin's case, he has type I diabetes, hypothyroidism and alopecia totalis. He is also 'lucky' enough to have a B12 deficiency. None of this stops his sense of humor – we are so blessed to have him!

When Colin turned 14 in 2009, we were so excited that he was finally old enough to go to FOCUS overnight camp Camp Infinity. He has been to Camp Hollywood for many years and always had a blast. Because of his diabetes, we were nervous for him to be away from us, but we knew he would be in good hands and that he would love it.

Colin's sister Carlie is 21 months younger than Colin. She and I decided that we should take the time that Colin would be at Camp Infinity to do a mother-daughter trip. Hmm, what should we do? At the suggestion of a dear family friend who had big connections, we decided to go to Cedar Point, Ohio, the largest amusement park in the country. Located on Lake Erie, Cedar Point has a beautiful beach and 71 rides, 17 of which are roller coasters. The resort is on the same property as the park, right on the beach, and

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How to Reach FOCUS

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



From the Editor...

by Lucy Cusick



Lucy and Josh

Ongoing Activities:

For **Share Groups, Workshops, Hospital Visits, and Medically Fragile MVP** events, contact elizabeth@focus-ga.org

For **Adapted Swim Team, Teen & Young Adult Activities**, contact brian@focus-ga.org

Check our calendar at www.focus-ga.org for the most up-to-date information!

"So Long, but Not Farewell"

Karyn Campagnone, usually known as Karyn Camp, left FOCUS + Fragile Kids at the end of September. Karyn planned and directed several locations of Camp Hollywood and Extra Special Saturday respite. We'll miss her at the FOCUS + Fragile Kids office, but hope to see her (and her family) at FOCUS activities!



Guess what? I don't know what my son did today. I mean, I know where he was, that he was safe ... but I don't know the details of his day.

Can you IMAGINE? I helped him dress for 14 years; helped him bathe for 16. I hauled him to therapy and doctors and IEPs and wheelchair sports. He still needs supervision and support which he now gets through our recently awarded NOW waiver. After knowing practically his every move for over 30 years, I'm not really sure what he did today.

It's an amazing feeling. One that likely only my FOCUS + Fragile Kids family understands ... and maybe even longs for.

Grateful.

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Sibling Saves for FOCUS + Fragile Kids

by Joy Trotti, Staff

Working to check families in at FOCUS family camp Under the Stars is incredibly fun! Sometimes I only see camper families once a year, and I see new haircuts, wheelchairs, and siblings at check-in. I hear first words, first day of school stories, and first exclamations upon arrival at camp. I get the best hugs from the kiddos in several families who've come for years! But, this year, I got something very unexpected.

A big Honda Odyssey pulled into the Welcome Center, unloading lots of kids and luggage. Mom to the kids, Patti Grayson, brought her 11-year-old daughter Abby over and said, "Abby has something for you."

Abby handed a sealed white envelope to me with "\$58.63 for focus" written on the outside and said, "It's for FOCUS and FOCUS kids. I decided last year to save \$100 and give half to FOCUS. It's my tooth fairy and birthday money.

And some is chore money. It took me a little longer than a year to save \$100, though, because I don't always do the best job about finishing my chores."

I laughed and gave Abby a quick hug, resolving to talk to

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Abby(R) enjoys a beach moment with sister Caroline

Captain of the Team

By Joey Pulley

I'll never forget the moment in December of 2005, when Ava's pediatrician said, "Sit down, and grab a pen." She continued with, "I'm going to pronounce something that I've never heard of before. Ava has something called duplication 17 P 11.2 syndrome. It's a duplication of the short arm of her 17th chromosome. You're going to learn about it and teach me about it. You're going to be captain of the team!"

So I began learning all I could and educating myself about her syndrome. Not long after she got diagnosed, her genetic disorder got a name, Potocki Lupski Syndrome.

Ava participated in a research study with Dr. Lorraine Potocki and Dr. James Lupski in Houston, Texas and was the 20th person diagnosed with her chromosomal disorder. Immediately, we were not alone. We had the best geneticists, we shared with our family and friends, and

we involved ourselves in local and online support groups. Although I was "captain of the team," I definitely was not alone!

