



## Olivia

by Janet Frey

Our journey began just over 4 years ago. My husband Adam and I had been married for a number of years and decided to start a family. In September 2011, we closed on our house in Decatur, left for the beach the next day and then moved in the following week. During the first week in our new house we realized we were pregnant! And a couple of weeks later we got the surprise of our lives – identical twins!

A few months and a much bigger bump later, we went into what was beginning to feel like a routine bi-weekly ultrasound to monitor our twins who were at higher risk for complications since they shared a placenta. Little did we know that our lives were about to change again forever. At this appointment, everything was not routine. Twin A did not have a heartbeat. The unimaginable had occurred. We had lost one of our babies and our world completely fell apart. We were quickly admitted and many hours later delivered our 2lbs 6oz baby via C-section on March 28<sup>th</sup> and learned that our twins were baby girls.

In the emotional weeks that followed, we watched Olivia grow ounce by ounce in the NICU at Piedmont while trying to reconcile well, everything. Olivia seemed to be coasting through her NICU stay with few complications other than not liking oral feeding. Once she mastered oral feeding we'd be able to take her home. But on May 19<sup>th</sup>, we got our second bombshell. Olivia's head ultrasound showed periventricular leukomalacia which usually leads to cerebral palsy and, in her case, did.

Fast forward to today, and we are the proud parents of a snuggly, chatty, happy 3 year old who also has cerebral palsy. Olivia can sit unassisted

in certain positions but does not crawl, stand independently or walk very well with a gait trainer. While her cerebral palsy and blue wheelchair make her distinctive, that is not what defines her. She would want you to know



that she loves reading books more than anything and always wants to make "love cards" for all of her friends and family. We want you to know that her smile lights up a room, and she brings more joy than we ever thought possible.

She has and always will be our best therapy. ■

*Save These Dates  
in 2016!*

**January 30, 2016**  
**FOCUS Annual Education  
Conference**

Dunwoody United Methodist Church  
Watch your email for registration  
information!

**February 27, 2016**  
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Information available by  
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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](http://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

November and December are always fun at FOCUS – we are planning for the next year! This year is a little different, however. We completed an extensive five-year strategic plan with help from the Georgia Center for Nonprofits and are excited about the future of FOCUS. We have a lot of work to do that's not really all that fun – like market analysis and technology assessments – but if the end results are communicating better with parents and offering innovative programs to children and families, then we're in! Be ready to jump in and help, we're gonna need it!

During this season of gratitude, we want each of you know that we are grateful for each and every child, parent, family, volunteer, donor, and friend. We are grateful to have the resources to continue to offer programs that help our families manage 'real life.' We love getting to know our children/teens/young adults at camps and activities. We hope that as new families find FOCUS, they feel welcomed and can find Comfort, Hope, and Fun with us. ■

## Tomorrow Will Be Five Years

By Kathryn Jackson

Tomorrow marks five years since the car accident which left Anne with a traumatic brain injury. Five years with our new Anne. Five years without the old Anne.

We've lived through so much heartache and pain. We've all grieved – each at our own pace and in our way – and we've come through to the other side.

We are a family marked by disability. We park in handicapped parking spaces and work together to lift Anne's wheel chair in and out of our van. Each child can assist Anne in walking to and from the kitchen table and help her get comfortable in bed. Her little sister helps Anne bathe and brush her teeth. And Anne's older brother carries her up the stairs and comforts her when she's angry or scared.

We live at a different pace. Anne's therapy schedule only allows one extracurricular activity per child per semester. Sometimes I feel like the world races by us like a time-lapse video – while we're stuck in our slo-mo world. Each frame of our lives is affected by Anne's brain injury.

Recently I was telling a friend that there will always be a part of me that will remain sad. Sad for the life that Anne will never live – sad for the milestones that she will never reach – sad that I will never see the old gleam in her eyes – sad for what we've lost. But our sadness does not minimize the gratitude we have for Anne's life and progress.

