

The Unknown

by Karyn Campagnone

When I was in high school, I worked at a fast food chain restaurant. One day, I was working behind the counter when a little girl came in with her mom and her grandmother. She was about two years old and had curly blond hair. She was carried by her mother and took turns kissing her mom and her grandmother while they waited in line. After each kiss, she smiled the biggest smile and giggled. The room was brighter with her in it. I remember noticing the little girl had Down Syndrome. As I watched them interact, I smiled and thought to myself, "God, if you ever decide to give me a special needs child, please make it one like her."

Fast forward to 14 years ago. I was expecting our first child. I vividly remember sitting in the doctor's office and hearing him explain that our baby, our first born, had Down Syndrome. I remember feeling my heart break, all the dreams I had for this baby shatter all around me. I remember sitting there in shock as the tears started to flow. This is not how this is supposed to be. I am young. I am healthy. We have no developmental or genetic disabilities in our families. How could this happen? Then, in the back of my mind, I thought of that blond-haired little girl. Of course, I prayed for this.

During my pregnancy with Tyler, I was faced with the unknown. I was concerned about his health. I was concerned about my ability to care for a special needs child. What if I made the wrong decisions? How would I teach him? How would others react to him? There are still unknowns about Tyler – mostly the same ones - his health, his future, how others would treat him. But, I have learned not to worry constantly, to laugh about situations,



and to take life day by day. I don't even notice how others react anymore. Most of the time, when people ask about Tyler, I am all too happy to brag on him!

I don't remember the exact moment I found FOCUS. It seems like FOCUS has always been a part of my life as a mom. Tyler's birth started a four-year flurry of hospital visits, so perhaps it was during one of those stays. Over the years, we enjoyed family activities, and I called the office looking for advice. We had two more boys, Logan and Joey; we didn't worry about having more children because we saw the love and adoration on the faces of siblings at FOCUS events. Logan and Joey love meeting other siblings, and they have grown up with a unique perspective of the world and with more compassion for those around them.

As Tyler grew, I experienced more unknowns, unknowns that I never predicted: the amount of love and joy Tyler brings to us and to everyone who meets him; the fact that he is a big practical

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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.

**From the Editor**

by Lucy Cusick

All that I have learned while being a mom of a child with special needs has served me well. I used the knowledge, the diplomacy, and the tenacity that I learned as 'Josh's mom' when my mom moved from NC to Atlanta and into a nearby assisted living facility last year. After the basic furnishings, orienting her to the facility, and helping her establish a routine, I shifted into high medical gear. I researched and found the various 'ologists' and thought fleetingly about which hospital to use, should she need one. I checked (and double-checked) her daily meds. Knowing that the 'whole person' is important, I encouraged her to join in the community activities – lunch outings, card games, and social groups.

After a month, she fell and broke a hip in the middle of the night. How fast the skill of '*pack-your-stuff-cause-you-don't-know-when-you'll-be-home*' comes back to you! Jeans, sweatshirts, socks, contacts, and phone charger are the necessities. Clean underwear and makeup are bonuses. Surgery was followed by admission into a facility for rehabilitation. Yikes. We're back in therapy – physical, occupational, and speech. Well, she graduated from speech pretty quickly because she would quickly tell you that she had NO plans to go to therapy..... Back to evaluating equipment, encouraging independence, thinking outside the box for a problem that MUST have a solution because surely we aren't the first ones to have this problem, and balancing the rest of life. Hey, haven't I done this already?

But, I learned a few more things on this geriatric journey. I learned that people do not expect more from the elderly. The care is less exact, less critical (really?), and more accepting of little progress. I don't mean they didn't care – not at all. My mom was loved by many; but I EXPECTED her to walk again (and she did). I EXPECTED her meds to be dispensed properly ALL the time, not just SOME of the time. Hmmmm. I'll just stop here.

The New Year started with a small stroke, which started an avalanche of the geriatric version of 'failure to thrive.' My 88-year-old mama just got tired. She died a peaceful death in early February, and we finally took her home to her beloved North Carolina. The day after her funeral, we woke up to three inches of snow. I'm convinced my mama and daddy, finally together again, sent me snow from heaven.