It's been almost 12 years since that day and although the years have held a myriad of emotions, we wouldn't change it for the world! Ava is currently in sixth grade in a moderate intellectual disability (MOID) class; She LOVES school, and is such a happy, content, and lovable kid! They call

the 17th chromosome "the happy gene."

She is always smiling, making someone else smile, or brightening someone's day. People often say that once Ava enters your life, you are never the same. I spent many years worrying about what Ava would and wouldn't be able to do. I have come to the conclusion that how a person makes you feel and the essence of their spirit is far more important than traditional standards and goals. She has definitely taught all of us so much more than we could have ever taught her. She is most definitely the MVP of our team!

Although I was "captain of the team," I definitely was not alone!



Ava Pulley

How FOCUS Made Our Lives a Roller Coaster!

includes a water park. We highly recommend it to anyone who loves the beach and rides!

So in July of 2009, Carlie and I dropped Colin at Camp Infinity and headed to Ohio for 4 days. We rode most of the coasters and had a blast! That began our quest to ride 100 different roller coasters together. Every year since 2009, during Camp Infinity, we have visited parks to reach our goal. This year, we reached – and passed – our goal at Hershey Park in Hershey, Pennsylvania. Together, we have: ridden 114 different roller coasters and visited 15 different parks in 9 different states. It



has been an amazing adventure, and we could not have done it without FOCUS. Colin must be monitored closely because of his diabetes and gets six injections each day. We are so thankful for Camp Infinity. We drop Colin off and don't worry for a second because we know that the volunteers and staff love him and take care of him as if he was their own. Without this overnight camp, Carlie and I could never have had this time together.

Thanks to FOCUS, for giving us the opportunity to go on such a great adventure, and for changing our lives. Everyone at FOCUS has always been wonderful to Colin and to us as a family. It has been so wonderful to have their support. We will forever be thankful!

On a side note, Colin went with us to Carowinds, a park on the SC/NC state line. In 2015 Carowinds had a new coaster called Fury 325. It is a giga coaster. That means the first drop is over 300 feet. Fury 325 is the tallest, fastest giga coaster in the world, reaching 96 miles per hour. Colin rode it with us! He's a trooper!



Coming Up...

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

October 6-8

Under the Stars 2 Family Camp (full)
brian@focus-ga.org

October 21

Extra Special Saturday Respite in
Chamblee & Acworth
annie@focus-ga.org

October 28-29

OctoberFest for Teens & Young Adults (full)
Sponsored by AMS Vans
annie@focus-ga.org

October 28

BooBQue for medically fragile families
Sponsored by 101 Mobility
elizabeth@focus-ga.org

November 4

FOCUS Day at Zoo Atlanta
Sponsored by Publix Super Market Charities
annie@focus-ga.org

November 11

Extra Special Saturday Respite in
Alpharetta and Peachtree City
annie@focus-ga.org

December 9

FOCUS + Fragile Kids AND Lekotek Holiday Party
lucy@focus-ga.org



Who's Taking Care of You?

By Sabrina Johnson



"I need you to come home as soon as you can," I sobbed to my husband. Through my tears I assured him that the girls were okay, but that he needed to come home, that while nothing bad happened, I was not okay. That conversation was three summers ago – I call it my Epic Meltdown. I had reached a point of no return, and I have vowed to never return.

Life was business as usual for us that summer. My two girls were home, and it was a day of mishaps and chaos. I can't remember everything that went wrong that casual summer day. I put the girls down for a nap and sat in my living room trying to regroup. The tears soon turned to sobs. I was exhausted, run-down, out of shape and sad. Some of you can probably relate. But that

day was pivotal for me on my path of special needs parenting.

When my husband got home, my crying had eased and I told him everything. How my days were exhausting, there was always some emergency popping up that needed my attention, I was sleep deprived from interrupted sleep. He understood. He knew. After all, he lived in our house too. Here

Parenting a child with special needs is hard. But the road is harder when caregivers lose their way.

was the difference between us: I had let my new role consume me, he had not.