We are thankful for her quick wit and crooked smile. Thankful for her simple faith and deep love of people. Sometimes I hold her in my lap and am overwhelmed with gratitude that I get to be her mom. I feel so privileged – so honored to be Anne's mom. She is a jewel and she's mine!

So tomorrow we will celebrate Anne's five-year milestone. We will thank God for her life. We will thank God for her progress. We will cherish her day and push our worries for the future aside. Anne is alive! And that is something worth celebrating :) ■

*Read more by Kathryn on her blog at [www.kathrynjackson.com](http://www.kathrynjackson.com)*

## Behind the Perfect Picture

By Cassandra Jeyaram

Every year I have visions of the “perfect” family Christmas picture. And every year my dream of a “perfect” family picture turns into a stressful event, and I swear that I will never ever do it again. Ever. So let me clarify what I mean by “perfect.” It’s not the pictures where everyone’s clothes match (down to their shoes and hair bows) and the kids are swinging carefree in the air from their parents and everything is “picture” perfect.



*The tree before falling over*

I know my limitations with our 6-year-old son who has Williams Syndrome and our feisty 2-year old who thinks she’s 20. I just want ONE picture where everyone looks happy. This year, I went to Herculean efforts to try to make it happen. Even after 6 years of running through this exercise, I \*thought\* I had arranged a smooth, sensory-overload-free

photo session with Santa. As you have probably guessed, I was wrong – yet again.

We had Santa come to the house instead of dragging everyone to a studio or to an outside location. We felt that we could control the many sensory variables at home. The idea was to whisk everyone into the room with Santa at the last minute. No travel time. No elements to contend with. Just be at home in our natural environment. Our friend, who is an amazing photographer and who has photographed our son before, was all lined up. He has the patience of Job and equipment that shoots faster than a two-year-old can tear off his clothes! We bought a special toy for the kids that played their favorite song – a snow globe that played Frosty the Snowman. (BTW, we’ve been signing Frosty the Snowman since July!) We made sure everyone had on comfortable clothes, and we didn’t even bother with shoes for our son. We adjusted the temperature and lights and let the kids watch their favorite TV program while Santa and the photographer set up. And then CRASH.

I had propped up the Christmas tree with 8, 20-pound boxes of kitty litter because I couldn’t find the Christmas tree stand after we moved. It didn’t work. Ok. No big deal. I set it up again ... CRASH. We cleaned up the mess, securely tied the tree to the door, hid the rope from the camera lens, and redecorated the tree for a THIRD time.

Finally, we brought the kids in to meet Santa, and at that exact moment, our neighbor cranked up his industrial leaf blower right outside our window. My son immediately headed behind the curtains, saying, “All done, all done.” That was it – once the sensory overload kicked in, there was no turning back. But, wait, there’s more! Another CRASH. Our little girl dropped the glass snow globe.

Out of more than 2,900 pictures, we got ONE photo with both kids smiling. ONE. Our “perfect” Christmas picture. And so while the entire process of getting ONE perfect Christmas picture sent me running for a glass of wine (OK, let’s be honest, two), it was worth it. Not just for the picture, but for what happened a few days later. Our son has just started saying two to three word sentences, without being prompted. We were swimming at the YMCA (in a deserted pool), and an older gentleman walked in. He had quite the impressive white beard, which apparently was not lost on our son. He immediately screamed with delight, “It’s Santa Claus!”

My “perfect” Christmas picture just gave me the best present. ■



*Our “perfect” Christmas picture*



# Believing in Dalia

By Rebecca Cheskes

When our daughter, Dalia, was born in 2001, I dreamed of so many milestones, including her Bat Mizvah ceremony. According to Jewish tradition, children become accountable for their actions at the age of 13. We call this a Bar or Bat Mizvah, which in Hebrew means “Son/Daughter of the Commandment.”

