

JULY 2018

ViewFinder

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



“They didn’t tell us that at the beginning: The moment you let love into your heart, your heart starts breaking. The only way to stop your heart from breaking is to stop your heart from loving. You always get to choose: either a hard heart or a broken heart.”

– Ann Voskamp

Sparkles of Joy

By Kim Forester

On our second anniversary my husband and I found out we were pregnant with our first child. We’re both rule followers and took pride in the mathematical tidiness of life: do good things and you’ll get good results. We met in college, we got great jobs, we got married, we started a family. And then came Evelyn.

How do you explain the overwhelming mixture of love, joy, fear and disappointment that comes with the birth of child who is different? How do you stand up, walk forward, even look in the mirror when you know each day only brings uncertainty? For the first few years of Evelyn’s life we didn’t know, day to day, if we’d experience a sweet smile during music group or a ride in an ambulance for seizures that were out of control.

With Aicardi Syndrome, and how it has affected Evelyn, we’ve dealt with seizures, a feeding tube, a trach, and lots of equipment, intervention, etc. For a long while, we felt that just as we cleared a hurdle and caught our breath, another challenge would arise. What helped us survive that time - what we WERE certain of, after the fog began to clear, were the following:

1. God is and will always be the center of our family, not Evelyn.
2. We are a team, we are individuals, and we will choose to work hard and laugh. Always.
3. Evelyn is a person first, and her diagnosis (Aicardi Syndrome) is only one small piece of who she is. (A very time consuming piece, but still.)
4. Attitude (and its saucy cousin: Perspective) may not change your reality, but it will change how you FEEL about it – and that can make ALL the difference in the world.

As she has grown, we have come to love our beautiful girl more every day. She is simply amazing, and all who know her would

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From the Editor...

by Lucy Cusick

Somehow we blinked and it's summer! Have you missed the newsletter? We hope so! We have new software and needed extra time to conquer it.

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at www.focus-ga.org



Lucy when learning a new database

Luckily, software challenges didn't affect camp (much!) and we are knee-deep into summer fun, as I write this. All together Camp TEAM, Camp Hollywood, and Camp Infinity will serve over 400 campers this summer – in August, we'll head out to Camp Twin Lakes for Family Camp.

We have a record number of new parents who have called and emailed – 250 since January 1! Many were interested in camp, many came from our growing relationship with Children's Healthcare of Atlanta, many need equipment that insurance and Medicaid won't cover.

We continue to work hard to continue to offer all of these programs to our children and their families. We are grateful to our donors, volunteers, and families! Comfort, Hope, Fun, Equip for Every Day Life!

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15 Minutes at a Time

by Mark Wallace Maguire

Most people don't know what to say when they discover you have a special needs child, and the fact is, I don't talk to most people about it. (As odd as it is, as this is open for anyone to read, I still don't talk to most people about it).

But, in the wake of Andrew's birth, I really, adamantly didn't talk to anyone outside of my wife those first few months. Too much confusion in me. Too much rage. Too much of a chance for the short fuse in me to be lit. And I didn't want that, and I knew that they wouldn't want it either.

I caught a few of the clichéd sayings but tried to ignore them. Would do almost anything I could not to strike out. Buried my feelings in myself.

Then there was my Uncle Mike. He invited me to dinner. I gave Uncle Mike the exception. Within a five year period, Uncle Mike had lost one son to drowning in a bizarre boating accident and another to suicide. He was single, divorced and alone in this world. He

had seen the dark side of life – seen? He had experienced it – and was still living through it. He had the fortitude to push forward with amazing resilience.

We sat at a corner booth in an Applebee's, of all places, to discuss the struggles and emptiness of life. Mike gave me a few pieces of advice then. One, he said, was when people give you the empty platitudes, just to smile and nod and walk away. Secondly, he said, some people say, "One day at a time." That's good, but he said on a bad day, he would go:

"15 minutes at a time."

It is a mantra and practice I have adopted on dark days. Just try to get through the next 15 minutes, then the next 15 minutes. Maybe eventually the

next hour. You think about the future and you can be beyond overwhelmed. You think about the present and you can feel the same way. Just 15 minutes at a time. You will make it. Then, maybe, when you're ready, one day at a time. But start small.

Mark Wallace Maguire is the author of a book "Confessions of A Special Needs Dad: Honesty and Hope for the Journey." His son Andrew is 11-years-old and was born with Cri du Chat, a partial deletion of the fifth chromosome and a hypo plastic corpus collosum. The book offers hope, healing, and, most of all, honesty, as well as an important reminder that you are not alone. The book is available on Amazon in print and on Kindle.