I said things to him out loud that I couldn't come to terms with inside. "I'm broken and I need help," I admitted quietly. We sat there and talked things through and devised a simple game plan to get through summer and ease some of my burdens. When fall arrived, I stayed true to my quest to turn things around. The answer was a year-long program through my church that helped me define who I am as a special needs parent, to remember my limitations, and who I am as a person. Not mom. Not wife. Not special needs parent. Just me.

What I realized during that year-long journey is that I was too busy trying to fix, do and make things right – all the time. My constant "doing" was not about my daughter Juliana's disability. The demands I put on myself were simply impossible. All my things needed to be done: therapy and doctor appointments had to be kept, add in a house with special diets for two children and there was no time left. Or so I thought.

We've all heard a version of the airline spiel given at the beginning of every flight, "In the unlikely event of a sudden loss of cabin pressure, oxygen masks will drop down from the panel above your head... Secure your own mask before helping others." That same advice should apply to parents when we are not flying. Perhaps the advice is more critical on the ground than in the air. For the rest of our lives, we have someone who will greatly depend on us; there is no way we can help anyone else, if we don't wear the mask FIRST.

When you know better, you do better. My goal now is to do and be better. Several weeks ago, I watched the sad face on my five-year-old as I headed for the door. "Mommy," she shouted, "I need to give you a hug. I wish I could go with you." I assured her that I would be back, that this is mommy's time to do something special for mommy."

I give myself that speech now at least twice a month. Sometimes, I don't even go out. I lay in my bed reading, writing or fiddling with my tablet while my husband gives the girls too much junk food and lets them

watch too much TV. It's my time to check-out and regroup, to put on my oxygen mask, and to remember that I can't lose myself again. There are a slew of things that need our time and attention, but 'ourselves' needs time and attention, too! I focused on: Who I am? Who do I hope to become? What do I love doing? What am I contributing? What brings me joy?

The next time you think that you don't have time for yourself, I hope you'll think of my Epic Meltdown. Then, think about these 5 ideas:

Health. When was the last time you put off a critical appointment for your son or daughter? Probably never. If I asked if you've put off an annual appointment for yourself your answer might be different. I want to be around for my daughters. I've realized that I increase the likelihood of that when I eat right, exercise and make my own medical care a priority too.

Hobbies. How would you spend a day if there were no constraints on your time? Yes, I know this is hard to imagine, but dream a little. What

things did you enjoy doing before you became a parent? Hobbies provide a release and an opportunity to experience things that make us smile or bring us joy. My husband loves to golf, I love to read and sew. We spend less time on hobbies now that we have children, but we both try to carve a little time for them.

Home. The saying goes that home is where the heart is. How's your heart (home)? Is it too full? Are there things spilling out of places that shouldn't be? I'm not talking about a white glove standard of home cleanliness, but your home should serve as a place of refuge and comfort. What I like most is that our home is cozy and filled with the girls' artwork and inexpensive treasures. I don't fuss over the little things but instead focus on keeping our house functional and safe for Juliana to navigate.

Happiness. This doesn't necessarily mean that every day you have the energy of a 25-year-old (unless you are indeed 25). I'm talking about that joy deep inside that reminds you of the good things you have. I keep my happiness

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Looking Back at the FUN!



From A Nurse Volunteer

I'm a veteran nurse but new to nursing at FOCUS. During my week at Camp Hollywood I was amazed by the children's resilience and their joy! It was obvious to me that FOCUS parents were raising their children to be people who are as independent and self-sufficient as possible and who know how to give and receive love. I saw acts of kindness given to fellow campers, and these children felt secure in a new environment. Hats off to FOCUS parents, and thanks for the opportunity to care for your children.

– Elaine Harris, RN, MS, CCRN

FROM PAGE 6

Who's Taking Care of You?

brewing with my faith, family pictures and memories of good days and family events. What brings you joy?

Handiwork. Your work, or handiwork, is what you produce whether you work in or outside the home. Do you have a sense of satisfaction or contribution? Yes, getting paid is the end game, but there should be more, and I believe that work/life balance is important. That balance looks different for everyone. At the end of the day, a healthy dose of work reminds us that we have talents and skills.

