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focus
Comfort. Hope. Fun.

Comfort. Hope. Fun.

Riley

by Faith Crum

When our daughter Riley was about 3 months old she was diagnosed with a chromosomal disorder called Trisomy 9 Mosaicism, or T9M for short. I know, that's a mouthful right? Simply put, it means that the entire 9th chromosome appears three times (trisomy) instead of twice but in only some (mosaic) cells of the body. A more common chromosomal disorder is Trisomy 21, also known as Down Syndrome, which means people with Down Syndrome have an extra copy of chromosome 21 (just a fun fact for ya!). Doctors literally know nothing about T9M. It is so very rare, less than 200 people in the world have it. It's pretty strange having to educate your doctors on your daughter's condition!

Riley had complications at birth. She wasn't breathing on her own at first and was in the Neonatal Intensive Care Unit (NICU). She stayed there for 2 weeks because she wasn't eating and needed a feeding tube. The NICU doctors found a few things that were concerning...long story short, it led us ultimately to an appointment with a geneticist. Aside from Riley's medical history, the geneticist pointed out some of her physical features that could mean a possible syndrome of some kind. I remember this made me so mad! To have somebody look at my daughter and critique her because she may not look like everyone else almost made me forget I was a Christian!

So what does this mean for Riley? It means that she has extra information in only some of her cells. The extra information could make her condition mild or severe, depending on what organs of the body are more affected. It's like this: if a car has an extra seat belt or extra cup holders, it wouldn't be such a big deal, right? But an extra engine or extra brakes could really affect how the vehicle runs. So far with Riley, we have just had a few extra seat belts and extra cup holders. Sometimes the cup holders don't quite fit the cup you are trying to put in it, but whatever! We make it work. For example, Riley has had to work extra hard through physical therapy, and in November she had surgery for hip dysplasia. She is now in a cast that goes from her chest down to her sweet little feet. Despite the confines of the cast, our baby girl doesn't let anything stop her. She certainly doesn't use T9M as an excuse!

I used to pray that God would heal Riley, that he would take this from her. I thought it was Satan's way of trying to bring harm to our baby girl. But I see now that Satan had nothing to do with the creation of Riley. God is the one who formed her. During the time that I was wrestling with the question of why this was a part of our lives, the Lord ever so gently showed me that it is for His glory. For it is His strength that is truly made perfect in our weakness. And I promise you, if you ever get the pleasure of meeting Riley, you will see a smile that reminds us all that God is good.

I never would have chosen this for Riley. But, thank God, He didn't ask for my opinion while he was putting her together, precious piece by precious piece, because I have fallen completely in love with Trisomy 9 Mosaicism. ■

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MISSION STATEMENT

FOCUS understands and supports the unique needs of families with children who are medically fragile or have significant developmental or physical disabilities. FOCUS offers comfort, hope and information to parents; accessible recreational and social programs for children and teens; and fun, inclusive activities for the entire family. A nonprofit founded by parents in 1983, FOCUS continues to embrace and strengthen metro Atlanta families.

SUBSCRIPTION INFORMATION

For subscription information, please call FOCUS at (770) 234-9111 or visit our website at www.focus-ga.org. Annual subscriptions to the newsletter are $15 for families (waived if necessary) and $30 for professionals.

Ongoing at FOCUS

MVP Events for Medically Fragile Families

For more information,
email **elizabeth@focus-ga.org**.

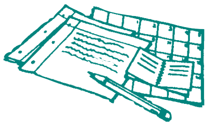
Teen / Young Adult Activities for ages 13 to 29

Please email **brian@focus-ga.org** for information on monthly social outings and other events for teens/young adults.

Share Groups, Hospital Visits, and more!

Email **lucy@focus-ga.org** if you want to get involved at FOCUS but can't figure out how to start!!

New Year's resolutions should really be reviewed at the end of the year, to see if any resolutions were accomplished. Here's my article from January/February 2014 – I've updated with parentheses and italics!