Camp Jabberjaw: Teaching vs. Talking

By Christine Kramlich

“What color is this?” “What shape is this?”
“What body part is this?” “How old are you?”

Can't you just see the eye rolling from the person being peppered with these questions? Being a teacher for 14 years, I had a very hard time taking myself out of this role, even when I came home at the end of a long day. So, when my daughter, Kyleigh, got her first communication device (Springboard Lite) at the age of 3, I set out to prove to the world the genius of my child. This meant that she had to be prepared to answer all of these questions and many more.



Bac and Kyleigh

However, using her communication device was laborious for her. She used a switch situated to the left side of her head mounted to her head array on her wheelchair to scan through the choices on her communication device. At first there were only 8 choices on the main screen, but to make her way through all 8 choices and get to the last one

without getting distracted by someone walking in the door, a phone ringing, her sister calling or the dog barking was nearly impossible. Thus, she had to wait through the same 8 choices again. The frustration on her face and mine was inevitable and the tears were numerous (mine, not hers). This communication thing was NOT working.

Two years later, everyone else (not me) was ready to throw in the towel. Obviously, my daughter, for some reason, was incapable of using this communication device. But I wasn't ready to quit on her yet. I heard about a camp at Mississippi State University called Camp Jabberjaw that was designed for communication device users.

The entire family is invited to attend. While the campers are working hard learning their devices AND having fun, the siblings are attending activities with campers their age and the parents are attending classes where they can learn about their child's device and how to use it.

While we were there, we met a guy named Bac. Kyleigh thought he was hilarious and Bac thought he was pretty funny, too, so they made a great match! Bac would tell jokes on his communication device (Vantage Lite) and Kyleigh would laugh uproariously. Bac taught Kyleigh that if you say “do” on your device and then “do”

“You have to LEARN TO TALK
before you can TALK TO LEARN.”

– Gail Van Tatenhove, SLP

FROM THE COVER
Sparkles of Joy

again, you can make your device say “do-do.” Well, when you’re 5 years old, this is comedy gold! Then, Bac taught Kyleigh that she didn’t have to go stand in the long line for food if she could tell her mom what she wanted on her device. And moreover, if she stayed at the table with Bac while mom waited in line, she could learn more things about her device like how to tell her own jokes and how to sass her mom by saying things like “make me.”

Fast forward two years and Kyleigh (age 7) was using her communication device (Vanguard) semi-effectively, at least well enough to communicate her wants, her needs and her thoughts. I called it “yoda-speak” but she got her point across. She would say short phrases like “go outside” or “foot hurt” or “want go.” She could add things to our grocery list and participate in some basic school activities, and she certainly could use her more refined sense of humor. She could write a “sentence” if forced to, but it didn’t come natural for her.

Middle school came and, with it, the technological advances of eye gaze (Accent 1000 with NuEye). Switches for accessing her device became a thing of the past. With this, Kyleigh became much quicker with

her device and ultimately a more effective communicator. She started presenting at conferences, texting friends and her personality really shined! Now that she had learned the power of true communication, she didn’t mind doing her school work on her device, including some amazing artwork, power point presentations and much more!

Which brings us back to Camp Jabberjaw where things came full circle this year. Kyleigh asked to go back to camp, not as a camper, but as a counselor. She wanted to do for someone else what Bac had done for her. Luckily, the directors remembered Kyleigh fondly and said they would love to have her back. She had the opportunity to impact the lives of many young people going to camp for their first or second time....campers who are just beginning their own communication journey.

I feel so blessed to be Kyleigh’s mom. She has such a heart for others and genuinely wants to see people do well. I am sure that one day, Kyleigh will be part of someone else’s story and I can’t wait to hear it. This isn’t the end of Kyleigh’s story either and I’m sure it’s only the beginning of many more stories that have yet to be written.

agree. Evelyn is almost 11 and in the fourth grade; she has friends and a huge loving extended family; she loves the beach and being outdoors; and she’s very patient and kind with her three (3! Tres! Trois!) little brothers. She’s also widely known as a fashion trendsetter and won’t be caught without at least one sparkly accessory.

But, this isn’t a ‘happily ever after’ story. This is a ‘sometimes I cry in the car’ and ‘sometimes a friend’s child passes away’ and ‘every cold is scary’ and ‘what if her brothers feel overshadowed’ and ‘what if she feels left out’ kind of story. Because as beautiful as it can be, love isn’t tidy. It isn’t organized. But I’ll take all the fear, the worry, the difficulty of Evelyn’s reality, over and over again - because one moment of joy sparkling in her eyes makes it all worthwhile.

And there have been thousands of sparkles of joy.

