

APRIL 2017

ViewFinder

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



Building a Container Around Our Big Ole Jell-O World

By Zarat Y. Boyd, PhD
Mom of Damian Jr.

Since our son's global brain injury at birth 12 years ago, we have been living in a big ole Jell-O world. Things are constantly changing, taking so many different shapes & forms. It's simply exhausting trying to keep things together.

2017 FOCUS and Fragile Kids Foundation MERGE!

These days, nonprofits that serve similar populations compete for grants and funding; merging not only makes sense from a less-overhead aspect, it makes life easier for families. When the idea was floated to both boards of FOCUS and Fragile Kids, they met separately and together for the better part of a year to work out the details before officially merging. One call for information on how to get equipment AND day camp (and more!).

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So, rest and renewal is like trying to hold and hug a big glob of Jell-O. You can try, but eventually it is going to fall through the grip of your arms. However, we have learned if you build a container around that big glob, life can be more manageable. The Jell-O glob mess of our lives has not changed, but we have found a better way to contain it.

The desperate need for a "container" became evident when our family founded Vertical Church in 2011 in one of the toughest underserved communities in the city of Atlanta. Spiritual advisors urged us to be very proactive in creating this "container" given the high levels of stress raising a medically fragile child while adding more stress of revitalizing a community.

We heeded their advice and created our REST AND RENEWAL CONTAINER. This container is just as important as sleeping, eating, drinking. And for us, it is just as important as the equipment, doc appointments, meds, therapies for our children. It is not a luxury. It is a necessity.

So, what does creating a container of Rest and Renewal look like? It means to prioritize, schedule, and PRACTICE a regular rhythm of restoring the spiritual, mental, emotional, and physical energy, and strength needed to thrive and provide the level of care and advocacy our children and families need and deserve. For us, we have a daily, weekly, quarterly, and annual rhythm.

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From the Editor...

by Lucy Cusick

COMFORT. Just before I started to write this article, I took a phone call from a long-time FOCUS mom. Little did I know that she called to tell me that her medically fragile teenager died this past week. No matter how hard this parenting a special needs child is, losing a child is the hardest part of the journey. And no matter how often I take those calls, it still brings me back to 'why we're here.'

You know, our daily lives are filled with chores. Make time for fun. We can help.



HOPE. At the annual FOCUS conference in January, Zarat Boyd, who also contributed an article this month, spoke about REST. What an inspiration – and, you know, I've lived the life of a parent of a child with a disability for over 31 years. I'm not easily inspired anymore! And comparing our lives to Jell-O – BRILLIANT. I hope you'll read her article and Marjan's article and learn from those who have gone before you. If you don't make a plan, no one will.

FUN. SIX FLAGS! DAY CAMP! You know, our daily lives are filled with chores. Make time for fun. We can help.

EQUIP FOR EVERY DAY LIFE! The merger with Fragile Kids Foundation has also reminded me 'why we're here.' While our children bring us much joy, life is also difficult. Our kiddos often need a lot of help to (1) stay alive, (2) participate in life, (3) be as independent as possible. Equipment is something that our medically fragile kids need to sit at the dinner table with the rest of the family; enjoy a movie; move from one place to another... activities that 'most' people don't even think about. Now, with the merger, we will offer grants for medical equipment that insurance and Medicaid will not cover ... and we will be fund raising for those grants! See page 3 for the details on grants!

Now, Let's Talk About ME: Since you're all used to me writing about MY life (and since I think it's all about ME!), here's the update: Josh (adult son with cerebral palsy) started a job at AMS Vans. He continues to learn new skills every day and is anxiously awaiting his very first paycheck! My broken ankle is healed, all that's left is a memory of diving out of the attic, a 'k'ankle (lots of swelling), and a healthy respect for our kiddos who cannot walk. Because of my attic adventures, Josh was awarded a NOW waiver and has the help he needs to work on independence. Daughter Jessica continues at Emory as a Master's of Divinity Student. She just threw a surprise party for me for my #NotABigOne birthday, and I was truly surprised to find our den filled with people!

Life is good. Sometimes hard. Always grateful.

FROM THE COVER

2017 FOCUS and Fragile Kids Foundation MERGE!

Who We Are. Fragile Kids Foundation began over 25 years ago to enhance the quality of life and well-being of medically fragile children with support, supplies, and prescribed medical equipment not covered by Georgia Medicaid or private insurance. Over the years, Fragile Kids adjusted their grants to items that Medicaid continued to deny and to the most common items families requested: lifts for vans, specialized strollers and seats, and stair or Hoyer lifts.