Yep. I've learned many things in this life, as a FOCUS mom and as a caregiver. One: Giving care can be exhausting, overwhelming, thankless, and immeasurably rewarding. Two: Being my mom's daughter was a privilege. ■

*Have you moved or
changed email addresses?*

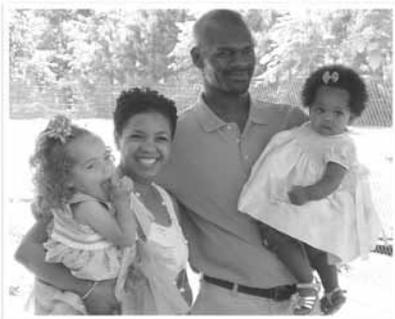
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Find us on Facebook at
<http://tinyurl.com/focusgeorgia>

Support

By Sabrina Johnson

Thank heaven for good support. I'm talking about this in several different ways— organizations that provide information and resources, those who help and encourage and good providers who make a difference. My thoughts on this post were prompted by a simple text message that I sent yesterday. Next week my husband Lamar and I will be attending the annual FOCUS Education Conference. FOCUS provides open arms of support with everything from family activities to share groups. The conference brings information to special needs parents from various professionals in the community.



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Okay, that gives you background to 'the what' of all this, so back to the text I mentioned. The conference is all day, so, of course, we need child care for girls. We are so fortunate to have a network of family and friends who are always there to help, those who provide much needed care for date nights, and those who come over for emergencies at a moment's notice. I kept forgetting to ask about babysitting for this day and thought it best to ask our network of supporters to come for a "shift" to make the day easier for everyone. I sent my text asking who might be available for a time from two to three hours. I had replies within seconds. All saying yes! My heart was so warmed. Paying for all day childcare would be so expensive. So having our family and friends be so ready to support us for this event really means a lot to us.

So while I'm on this topic of support, I don't want to leave out our team of therapists and teachers who also make a difference. These people go above and beyond the call of duty, and I don't think they have any idea of what this means to us. Hopefully, they will all read this and know how much they are appreciated. We are thankful for all the help that we get from our personal network and those who help on a professional basis. Thank you so much for all you do.

Imagine life without support. In our case, sometimes we need sitters, encouragement or a kind word. You likely need something different; but we all need support of some kind. Early on in Juliana's diagnosis, I kept reading about setting up a support network. I didn't go around polling our friends and family to see if they could be counted on. But soon it became obvious on whom we could rely. Those are our go-to people and for them I am truly grateful.

It's January and thus we are still in the season for resolutions and goals. If you have been navigating life without a support system, please, please stop. We all know the infamous quote that "No Man Is An Island." Don't do any part of life's journey alone. Many people in our lives are ready and willing to help or be there. Give them the chance to do so. This year, will you make it a point to ask? Just ask. ■

FOCUS parent Sabrina Johnson blogs about "living and learning as a special needs parent" at <http://julianasjournal.com>. See page 6 for more!

Are You HIPP?

Some resources feel like a best-kept secret! Georgia has a program for Medicaid members called HIPP (Health Insurance Premium Payment). If your child has Medicaid, then he/she is a "Medicaid member" and can apply for HIPP. From a parent on the FOCUS Facebook page: *Once an individual has been APPROVED for Medicaid, you may then apply for HIPP. A calculation is made to determine if it is more cost effective for the state to give the child a separate insurance policy or just reimburse the family for the premiums it pays through its employer. For us, it is cheaper to reimburse us each month for our the ENTIRE FAMILY'S premiums through my husband's employer than it would be to pay for a separate policy for just my one child. I submit paystubs each month. They are processed in about a week and a check is mailed to me. Easy and a super perk! Here is the website: <http://dch.georgia.gov/health-insurance-premium-payment>.*

How can FOCUS support YOUR family?

Share groups, hospital visits, workshops, respite care, summer camps, teen & adult groups, newsletter, swim team, and family activities. We work hard to offer all programs at a reduced rate – no program is completely supported by fees. What program means the most to you family and what program do you wish FOCUS offered? Send replies to inquiry@focus-ga.org

Volunteer at FOCUS!

Volunteers are critical to FOCUS programs! If you are interested in volunteering, please check out our website at www.focus-ga.org for the age requirements or email volunteer@focus-ga.org.

Upcoming Activities & Registration Info!

FOCUS sends a weekly email to parents, with reminders about upcoming events. If you do not receive this email, then we likely do not have your correct email address. Call or email inquiry@focus-ga.org to confirm or change your email address. To request a paper application for any of these activities, please call 770-234-9111.