From the Editor

by Lucy Cusick

Merry, merry and happy, happy ... yeah, well, whatever. This holiday season has been less than merry and happy for me. I won't bore you with the list of personal difficulties since we all have our burdens – suffice it to say that I am looking forward to a new year. Some of the struggles will continue, regardless of the change of years, but I am slowly changing my reactions to the struggles. I don't really do New Year's resolutions anymore – but I do use the new year to continue working on the things I should already be doing:

1. Exercise. Yep. I hate it. But, as I get older it takes 'more' to feel the same. Exercise is one of those 'mores.' It might just be walking the dog, but I'm aiming for three long walks and one yoga class a week. *(Epic Fail. As the year progressed and the dog and I gained weight, I did improve. But I renamed it a "Monday Resolution.")*
2. Eat less. Of everything, but especially of sugar. It's addicting. One Hershey's kiss leads to a bag, which then makes me want a nap, after which I crave potato chips. It's a delicious and fattening cycle that makes me feel terrible. Especially when standing in front of my closet. *(A little more success. Only purchased Nutella once.)*
3. React less. My reactions are often my problem. Sometimes no action is necessary – patience might prove valuable ... perhaps someone else will react so I won't have to. *(Some success. Refusing to comment on Facebook statuses helped.)*
4. Drink a Diet Coke a day. I don't care if it cleans toilets and removes nail polish. I will only drink one, however, and drink water the rest of the time. Well. Except for coffee in the morning and wine on the weekend. *(Woot! Complete Success!)*
5. Plan a vacation. I didn't plan one in 2013, so guess what? I didn't get one. (Sorry, Camp Hollywood is only a vacation if you have a child attending!) For one week in 2014, you will find beach photos on my Facebook page. Don't worry, none will include me in a bikini. See #2. *(Check Done! Our family enjoyed a few days at St. George Island, thanks to generous friends who share houses. No bikini photos, as promised!)*
6. Enjoy more, instead of doing more. I now make a conscious effort to enjoy whatever I am doing – from standing in line at the grocery store to watching a movie. Don't rush to 'git er done' but enjoy the

(Continued on page 4)

Journey of Hope

By Corey Lowe

Along with the rest of the world, my world turned upside down on Tuesday, September 11, 2001. At 8:52 pm on this tragic date, I became a first- time mother to a beautiful baby girl, Victoria Elizabeth. Fast forward a few months and all the fears about raising a child in a world among terrorists quickly became the least of my concerns.

"My baby's having a seizure! My baby's having a seizure," I screamed, standing in the mall, holding 3-month-old Victoria. We went straight to the emergency room (where we had already been three times for odd movements that Victoria made). After a battery of tests, a doctor told me the results. *"Your daughter's brain activity is grossly abnormal,"* were his first words. I am sure this doctor introduced himself, but I could not wrap my mind around what he just said. That sentence is forever etched in my memory. As we stood there discussing the horrific side effects of various "lifesaving" seizure medications, all I could think about was her future. The tears began to fall as I remembered my dreams of future mommy-daughter dates and planning for her wedding. I wanted to tell the doctor that this is not the life that I planned for her.

It's been 13 years since we were diagnosed. Since then we've added two children, changed careers, moved a few times, and tried every anti-seizure medication (FDA & Non FDA approved) the doctors have recommended. We flew to Detroit to see a well-known brain surgeon. We tried the ketogenic diet and she had Vagal Nerve Stimulator implanted in her chest. However, Victoria continues to seize multiple times a day, which often causes her to stop breathing or to fall and injure herself.

About two years ago, a fellow special needs mom in California told me about cannabis oil. We didn't really consider cannabis oil as an option for Victoria since it's not legal in Georgia, so we just kept doing the best we could, trying different meds and hoping for the best. Time passed and information about cannabis oil kept re-surfacing; I began to network with other parents who had the same common goal: to improve the quality of life for our children with seizures. Cannabis oil is legal in Colorado, as well as 23 other states, and many Georgia families began moving there to see if a particular strain of cannabis oil called Charlotte's Web worked for their children with seizures.

In January 2014, Representative Allen Peake sponsored House Bill 885 to allow the use of cannabis oil for specific medical conditions and research. I lobbied nonstop along with other parents, and we had good momentum. The bill passed the House and the Senate but got caught in the middle of politics. Our chances of having access to cannabis oil in Georgia died as the clock struck midnight on March 20.

With Victoria's seizure activity steadily increasing, I needed to make some difficult decisions. We didn't know how to make this happen – but she deserved a chance to be seizure free. There was so much to consider: our family being separated and finances, to name just two. Thankfully our prayers were answered when Rep. Peake announced that he established a nonprofit titled "Journey of Hope." This fund would help Georgia families move to states that allow access to cannabis oil. This was the first glimmer of hope for Victoria since March 20.