“A broken heart is really an abundant heart — all those many beautiful pieces only evidence of an abundant life.”

— Ann Voskamp



Coming Up...

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

August 10 – 12

Under the Stars Family Camp (full)

August 25

SummerFest Fund Raiser at Monday Night Brewing

September 15

FOCUS on Moms

September 23

Aquarium Day

(Registration goes out by email in late July)

October 5 – 7

Under the Stars 2 Family Camp

October 13

Blue Ridge 250 Motorcycle Ride

Equip for Every Day Life

For many of our kiddos, equipment is the key to an easier life – easier, not easy!

The right equipment can help a person be independent, more functional, and more mobile. The Fragile Kids Foundation has awarded grants to medically fragile children for over 25 years – now, merged with FOCUS, we continue this wonderful program: healthcare grants; lending library grants; and beach wheelchair loans. The most common grants are for folding, medical strollers; specialized seating systems; funds towards a wheelchair van lift (parents must have the van or be able to qualify to finance a van); and various kinds of home lifts.

There is an application process! Go to our website at www.focus-ga.org for the details and the guidelines.

Here are just a few of the notes of thanks we have received from families about equipment.

MIKAYLA

We are so grateful to organizations like FOCUS-Fragile Kids for seeing the value in differently abled children like Mikayla. Every single person that meets this sweet girl is forever changed for the better.



Mikayla with her Convaid stroller

Support from FOCUS-Fragile Kids helps those who love Mikayla to give her the best possible quality of life. The generous support from your donors recently supplied Mikayla with a new super cool, fire engine red Convaid stroller that allows her to go places, see things and participate in activities that previously were not possible when using a heavy motorized wheelchair.

I would like for you all to know that sweet little Ms. Mikayla is more than what you see. She is intelligent, clever and has a crazy/funny/goofy sense

of humor. Just because she cannot talk, does not mean that she cannot understand every word you say. Just because you cannot understand her does not mean she cannot communicate. Just because she cannot walk, does not mean she's not going places. This little girl is a powerhouse ... a force to be reckoned with! She will never lay down, give up or settle for being labeled as disabled or discounted as a second-class citizen. She will not sit idly by and be ignored. Never underestimate the power of this strong willed child. Tell her she cannot do something and she will. Tell her she is forbidden to do something and she will. Tell her she is not capable of doing something... NOT A CHANCE!

Mikayla has the ability to thrive, and the right to an inclusive/mainstream, academically-

challenging educational setting and the very best life possible. Donors to your organization make these things possible. Thanks so much from Mikayla's very grateful Gigi!

JOSEPH

From the extremely grateful family of Joseph: Your generous support, of helping provide a van ramp system to our family, means more than we could ever say. Behind these smiling faces are family members who work tirelessly together as a team on a daily basis with an awe-inspiring love for Joseph. These sweet boys give countless hours of care, hard work, and love to ensure Joseph has the fullest life possible, and this is not an easy task. However, you have made the task much easier! *You made Joseph's life better! You made our lives better! You are truly heroes in our eyes!*



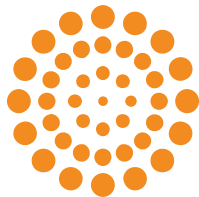
Joseph and his family

Sad Good-Byes, Happy Hellos

Annie Garrett, Program Director, left FOCUS + Fragile Kids in mid-May for a new opportunity with the Jewish Federation of Atlanta. We wish her the best of luck and know that we will see her occasionally at various FOCUS + Fragile Kids activities.

Elizabeth Hewell, Program Coordinator, left in mid June and will be missed by many parents. She insists that she is just trading in her 'red' shirt (staff) for a 'gray' shirt (volunteer) and promised to stay in touch. We will hold her to that!

Joining FOCUS + Fragile Kids is Keena McCurn, mother of Kendall and long-time FOCUS mom. From Keena: *I am so excited to be on board with FOCUS + Fragile Kids! I love to serve in the Special Needs and Deaf/Blind communities by advocating, speaking, training and being a resource to other families. For six years our family was blessed with a special needs child, Kendall, before she passed away last June. I believe it is important to continue to be a resource for other special needs families and look forward to helping FOCUS + Fragile Kids carry out their mission.*



Family Fun Ride Trail Ride
Thanks to Sam Shaw, Ben Cheatwood, and all the riders and donors – what a great day to benefit FOCUS + Fragile Kids!

Looking Back at For the Love of Children

Thanks to our honorees, sponsors, and donors, For the Love of Children was our most successful ever!