May 4, 2014 FOCUS Day at Six Flags Over Georgia

Registration information will be sent by email on March 18.

May 27 – 30*

Camp TEAM day camp
at Mercer University

June & July*

Camp Hollywood day camps

*Brochures and applications for all day camps were emailed to FOCUS families on February 10. Call if you didn't receive yours!

UNDER THE STARS FAMILY CAMPS

August 8-10**

Under the Stars Family Camp 1
at Camp Twin Lakes Rutledge

October 3-5**

Under the Stars Family Camp 2
at Camp Twin Lakes Will-A-Way

**Brochure and application for family camps will be emailed to FOCUS families on April 16.

Please read each email carefully and note the registration steps for each program! If you know a family who might benefit from our programs, please have them call FOCUS and we will send the info to them!

New at FOCUS:

Fridays at FOCUS!

Join other FOCUS parents to learn (and laugh!) for 2 to 3 hour workshops on various informational (and fun!) topics. You must RSVP for Fridays at FOCUS by emailing elizabeth@focus-ga.org or calling 770-234-9111 ... be sure to let us know which date you want to attend!

Friday, March 21 – 10:00 – 1:00 pm. Preparing for the Unexpected & SSI

Matthew McManus and Sara Khaki will be offering a two part lunch and learn session on March 21st. Part 1, "Ready or Not? Preparing for the Unexpected," shares tips on how to develop a proactive strategy for protection and preparing for the unexpected. Gain insight on a broad range of preparedness topics, including do you have the right amount and kind of life insurance for your life situation. Part 2, "Understanding the Standard for Child SSI: Would your child qualify for disability?" including an overview of the general process for qualifying.

Friday, March 28 – 10:00 – 1:00 pm. CPR

Each participant will receive certification in Adult, Child & Infant CPR and First Aid. The cost of the course is \$25. Reservations and payment required prior to class.

Friday, April 4 – 10:00 – 11:30 am.

Your Dependent with Special Needs: Making Their Future More Secure

Families with children and other dependents with special needs, no matter what the age or disability, face many serious questions about how to best prepare for their future well-being. In this workshop Jodi McMahan addresses such critical issues, such as protecting government benefit eligibility for Supplemental Security Income (SSI), creating Special Needs Trusts, and the importance of a will. Taking steps now can help arrange for a loved one's well-being today and tomorrow.

Friday, April 18 10:00 – 11:30 am. Financial Focus by Matthew McManus

Description TBA

Friday, May 2 – 10:00 – 1:00 pm. NOW/COMP by Heidi Moore

This workshop will provide information on the New Options Waiver (NOW) and the Comprehensive Supports Waiver (COMP). In this session for beginners, Heidi will explain how to apply, the services available, and more

Friday, May 9 – 10:00 – 1:00 pm. Deeming Waiver by Debbie Dobbs

This workshop will help you understand the application process for the Deeming Waiver.

Always check the FOCUS calendar for up-to-date information on all FOCUS activities.

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Alison & Terri Utterback
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Beth & Charley Vogel
Chris & Bill Willson
Iola & Bill Winesett
Sallie & Mark Winokur

Memorials

In memory of Rusty Townsend
by Mary Ann & John Masters
In memory of Sal Bartolone by
Barbara & Matt Battiato
In memory of Carolyn Treppunti
by Barbara & Matt Battiato
In memory of Christina Daniels by
Phyllis & John Zekauskas
In memory of Karl Brummer by
Sharon Rivera
In memory of Eleanor Elio by
Sharon Rivera
In memory of Jane Lennon by
Jane & Michael Langan
In memory of Elaine Burns by
Barbara & Matt Battiato
Susan & Jim Calhoun
Audrey Gargiullo
Green Mellen Media
Pete & Pauline
Giannakopoulos
Karen & Bill Greenfield
Elizabeth & Mark Hewell
Cassandra & DJ Jeyaram
Bebe & Charlie Joyner
Anna & Andy Kostopoulos
Celia & Frank Lawton
O'Connor & Company
Cindy & Mark Overbye
Golfo & Greg Pappas
Helene & Dick Prokesch
Sharon Rivera
George & Lillian Rothkopf
Kathie Teta
Joy & James Trotti
Patty Vastakis
Bill & Iola Winesett
Williston Peanuts