Parents of two medically fragile children who shared a hospital room founded FOCUS in 1983. They found information and hope in each other – and realized that there were more families of undiagnosed children who needed support. FOCUS was founded to help parents find comfort and hope – and as we grew – to offer fun, recreational, AND accessible programs for children and the entire family.

And, so now we are doing business as FOCUS + Fragile Kids – but we'll answer to most anything! While the Equipment Grant Program is specifically for medically fragile children, FOCUS + Fragile Kids will continue to help parents and offer programs to children with many diagnoses, such as mitochondrial disease, Down Syndrome, autism, cerebral palsy, developmental delay, and other conditions. So, what is the Equipment Grant Program, you ask? Continue reading!

What Equipment Is Funded. Equipment Grants are for items that insurance and Medicaid deny. The most common requests are for wheelchair van lifts, stair-lifts, and overhead lift systems; specialized car seats and strollers; and other seating systems such as Rifton chairs, Tumble Forms, or Tomato Seats. For van lifts, the parent must either have a van that can be modified or be able to purchase one.

Who Is Eligible & the Application Process. Parents or legal guardians of a medically fragile child, who is age 21 or younger and is a legal U.S. citizen with a primary residence in Georgia, may apply. The application is found at www.focus-ga.org and must include a letter of medical necessity from your child's physical therapist or other medical professional.

A medical review committee meets four times each year to review each application. The committee determines if the request is eligible for funding and considers age, disability, medical necessity, and parent income as determining factors. If eligible, then the parents are notified and FOCUS + Fragile Kids begins fund raising for that request. The process from application to receiving the grant might be as long as 9 months. We hope to shorten the process, but, for now, we are erring on the long side.

Loaned Equipment Program. Young children might only need equipment for a short time, until they either reach their goals or outgrow the equipment. The Loaned Equipment Program allows families to borrow items such as specialty seats and strollers. We only take specific pieces of equipment for the Loaned Equipment Program. Items in the loaned equipment library are cleaned, conditioned, and shared as long as they are in good shape!

But Wait! There's More! FOCUS + Fragile Kids also has All Terrain Wheelchairs so that medically fragile children can enjoy the beach and participate in outdoor activities such as school field trips and church outings. There is a separate application for borrowing the beach chair which can be approved much faster!

We are very excited about the merger and the opportunities for parents to 'get what they need' to make life a little easier. There's more info on the website – or give us a call with questions!

"For the Love of Children" Gala Honorees



FOCUS recognized **Saxon Dasher, Tori Chimberoff, and Scott Chimberoff** as the 2017 Comfort, Hope, and Fun Honorees at the 34th "For the Love of Children" Gala on February 25. Guests enjoyed bidding on silent auction items, dancing, and a delicious dinner. Special thanks to our honorees for filling up the ballroom and to host and emcee Tom Sullivan (www.tomonair.com). See gala sponsors and donors in the "Thank You" listing.

Intensive Self Care Begins At Home!



I want to forget the last year of my life. We thought we had this whole “parenting a medically fragile child” thing figured out, but after a decade of learning from others and developing our own best practices, our team lost this year. For the first time, we experienced a bad IEP meeting—I’ve heard about them, never had one! **Our daughter’s medicines stopped working. Our bodies started falling apart.** The “best caregiver ever” started nursing school, leaving us with “she will do for now.” Volunteer work no longer healed me because instead of hearing a ‘thank you’ occasionally, I heard ‘you are so lucky to have the time to do this.’ Really? I am so lucky to leave my kid with a sitter just to make sure you have everything you need? So lucky. Our daughter’s screaming got louder, the high ceilings of the “dream home for someone in a wheelchair” made her sound even louder. I didn’t run that marathon. The van I wanted so badly became a source of tension. It turns out that van with the wheelchair lift goes where my daughter goes, and I don’t always need to go where she goes. For the first time in years, my close friends and I voted for different people...I think you get the picture now. I tried and I tried, but even my extreme plans to relax for a few days ALONE during a work trip to Hawaii turned into an Airbnb nightmare story. October left me in tears. November started out with the song “November Rain” on repeat and ended with the song “I hate you, I love you” playing inbackground while I walked back into a rocky relationship with Nutella.