Honorees Tom Sullivan (L) & Russ Spencer (R)



Honoree Jim Shevlin with wife Ann



Honoree Lynn Dukes (center) with daughter Alexis & mom Carolyn Fleetwood



Parent Speakers Kristen & Will Rohde



Honoree Dr. Athanasios Verras (L) with Nick Kostopoulos

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Cathy & Pierce Nelson
Betsy & Todd Oglesby
Kelly & Thad Peterson
Lisa Petersen & Bob Nariss
Lyn & George Plaza
Louise & Michael Plonowski
Brie & Geoff Pollak

Sharon Poulos
Angie & Gerry Poynter
Erin Presley
LeeAnn & Bill Ramsey
John & Joyce Ryan
Diane & Marc Salatino
Madeline & Simon Sater
Steve Scales
Patti & Steve Secrest
Cyndy & Tim Seilhan
Kelsi Shevlin
Tom Shillock
Crystal & Bubba Sloan
Jessica Sloan & Andy Berlo
Michelle Sorensen
Isa & Russ Spencer
Nikki & David Stephenson
Frances Stewart & Norman
Fickling
Rob & Sabrina Storm
Lynn & John Stuhrenburg
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Athanasios Verras
Megan & Ryan Vette
Patty & Kevin Walter
Dottie Warren
Charla Weinsier
Sarah & Ed Wiley
Susie & Tom Williams
Sherri & Greg Youngblood
Linda & Dave Zilles

**FOCUS + Fragile Kids Golf
Tournament**

Fairway Angel
KPMG

Eagle Angels
CDW
Cognizant
GuidePoint Security
The Intersect Group
Microsoft
Netskope
Nextthink
North Point Endodontics
Nutanix
Reliaquest
Southeastern Steel
Sovereign Systems
TEKsystems
Trend Micro

Birdie Angel
CyberArk

Hole Sponsors

AT&T
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Check Point
CWPIIM
Exabeam
MATRIX
NetApp
N4Mative
Rapid7
RDW
Sibley Heart Center
Cardiology
Trend Micro
United Community Bank

Golf Donors

Peter Black
Andrea Bowles
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Laree Brown
Randy Brown
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Cisco
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Vickie Henson
Intellinet
Jabian Consulting
Jimmy Lockhart
Doug MacMillan
McGriff, Seibels & Williams
Pete Moraitakis
Srin Ratnam
Sayers
Chris Swinn
Przemek Szczepanik

Thanks to our Tournament

Chairpersons:
Curt & Trevor Smith
Przemek Szczepanik
Dan Dubowski

*Thanks to Atlanta National
Golf Club and White Columns
Country Club for their
patience and support!*

Looking Back at the FUN!



Camp Hollywood, Jr.



-FAST Fins Swim Meet



Teen & Young Adult Prom at Lovett



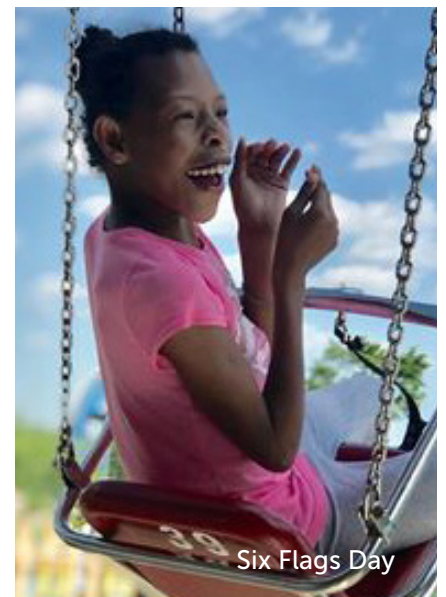
Family Activity "Dance with Me"



Six Flags Day



Family Bowling




Six Flags Day

Donor Spotlight

Mark & Marcia Miller supported the Fragile Kids Foundation through their family foundation and have embraced the merger with FOCUS. In the summer of 2017, they purchased two new beach wheelchairs to loan to families. For Georgia Gives Day in 2017, Marcia, the CEO and founder of Mud Pie, and Mark, the CFO, along with Mud Pie employees, funded three wheelchair van lifts AND gifts for our kiddos in the hospital. In 2018, they 'cleared the waiting list' of equipment for the first quarter. We are beyond grateful for their generosity and support.

How to Reach FOCUS

 770-234-9111

 www.focus-ga.org

 inquiry@focus-ga.org

 <http://tinyurl.com/focusgeorgia>

From Gabrielle's Family

Thanks a million! We picked up Gabrielle's mobility vehicle with the ramp installed. We are very thankful for the contribution from FOCUS + Fragile Kids because it made this possible. Thanks again for all you do to help kids with disabilities be the best they can be.