Honorarium

In honor of Claire Gibbs' Birthday
by Karen Carlson
Ben Grynol
Chelsea Hinkle
In honor of Bonnie & Marc Hayes'
50th Wedding Anniversary by
Sarah Anderson
In honor of Shari Dacon by
Valine & Stephen Georgeson
In honor of Matthew Ladd by
Lizabeth Mahaffey
In honor of Kirk & Scott Lawton by
Celia & Frank Lawton
In honor of Florence & Bob
Fortenberry by James & Janet
Fortenberry
In honor of Jenny & Hannah
Harris by James Boler
In honor of Lucy Cusick by
Betsy Primm

Fund Raising Events at FOCUS

"FORE FOCUS"
May 7, 2014

Bear's Best Atlanta

Tournament Chairperson: Curt Smith



SummerFest at SweetWater Brewery August 16, 2014

Raise a glass and celebrate FOCUS camps
with SweetWater brews, brewery tours,
cornhole tournament, and food.



Ride for TEAM FOCUS in Spin for Kids October 18 (mountain ride) and October 19 (road ride)



Email lucy@focus-ga.org for information on any
of these fund raisers or if you (or someone you
know) would like to plan a fund raiser for FOCUS!
FOCUS fund raisers support FOCUS programs
and help keep the cost low to families.

Beginning Steps to Understanding Orthotics

By Sabrina Johnson

It makes more sense to me now, but there was a point when I was lost in the world of orthotic acronyms and what supports actually do. In its technical description, an orthotic (also known as a brace or orthosis) is anything that goes on a body part to improve or support its function. Therapists and specialists deal with orthosis on a regular basis so it all makes perfectly good sense to them. When a recommendation is made that your child might need orthotics, it could leave you grappling to figure out how necessary they are and what the outcome will be.

When it was time for Juliana to get her orthotics, I was really confused. Yes, it was explained to me and I wrote the information down, but it took some time for it to really make sense. It was very intimidating to put this little contraption on her foot. I was so nervous that if I got it wrong, I would ruin her feet. I didn't realize it at the time, but I was very fortunate to be referred to CH Martin for her braces. A local leader in the orthotics industry, CH Martin has been very good. In fact, I asked Juliana's orthotist, Jackie McCutchen, to allow me to pick her brain; I hope that it will help someone else who may be new to the world of orthotics.

What is your professional background and how did you end up doing what you do? After serving in the Marine Corp, I returned to get a degree in Health Science. I completed an externship at CH Martin and I have been here ever since. I like the kids I work with and I am going into my 14th year as a trained, licensed and certified orthotist.

There is so much to learn about orthotics. Can you give me a summary of the most common orthotics that you fit? What is the purpose of each?

I'll review those that are most common with children from the greatest to the least amount of support:

- **Knee Ankle Foot Orthotic (KAFO):** Goes all the way up the leg to support the knee joint
- **Ankle Foot Orthotic (AFO):** This is probably the most common orthotic. There are a lot of varieties. It fits just below the knee and encompasses the foot. Support is given to the ankle and foot with the AFO.
- **Supramalleolar Orthotics (SMO):** With SMO's, support is concentrated to the posture of the foot and side to side instability. There is more control for the ankle, heel and arch.
- **University of California Berkeley Laboratory (UCBL):** Similar to the SMO, it sits just below the ankle bone. The UCBL (named by the lab that developed it) supports the arch to help with pronation (the condition that occurs when arches fall to the ground)

- **Arch Support:** Made out of cork, these low level supports go into the shoe to help support the arch.

When parents are new to the process, things can be so confusing. I know every company works differently, but can you walk me through what you do when you get a new client for a fitting? The first appointment is the fitting of the mold that we use to make the brace. This could generally take 45 minutes to an hour. The parents may have to assist the orthotist in keeping the child still while measurements are taken. We make a plastered mold on the targeted area(s) that create what is similar to a cast. This is then sent to the manufacturer to make the orthotic. A follow-up appointment occurs in about three weeks when the brace is ready. The parent and child will return for a fitting and any adjustments are made at that time.

When parents return for the follow-up appointment it is a good idea to bring the shoes that the child will be wearing with the brace most often. The child will wear their new brace with their shoes and the orthotist will observe the child one last time to ensure proper fitting. This process may look different for another provider, but this is generally the way our appointments work.