Soon after the last day of school, a generous friend loaned us a vehicle so we could begin Victoria's Journey of Hope. We arrived in Colorado in mid-June, and we saw two neurologists right away. They agreed that she needed relief, and they were anxious to see the girl behind the seizures; I was anxious, too!

Victoria began receiving cannabis oil on June 18. We administered the oil by mouth three times a day. Oddly enough, Victoria would always fight me when I gave her seizure meds, but I when I gave her cannabis oil, she would tilt her head back and open her mouth! It was simply amazing! The results were immediate: she began to play purposefully with toys, her eye contact was incredible, AND her seizures were greatly decreased. In early July, she brought my mom a book, sat next to her, and spoke her first word, *"Book."* I had waited 13 years for that one word.

We had our answer – cannabis oil was miraculous for Victoria. But, summer was ending and I needed to return home to my other children and husband. I could not bring cannabis oil with me, as possession is still illegal in Georgia. Victoria's seizures are back, so we are fighting harder than ever for access to this life-changing medicine. We hope to continue Victoria's Journey of Hope this spring when Georgia legislators pass House Bill 1 which would provide for the regulated use of medical cannabis to treat certain medical conditions. ■

At least 10 FOCUS families have moved, hopefully temporarily, to Colorado for access to cannabis oil. FOCUS does not advocate for or against legislative issues; we care for families by offering support, information, and programs for the children and the entire family. We care for these families and hope that their next journey is to Georgia!

Leaning In

By Laura Boggs

My husband Luke and I climbed into the front seats, both bitten and bleeding – me by a bunny I'd been holding up to show our special needs daughter, Sadie, and Luke by Sadie. I shut the passenger door.

"Good times."

It was a nice thought, he assured me, popping around the corner to the local nursery for hot dogs and a visit with Santa and a stroll through rows of fragrant Christmas trees. There was even a petting zoo. Who doesn't love a baby llama?

But it wasn't Sadie's day – or ours – and she would have none of it. Maybe she was sleepy or thirsty or cold, or there were too many people there, or llamas smell funny. We chased her in circles for a while until we could finally get her safely back in the car.

During the miniature outing, I spotted a pair of preschool-aged twin girls, all curly heads and matching jackets, smiles and wonder.

"Remember those days?" I said, thinking of our now 16-year-old twin daughters. "When we were all about getting the girls dressed up and taking them around?"

"That," Luke said quietly, "was a really long time ago."

I frowned at him. "So what's your point?" That we're older? Grayer? Fatter?

Later that night, he told me he meant "a really long time ago" in a metaphysical sense.

"Oh," I said, turning down the covers on our bed. "You mean back when life was easy and fun?"

"Yep, pretty much."

Well, there it was, hanging out there. We don't usually say things like that, allow ourselves to go there. We love Sadie with all our hearts, and then some. She's a joy – and a mess.

But we're tired.

My spouse is an optimistic guy, sometimes annoyingly so. His comment came from a place of deep exhaustion, I know. But there's this: look at us, getting ready for bed and being all calm and on each other's side.

There might've even been a hug.

So what if the photos from a dozen years ago tell a different story, of carefree faces and wide-eyed naivete? We're not alone – whose faces don't morph into something a little sadder? If we're honest, aren't we all a tiny bit disappointed? Most adults I know are walking around semi-shocked at how upside-down stuff turned out, how hard it is to be human. A lot of us grew up being told we were special and the world was going to be our oyster if we studied hard, worked smart, played by the rules.

We bought the subtle lies and, in our bitterness, forgot about grace.

From what I can tell, we grownups with a little life under our belts complain more, sigh more, drink more. Some of us get harder; some softer – others vacillate between the two. We neglect to say thanks.

But the good news is we can offer each other knowing looks, real laughter, fresh levels of candor. The better news is maybe we'll learn to lean into the pain and still come out okay. ■

Laura is the mom of 12-year-old Sadie and 16-year-old twins. On her blog Huckleberry Friend at www.lauraboggs.org, she writes, "I used to Not Write. I was so busy being a responsible adult, I forgot how to play. Now I play, and I'm probably less responsible, but much happier."