Then during a routine appointment for my daughter, I met a nurse who has a 25-year-old daughter with the same condition as my daughter. I thought, “Wow, this story goes on. Is this what the rest of my life is going to look like?” I realized I need to rethink my best practices because if I am struggling so much now, what will I be like when my 10-year-old is 25? I went through the stack of cards where I have written down things to do when I am anxious or sad. The

card with go for a drive? In the trash because the beautiful country roads and old trucks around here have been replaced by traffic and luxury crossover vehicles. Watching the cows on one of the nearby farms, trashed. The farms are now subdivisions with giant homes and fancy names that scream, “Look at me, I am rich!” The one with the word RUN on it went in the trash: injury. The card with call so and so? In the trash because so and so is unable to

The new plan—because, let’s face it, if I don’t come up with the plan, then there will be no plan!

relate to the current issues in my life. The new plan – because, let's face it, if I don't come up with the plan, then there will be no plan!

To do lists. The strict daily schedule list has turned into task lists where I only work on what is important. I do the important stuff and then I take a break. A break? Yes, because when my child is sick, I rarely get a bathroom break. I have 10 years' worth of break time saved up and I will use them any time I can. All the unimportant stuff can wait until they find a cure for my daughter's condition or until I win the lottery and hire a staff of 20.

Meal Planning. Something I learned from Ellen Stumbo: Every night ask yourself: What is for dinner tomorrow night? Most nights I come

but I had to learn the hard way what happens when we overuse our body and don't make the time to recover. There is no triathlon or a marathon that is worth me not being able to pick up my daughter. Recovery is now a part of my workout plan because when I go home from the gym, I still must lift 75 pounds of cuteness. Go workout, but don't do it because you hate your body, do it because you love your body.

That voice in your head. I thought I had killed all the negative self-talk, but spend a couple of days in "Marjan's World 2017," and I assure you Ms. Negative will show up out of nowhere and take you down. I needed a stronger war plan. When I went through a tough breakup in my 20s, a counselor told me to write good things about myself

have the time to shave your legs below your knees because your green eyes are gorgeous and your smile is contagious." If that does not get rid of Ms. Negative, I fight her by writing down the good qualities of a friend or writing a thank you note. It's remarkable the change in us when we focus on the goodness in others.

Church. Did you know you can watch it online?

Service. I am blessed enough to have served on a board of an incredible nonprofit that has made my daughter into an athlete. Double blessed because I work for a nonprofit which serves wounded veterans and Gold Star families. While I am committed to both, I needed to find a quiet way to serve. Nothing big or on social media. For a couple of hours every month I spend time with mothers who have babies in the NICU and who might be future FOCUS moms. It's fantastic because there are no kids in that lounge, and sometimes we eat fried chicken. They talk, I listen. They ask questions, and I pretend to know the correct answer. We laugh and we cry. Those mothers don't ever need to thank me, but I always thank them. I thank them for reminding me of where I was a decade ago. I thank them for showing me even in midst of uncertainty it's okay to take the time to get a shower. I thank them for reminding me of who I was and how far I have come. Friend, love yourself and find a way to serve others.

Some of you may be in a place where you need to walk away from that toxic relationship, the job, the neurologist, or school. You may be correct about that PT from last year

being the cause of all your child's current issues. Maybe this town is not the best place for you. But even if think it's time to go, do you know who will still be there? YOU. Therefore, before you make any major changes, or pray for some people to magically disappear, fix yourself first. Make sure YOU are not the issue. Go to counseling, get medication if you need it, and pray, before you make any changes.

As I wrapped up the year, I realized it was impossible to erase a full year of my life, therefore, I chose to focus on the good memories we made. Good memories like watching my friend finish her marathon, realizing even though my friends voted for the wrong person I can still love them unconditionally, hitting a wall and having no choice but to rely on my faith, listening to so many interesting audio books during the many hours stuck in traffic, finding a concealer that actually covers up the dark circles around my eyes, working with people who understand my working hours can go from 40 hours a week to 10 depending on the length of my daughter's last seizure. Friends who have become family. Georgia Tech beating Georgia. Recognizing the toxic people who were here last year did not come into 2017 with me. I stopped running last year but the friends I made while I was running are my forever friends. The numerous hours in the hospital mean there are hospital employees who call me by my first name, because I am no longer just Rebecca's Mom.

The best is yet to come.



up with a good plan but now I am okay if the answer is Chipotle or Chick-fil-A...again and again. I rely on a pressure cooker instead of a slow cooker for dinner because sometimes life is hectic, and the slow cooker doesn't work if you don't remember to turn it on.

Exercise. Still very important for my body and mind. It is a priority,

every day. I was breaking up with last year, but instead of writing the cards I stand in front of a mirror and I tell myself wonderful things about me. You should see the faces of the selfie taking ladies in the locker room when they see me looking in the mirror and telling myself "Whoa, sexy Mama, not only are you a good friend you also look fantastic. Baby, it's okay that you only

FROM THE COVER

Building a Container Around Our Big Ole Jell-O World

A Glimpse of Our Container

Daily: time of solitude and silence. This is huge... 1–30 min. of slowing down and quieting our minds and hearts. This is great in the bathroom and vehicle.