By profession, I am a Bar/Bat Mizvah tutor so as Dalia approached 10 years old, my desire to plan a Bat Mizvah ceremony for Dalia became stronger, perhaps bordering on an obsession!

Dalia is a sweet girl who is on the autism spectrum, has sensory issues, and is nonverbal. She uses sign language and her Dynavox Maestro to communicate what she needs and, sometimes, what she thinks. While I have tutored students with various special needs over the past 17 years, I’ve never had a student quite like Dalia!

I took it as a personal mission to craft a Bat Mizvah service for her to celebrate in a way that would be meaningful for her, as well as those in attendance. I daydreamed for the better part of 4 years about what it might look like, talked to people in the Jewish community, and consulted with those who modify various life cycle events in the Christian community.

My first goal for her service, was for her to be able to “chant” the blessings before and after a selected reading from the Torah, the Jewish bible. Being called to chant these blessings is the hallmark of any Bar/Bat Mizvah ceremony, as it is the symbol of being an adult in the Jewish community. I found a Jewish special needs organization in Boston called Gateways that designed picture symbols to go along with the Torah blessings. Although it was a painstaking process, I converted them to a format that could be loaded onto her Dynavox Maestro and attached music files to each one. This way, I could teach her how to press all of the individual buttons in sequence, so that she COULD independently “chant” the Torah blessings.

From there, I tried to create a service that I felt was authentically Jewish, adding small pieces that would give Dalia the spotlight as often as possible. For one of the prayers that I sang in English, she learned to fill in the blank for some of the words, which was one of the most beautiful parts of the ceremony. It was as though she was singing along with me! I also asked 2 artistic teens in our community to design a life-sized laminated prayer book to have on an easel in the front of the synagogue. Dalia learned to turn the pages on the easel, in front of all of our guests.



She followed along with the prayers in her service in a binder, the same way my students would do.

Repetition and practice are important in Dalia’s learning, so we even did small parts of her service in front of the 3<sup>rd</sup>-7<sup>th</sup> grade students in our synagogue Sunday school for 4 months prior to her ceremony. While this enabled me to see if Dalia would actually tolerate doing the service in front of people, it also showed the Sunday school students that Dalia was smart and capable, even if she couldn’t talk to them in a traditional way! They got quite a kick out of watching her find the rabbi’s basket of candy and managing to eat a handful before I noticed! We also did dress rehearsals at one synagogue where I have worked for the past 17 years; dozens of my former and current parents came to see the service. In addition, we held a dress rehearsal at our synagogue during the week prior to her actual ceremony. The fact that she cooperated in front of people as I sang the prayers was testament to the fact that she realized the importance of this service!

I am grateful that I was able to design a service that reflected Dalia, her personality and her gifts. This would not have been possible without a wonderful rabbi, whose instructions to me were “do whatever you want, you know Dalia best.” I read often on the AAC (Assistive and Augmentative Communication) websites that the most important thing is to PRESUME COMPETENCE. So I did, and, as time went by, I started believing in Dalia.

A mother’s dream came true last President’s Day on the occasion of Dalia’s Bat Mizvah. It was such an honor to give Dalia the gift of our Jewish heritage in a way that she could enjoy it and to have our family and friends witness the beautiful service. It was truly a blessing that I will never forget. ■

# Thank You

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Mobility Works  
For a complete list of climbers & donations go to: [www.focus-ga.org/focus-climbs-kids/](http://www.focus-ga.org/focus-climbs-kids/)

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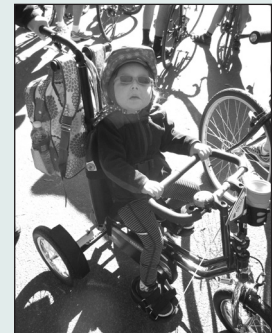
For a complete list of Models and donors, please go to: [www.focus-ga.org/how-focus-can-help-you/family-activities/fashion-show/](http://www.focus-ga.org/how-focus-can-help-you/family-activities/fashion-show/)



## FOCUS Climbs for Kids September 27

Twenty teams – a FOCUS kiddo and a FOCUS Friend – faced their fears and conquered the wall at Stone Summit! This event raised almost \$20,000 for FOCUS!!