Parenting a child with special needs is hard. But the road is harder when caregivers lose their way. I know, I was there. It took my Epic Meltdown to make me change. Now, I'm on a quest to keep myself on track with those 5H's that will help me be a better mom, wife, and person. I hope that they help you, too.

Sabrina is a wife and mother of two who shares her new normal on her blog Juliana's Journal. She is the author of Forward, an e-book that helps navigate first-steps in special needs parenting. Visit julianasjournal.com for more stories of encouragement and inspiration.

FROM PAGE 3

Sibling Saves for FOCUS + Fragile Kids

her later about her gift – after the check-in traffic at camp died down. I wondered how this young girl with the sweet smile and shiny blond hair even knew that FOCUS and FOCUS kids might need money. "Abby," I asked later, "Why did you decide to give your money to FOCUS?"

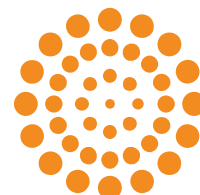
Abby answered slowly and thoughtfully, "I see kids with special needs and read books about them, so I know they need help. At my church, they talk about helping others. I know FOCUS has camps for kids with special needs and decided that this would be my way to help.

"My sister Caroline [who has autism] is an inspiration to me. She's usually sweet, adorable, and even hilarious. So when she's in a bad mood, I try hard to make her happy again. She teaches me so much, and I'd rather have her than any other sister in the world. I often wonder what she's thinking, though. She speaks, but it's hard to understand her."

When asked if she had any advice for other FOCUS siblings, she said, "Sometimes your parents have to focus on their special child, and you may feel left out. You might think that you're not getting your fair share of attention. But you have to remember that your special sibling needs extra help, and your parents are doing the best they can to make time for you."

Observation, reading, and listening in church aren't Abby's only influences. "My dad shows me how to deal with others and with Caroline – and what to do when you can't deal with them," Abby giggles.

In a more serious tone, she says, "My mom is always busy – cooking, working, and taking care of four children. She reminds me that I have to do my part, play my role. And I try." Even at eleven, Abby Grayson is doing her part to be sure that FOCUS kids have the programs and help they need.



Waiver Payments at FOCUS

by Rebecca Cheskes



Our family has been part of FOCUS for many years, as my daughter is now 15 years old. We have benefited in so many ways from the various programs that FOCUS offers.

One of my favorite things about FOCUS is their 'family days' at fun local venues at a very discounted rate, such as trips to Zoo Atlanta and the Georgia Aquarium. The staff works tremendously hard at securing grants to make the fees reasonable for our families. *(Fact that I learned while writing this article: FOCUS pays \$40 PER TICKET for Six Flags tickets, \$55 PER TICKET for Aquarium, \$35 PER TICKET for the Zoo ... tickets include parking and a meal! FOCUS only asks for \$20 per ticket. Now, do the math if 500 tickets are sold ... !)*

We are so fortunate that FOCUS accepts payments from the NOW/COMP waivers and Family Support Funding. *(If you do not know what these funding sources are, consider coming to a FOCUS workshop!)* Some nonprofits do not accept the waiver because it is a lot of extra work. The nonprofit also must wait until after the event for payment and last minute cancellation means no payment (but tickets were reserved so the agency had to pay for them). Here's what waiver / family support families need to do for FOCUS:

- Make sure you can really attend the event before you register!
- When you register for the event, check that you plan to use waiver / family support funds.
- FOCUS will review your registration and send you an email to send a check to FOCUS for the full amount of the activity (which is your commitment to come to the event AND to submit the invoice to your provider).
- Once that check is received, FOCUS will email an invoice to you. You should send that

invoice to your provider. Your check will NOT be cashed unless FOCUS does not receive payment for the activity.

- Once FOCUS receives the payment, your check will be returned to you.

We are so grateful to have all the programs FOCUS offers – and to know that FOCUS keeps the costs as low as possible AND goes to all the trouble of accepting waivers /family support funds. It's our turn to be responsible and do our part!! Thanks FOCUS for all the memories over the years!



MVP UnBirthday Party



Under the Stars

Looking Back at More FUN!



Camp Infinity