Weekly: date day and Sabbath. This is simply a day to stop and rest. We have set Fridays to avoid regular work, minimize stressors, and do things that bring joy and delight. We have many heart-to-heart conversations on these days. Here are some ideas: <http://www.exploregeorgia.org/things-to-do>

Quarterly: couple's getaways. We are masters at staycations, vacations, or local trips. Priceline.com and overnight respite organizations like Southwest Christian Care <http://www.swchristiancare.org/> are our dear friends. You can do a great deal with little to no money.

Annually: ministry sabbatical. We take the month of June off every year from our ministry to enjoy our wedding anniversary, rest, travel, and spend time together. This last year, I took a silent retreat. I went away to a beautiful, secluded place for a couple of days and just observed and listened. It was an awkward experience because I am used to talking but invaluable for seeing new things in new ways.

A couple of things to remember...

Know that you are worth this gift. We all have renewal deficits just like many people have vitamin D deficiencies. For many, they just need to spend 15 minutes out in the sun and receive the refreshing light of the sun to help uplift the body. Same for us, we just need regular doses of refreshment to keep us functioning well. You are worth it!

Face it. Truly face the emotion that may be swirling around or buried alive that keeps you from caring for yourself. Is it guilt, sadness, anger, regret? Take time to process the emotion with a friend, counselor, or trusted group so that you can enjoy the benefits of regular rest and renewal.

Embrace the reality you are not God. Embrace the reality that you cannot be there every moment with your loved one now or even later. We are not God. So it is important to incorporate a team of champions to ensure that your family member(s) continue to get the loving care they deserve.

Release and let others help. Test, train, and trust other responsible caregivers such as family, friends, and hired workers to effectively care for the needs of your loved one. You already have super powers, but you don't have to display them all the time. Sit down somewhere, seriously. Can you just be and let others learn and benefit from learning to care for your loved one? We should not rob others of this joy.

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“Dad, Where’s the Plunger?”

FOCUS dad Richard Holloway wrote this article, which was published in *Future Reflections*, a magazine for parents and teachers of blind children. Much of learning is visual so children with visual impairment must learn non-visually. Many children with developmental delay process differently and could benefit from ‘hands-on learning.’ This excerpt describes Richard’s realization that he must help his blind daughter fill in important information gaps. For the complete article, please go to <https://nfb.org/future-reflections>.

“Dad, do we have a plunger?” my daughter asked one afternoon. “Where’s the plunger?”

I was a little concerned. Why would my eight-year-old daughter possibly need a plunger, after all? This just couldn’t be good!

“I want to know what a plunger feels like!” she explained.

Wow! I had done it again. I pride myself on describing the visual

world to my blind daughter, but there it was--another little hole in her understanding. Did we have a plunger? Sure. Was I going to let her explore it with her hands? Well, no, that didn't seem the best plan. You might find ours to be as well-washed as any slightly used plunger anywhere, but I'm not going to put it into a child's hands for tactile exploration. "I'm sorry," I said, "We don't have a plunger that you can touch. It isn't clean enough. But what if I take you to the store and let you explore a new, clean plunger?"

Kendra was delighted with the idea. That's how I came to take her on her first Home Depot expedition. There was nothing I needed to buy. This was an outing of exploration, a true quest for knowledge. We made our way to Home Depot's plumbing aisle. Not only did Kendra get to look at a plunger. She soon learned that there are different styles of plungers, made from different materials, and that they come in various sizes. She was fascinated and full of questions.

After a while we moved on. I had blocked several hours of the day for this outing, just in case. Where should we head next? Toilet seats!

There was an entire wall of them only a few feet away. Standard length, elongated, with lids, without lids, plastic, wooden, hard, padded, even some with a cutout in front--which prompted another whole discussion! The greatest fascination for my daughter was why the seats were arranged vertically on the wall that way. I began to realize how much information she was missing, information that most kids pick up

without any special effort on anyone's part.

What about whole toilets? We have never encouraged Kendra to explore toilets with her hands, but brand-new ones are as clean as anything else in a store. We checked out the toilets, then moved on to tubs and showers. Next we found sinks for both the bathroom and the kitchen.

Before long, we had examined all the plumbing supplies we could find. We began to roam the store's other aisles. Appliances, Carpet and Flooring, Lumber, Fencing, Landscape. Kendra hates the noise of lawnmowers and other loud machines. In the store she understood that they were turned off and would make no frightening sounds, so she explored them freely.