From the Editor

(Continued from page 2)

> process. This takes effort for me – and practice. I sure am enjoying assembling this newsletter. Hhmmm. *(Some success, possibly because I have less to do now (see below). This will likely always be a work in progress!)*

If I manage to do all of these things, in the same day, I'll be enjoying a day on the beach (#5), taking a long walk after a dawn yoga class (#1), drinking a Diet Coke (#4), but not saving the drowning person (but hoping someone else will) (#3). Yep. Happy New Year! *(No, this isn't how it all went down – but it was cute!)*

After losing my mom in February, I added two more resolutions: apply for the NOW / COMP waiver for Josh and update my will. Great news – NOW / Comp application is complete and Josh is officially on the waiting list! And, my will is in the works and should be complete by February 1, 2015.

For 2015, I resolve to not NEED my will. ■

Extra Special Saturday Respite Spring 2015!

FOCUS offers Extra Special Saturday (ESS) respite in six locations each month so parents can enjoy a break – and children can enjoy some fun! Caregivers at each location are experienced in caring for children with special needs; a nurse is on-site to manage G-tube feedings, seizures, and other medical care. Ratio of caregiver to child is 1:4; community volunteers are often there to help and play. ESS is from 10 am to 2 pm and is free to parents, although small donations are accepted.

ESS is especially for children with disabilities and their siblings, ages 1 to 12 years old. Children enjoy free play and music so parents can do boring things like run errands or meet a friend for lunch!! For the first ESS, parents must complete a short application that will be kept on-file for future ESS dates.

For registration information and an application, please go to www.focus-ga.org/how-focus-can-help-you/children-teens/extra-special-saturday-respite. In a nutshell, you will need to bring lunch, extra clothes, diapers, and any medication to be given during ESS. **All medications _must_ be in the prescription bottle, with correct dosage on label.**

Register soon since locations fill up quickly. For most locations, you can register for three months and choose the wait list for two months. This keeps some availability for new families who are just figuring out ESS! If you need help or have questions, call FOCUS!

Acworth:

Summit Baptist Church
4320 Moon Station Lane, Acworth 30101
You may register for all three months and choose the wait list for two months.
January 10 – February 7 – March 7
April 18 – May 2

Alpharetta:

Alpharetta Presbyterian
180 Academy Street, Alpharetta 30004
You may register for three months and choose wait list for two months
January 24 – February 21 – March 28
April 25 – May 16

Chamblee:

Embry Hills Methodist Church, 3304 Henderson Mill Road, Atlanta 30341
You may register for three months and choose wait list for two months
January 10 – February 7 – March 7
April 18 – May 2

Cumming:

North Lanier Baptist
829 Atlanta Hwy, Cumming 30040
No January – February 7 – March 7
No April – May 2

Marietta:

Mt. Bethel Daycare
615 Woodlawn Drive, Marietta 30068
You may register for three months and choose wait list for two months
January 10 – February 7 – March 7
April 18 – May 2

Peachtree City:

Peachtree City UMC
225 Robinson Road, Peachtree City 30265
You may register for all three months and choose the wait list for two months.
January 24 – February 21 – March 21
April 25 – May 16

Coming Up at FOCUS!

Always check the calendar at
www.focus-ga.org
for the details of all programs!

Let's face it – the FOCUS newsletter is not the best way to stay current at FOCUS! By the time you receive this newsletter, Extra Special Saturday respite will have started, registration for the annual education conference on January 31 will have begun.

So, why print and mail the newsletter? Families tell us that they like to throw it in the car to read during therapy, to keep for future reference, or to pass on to grandparents or other parents. So, we'll continue to print and mail, we'll continue to have upcoming events, but it you REALLY want to be 'in the know,' go to the FOCUS website, follow the Facebook page (http://tinyurl.com/focusgeorgia) AND make sure that we have a correct email address for you. We send weekly emails with reminders and updates about FOCUS activities.

With all that said, already going on and coming up at FOCUS:

January 31, 2015

FOCUS Annual Education Conference at Dunwoody United Methodist Church. The brochure is available on-line – none were mailed! Email elizabeth@focus-ga.org for more information.

FAST Fins Registration has begun!

The season begins February 13. Criteria for swimmers and registration information is on FOCUS website. Please email brian@focus-ga.org with questions.

February 28, 2015

"For the Love of Children" dinner, dance, and silent auction, recognizing Frank Berenson, MD of PANDA Neurology. For information on For the Love of Children, please contact lucy@focus-ga.org

"Fridays at FOCUS"

will resume in January. These workshops will be announced by email and will be on the calendar of the FOCUS website. If you have an idea for "Fridays at FOCUS," please email elizabeth@focus-ga.org

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Ten Things To Know When the First Wheelchair Arrives, or Rolling With Children

By Marjan Holbrook

The modern mom's guide to rolling with a kid in a wheelchair: 10 things I wish I had known the day my daughter's chair was delivered.