I've spoken with you before about the irreversible effects when children do not get orthotics. Are there any signs that parents should look for to consider an evaluation for early intervention? Parents should be as proactive as possible. I recommend that they always see a pediatrician and even better, a pediatric orthopedist. It is helpful to see a specialist as orthopedists can monitor how a child is changing, their correct range of motion (the extent to which a joint or group of muscles can be extended) and alignment.

Whose call is it to make a decision about orthotics? The parent, doctor or therapist? It's a combination. The prescription has to be signed by the doctor. If the parent notices a problem, they can bring that to the therapist or doctor. Or it could be the other way around when the doctor or therapist notices a need or problem. There could be a difference of philosophy that varies. So ideally it is a joint effort. Again, I don't think it is a bad idea to see an orthopedist for another professional opinion.

What can parents do to ensure that their child is having proper fitting and comfort if they are wearing orthotics? It's important to keep in mind that some companies don't fit children, so

(Continued on the back)

Looking Back ...

FOCUS Education Conference. FOCUS families enjoyed a day of information and networking at the 27th annual FOCUS Conference. Thanks to Dunwoody UMC for hosting, Chick-fil-A for donating lunch, and the speakers and exhibitors for sharing their time and knowledge.



MVP Valentine's with Character. The 8th annual MVP Valentine's With Character was a fabulous afternoon! Children enjoyed dress-up, arts and crafts, photos and autographs with princesses from Fleetwood Dance Theater and superheroes from Hero Alliance, and magic by The Amazing Zapatelli. A special thanks to the Greek Orthodox Cathedral for the use of the beautiful church, the Philoptochos Ladies Auxiliary for providing the delicious desserts, Marie Reynolds for her face-painting ability, and the Junior League of Atlanta for volunteering.

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 Mackenzie@focus-ga.org for information on monthly social outings and other events for teens/young adults who enjoy socializing but require only a 1:8 ratio and do not need a nurse.

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!!

The Unknown

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joker; that songs sound so much better when he sings them; and that his laugh is so contagious.

And, who would have known that I would join the FOCUS staff? I always explain that I have been a part of FOCUS for 14 years! I am now more aware of all that FOCUS offers – as a staff member, I am helping with registration of various events to meet and get to know families. I recently helped with the annual FOCUS conference and attended sessions on IEPs and Deeming Waivers. I thought I had a handle on everything – boy, I was wrong! I learned so much! Driving home, I was actually mad at myself for not being more involved!

I look forward to helping other families during their 'unknown' time – I want to give hope to them, just like FOCUS gave to me. ■

Beginning Steps to Understanding Orthotics

(Continued from page 6)

the provider you choose is important. An orthosis has to be comfortable and functional. If they are doing that, they are still sufficient. Look for signs in things that change—such as red marks that don't go away after 15-20 minutes, darkening areas or calluses. If your child is suddenly being stubborn about wearing the brace, it could be the sign of a problem.

In general do children outgrow orthotics or will there always be a need for the support? Braces do a lot of things. They help children in walking, maintaining range of motion and not tripping over their own feet. The purpose is to keep the child aligned so that they are growing properly. As they grow, hopefully they will need less support. Children with some diagnoses will always need support but many kids are able to step down in the level of bracing support. ■

Pediatric Orthotic Companies in Atlanta (from FOCUS Facebook posts!)

CH Martin
Atlanta Prosthetics & Orthotics
Georgia Orthopedic Resources
Hanger Prosthetics & Orthotics

FOCUS parent Sabrina Johnson blogs about "living and learning as a special needs parent" at <http://julianasjournal.com>. See page 3 for more!

More new programs at FOCUS!

- **FOCUS on Sibs.** Siblings of children with special needs sometimes need a little extra attention and some time away from their sibling(s) with other siblings! FOCUS is pleased to have Jennifer Tumlin Garrett plan and facilitate special afternoons just for siblings. FOCUS on Sibs is three sessions and has only a few spots available. For more info, please contact joy@focus-ga.org or call FOCUS.
- **FOCUS on Dads.** FOCUS on Moms was such a success in 2013, that we decided to expand to include siblings AND dads! If you are a dad and would like to receive emails about upcoming new activities for dads, please send your name and email to elizabeth@focus-ga.org.
- *Tentative Dates as of printing:*
- **March 22, 10 am to noon** – Bowling at Stars and Strikes Sandy Springs
- **April 12, 9 – 11 am** – Share Group with special speaker at FOCUS office
- **May 17, 7:05 pm** – Gwinnett Braves game with pre-game tailgate (5:30).

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