The Home Depot outing left me exhausted. It involved several hours of intense describing and explaining, but the effort was well worthwhile. Chances to supply missing information are almost everywhere. We've found many of them close to home. We have learned a lot together, but a great deal remains for us to explore. This learning process is never really finished.



Do You Get Our Monday Emails?

With apologies to Dr. Seuss & Sam-I-Am

Our Monday Email

Our Monday Email

Do you read our

Monday email?

Do you know

What's new with us?

If you do not know

What's new with us

Then reading email

Is a Must.

Would you like it

Here or there?

If you would like it

Here or there

You must tell us

Please, please share!

If you don't read

Our Monday news

Then you'll miss out

There is no doubt.

Got it? FOCUS + Fragile Kids announce all activities BY EMAIL! If you do not receive our Monday emails OR you do not READ our Monday emails, then you'll be sad, which would be bad. Email Updates to inquiry@focus-ga.org.

Embrace the reality that you are not God. Embrace the reality that you cannot be there every moment with your loved one now or even later. We are not God. So it is important to incorporate a team of champions to ensure that your family member(s) continue to get the loving care they deserve.



Zarat, Damian Sr.
& Damian Jr.

FROM PAGE 6

Prepare a system. Create a system that works for you and your family. We have created cross-training opportunities, "How-to" manuals, care logs, medication logs, back-up scenarios, and communication strategies to ensure that when we are away we can actually be away.

Building and protecting this Rest and Renewal Container is the key to restoring the vitality that we cherish and dream of. Praying for you. Be encouraged. Start today.

About Zarat

Zarat is mom and advocate of Damian Jr. She and her husband, Damian Sr., have been married for over 16 years. They founded Vertical Church www.verticalATL.com in Southwest Atlanta in 2011. She founded MaxLife, Inc. www.themaxlifesolution.com, a consulting practice for leaders and leadership teams, in 2003. She also serves as President of Vertical City, Inc., a 501c3 community impact organization revitalizing underserved communities.

As a family, they treasure the beauty of life that God has provided and want as many people as possible to do the same. Zarat was the keynote speaker at the annual FOCUS Conference in January 2017 and inspired both parents and professionals.

How to Reach FOCUS

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



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Memorials

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by Linda Preuss
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by Patty Vastakis
In memory of Elaine Burns
by Lolita Watson
In memory of Julie Lyons by
Ann Murray
Kenneth Kates
In memory of Coleman Miller
by Teresa & Butch Miller
In memory of Jennifer Smallman
by Carol & Ralph Smallman
In memory of Michael Gabriel Moir
by Lindy & Bill Moir
In memory of Logan Beasley on his
birthday by Susan & Doug Beasley
In memory of Robert E. Fortenberry
by James & Janet Fortenberry
In memory of Karman Hurst
by Doreen & Burt Wittenberg
for the Liam Vilensky Camp
Scholarship Fund
In Memory of Wesley Bigbee by
Fred Ablan
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Halbert Family
Kathy & Dino Pampolina
Brian Ritter
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Honorarium

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by Anne & Robert Shoemaker

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by Julie & Steve Smith
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by Edward Turner
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In honor of Annie Garrett and her
new position by Eric Robbins
In honor of Lindsey Welch
by Gina & Todd Cunningham
In honor of Liz & Mike Englert
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Thanks to all the attendees who supported "For the Love of Children." Space prevents us from listing all our supporters!



Welcome to FOCUS + Fragile Kids

Big welcome to Jill Gossett, our very first official development director! Jill was the development director of Fragile Kids for almost 11 years, then acted as the Interim Executive Director for a year. We are thrilled to have her – she brings to FOCUS + Fragile Kids new energy, lots of optimism, great ideas, and amazing cinnamon rolls!

And, our Elizabeth is back! (But, if you get our emails, you know that already!).

Coming Up...

May 7, 2017
Six Flags Day!

May 22, 2017
FORE FOCUS + Fragile Kids Golf Tournament.
Email lucy@focus-ga.org for information

May 30 to June 2
Camp TEAM Day Camp at Mercer University

June & July
Camp Hollywood Day Camps

August 27
SummerFest at Monday Night Brewing

Under the Stars Family Camps
August 11-13
at Camp Twin Lakes Rutledge

Oct 6 – Oct 8
at Camp Twin Lakes Will-A-Way

RETURN SERVICE REQUESTED



Looking Back at the Fun

While we've been busy doing merger stuff, moving the Fragile Kids office, training new staff, and building a new mobile website, we've continued all of our programs! Here's a peek at the FUN we've had since November! We'll try to be timelier with the next newsletter!