1. **Accept the chair.** There is no denying it. It's not a stroller, it's a wheelchair. The day our first chair was delivered, I didn't even want my daughter to sit in it. *"No, Chuck, there is no need to have her actually sit in that. No, you don't have to adjust it now. The monogram looks good."* My father in law asked, *"What should we call it? A cart?"* Mother in law asked, *"You are not giving up on her walking one day, are you?"* I had many questions, a two year old, a newborn, a dog, and a husband who is an optimist. Being an optimist is a good trait unless your wife is hormonal and mad at the world. Once I accepted the fact that my daughter is not walking and this chair is going to get her places, the chair became a part of our new normal.

2. **Make the first outing short and easy.** Only go to a place that you know is handicapped accessible. This means that if it was easy to navigate when your baby was in a stroller, then it will most likely be okay with a wheelchair. As of now, they don't make wheelchairs with an attachment to carry a younger sibling. If you have another child under the age of one, consider wearing a baby carrier.

3. **Make no major decisions without considering the wheelchair.** We had just moved to Georgia and were in the market to buy a house around the time Rebecca got her first chair. I desperately wanted to buy a one level home. My husband wanted a newer, lower maintenance house. So how did we end up in a new three story home? I said no, no, no ... until I walked into the master bedroom. Gorgeous, there was even a washer/dryer in the master closet. Our realtor encouraged us, *"Your daughter is so little, only 2 years old, you should be more positive and think about her walking one day."* I should have said, *"Dr. Realtor, walking and walking up stairs are not the same thing."* But, I was a fool in love and thought that if I had a closet like this, surely I would not wear black yoga pants every single day. *"Fantastic investment,"* said the family member with three healthy girls. Did I mention I was hormonal and in denial? My crush on the closet costs us a lot of struggles and years of back problems. It also led to my four year affair with Nutella.

4. **Get a handicapped parking tag.** This is a necessity and it will make your life easier. Bonus: During the busy holiday season you will love your child even more than you do now because you can park near the entrance. Warning: using the tag when your child is not with you is rude, tacky, lazy, and illegal.

5. **The most important advice to a mom who is getting her child's first wheelchair delivered soon: Start building your team.** The major players are mothers who have raised children with special needs and those who help me take care of my daughters. When I need advice or support, the first people I call are the women who have done this before. When I am overwhelmed, I call a person whom I know loves to spend time with my kids.

6. **People will stare.** No, it's not in your imagination. They really are looking at you so pay attention to #7 and #8.

7. **Dress your child age appropriately.** This was easy for me until my daughter was in first grade. Then I looked at the other kids her age and realized I was dressing my first grader like a baby. I kept her hair very short because we were tired of combing out the knots she got in the back of her head from leaning on the headrest. Even though she spent most of her time in a bright pink wheelchair, people often asked, *"Is he your son?"* I had not given much thought to the way she looked, because I had been in survival mode for years. My child has enough issues; the least I can do is to make sure she looks her best. No more "cutest baby in the world" bibs, and we let her hair grow. Yes, knots are a pain, but well worth it when I hear another child tell my daughter, *"I love your beautiful hair."*

8. **Dress yourself age appropriately.** Ladies, no mini-skirts if you are going out with your child! Having a child in a wheelchair means you will be bending over ... you get the picture. You don't have to live in stretch pants either. I buy longer dresses and short skorts (skooters) for outings with the kids. Look your best because, like it or not, you are a celebrity … everyone is staring! Recently, my younger daughter asked me why everyone was staring at us at the mall. My heart broke, and I wanted to cry. But I put on my sunglasses and said, *"Honey, they must have us confused with the Kardashians. Bet they are wondering why we are in the clearance section at JC Penney."*

9. **Prepare for some ugliness.** But you will also see goodness like you have never seen before. Random strangers will help you.

10. **Your child is going to do amazing things in that chair, the things other kids do.** My daughter plays baseball, goes to dances, runs in races, and makes friends!! ■

Looking Back at the Fun ...

MVP Boo-B-Que – October 25

OctoberFest Retreat for Teens & Young Adults – November 1-2

FAST Fins Swim Meet November 1

FOCUS on Fashion – November 2

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Looking Back at the Fun

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Snacks with Santa November 30

FOCUS & Lekotek Holiday Party December 6

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