Check out the climbers and donors at [www.focus-ga.org/focus-climbs-kids/](http://www.focus-ga.org/focus-climbs-kids/)



## Spin for Kids

TEAM FOCUS rode again!!  
So many thanks to those who rode and raised money for FOCUS programs at Camp Twin Lakes!



# Looking Back at the Fun ...

## Moms' Day Off on Lake Lanier – October 25

Thanks to Jennifer Dicello and her Mary Kay friends and to Tommy Bagwell for his beautiful houseboat for a day!



## FOCUS Day at the Georgia Aquarium September 20

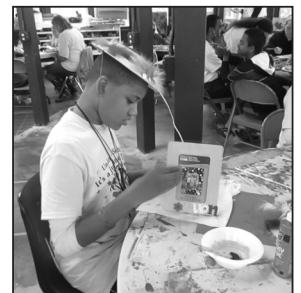
A day with the fishes!



## FOCUS Family Camp

### Under the Stars 2 – October 2-4

Thanks to the Luther & Susie Harrison Foundation, the Imlay Foundation, TEAM FOCUS in Spin for Kids, and Camp Twin Lakes for their support of Family Camp!



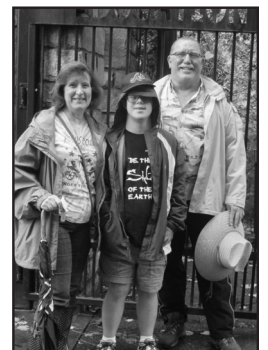
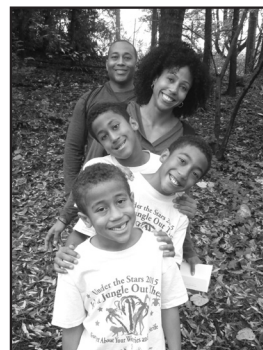
## MVP BooBQue – October 25

A fall celebration of our medically fragile kiddos!



## Zoo Day – November 7

Renamed "Rainforest Day," the weather looked formidable ... but held out for a great morning of fun with FOCUS friends at Zoo Atlanta!



## OctoberFest for Teens & Young Adults

### October 31 – November 1

A fall camp retreat – fun and adventure.

Thanks to 35 great volunteers, John & Mary Franklin Foundation, Resurgens Charitable Foundation, Triad Foundation, TEAM FOCUS in Spin for Kids, and Camp Twin Lakes.



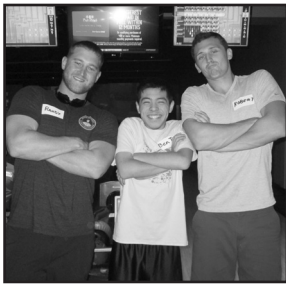
**FOCUS on Fashion – November 8**

Models, dancers, desserts, oh my!! What a fabulous afternoon! Check out all the models and donors at [www.focus-ga.org/how-focus-can-help-you/family-activities/fashion-show/](http://www.focus-ga.org/how-focus-can-help-you/family-activities/fashion-show/)



**Teen & Young Adult Activities**

Monthly gatherings with FOCUS friends. Thanks to the Mercer University Physical Therapy Department and to community volunteers who help with these activities.



**Fast Fins Swim Meet – October 24**

Eight teams, one pool, great fun! Thanks to all the awesome coaches and volunteers!



**Extra Special Saturday Respite**

Parents enjoy a few hours off, while children have fun! Thanks to all the wonderful volunteers who spend their Saturday mornings with FOCUS!



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FOCUS depends on donations from individuals, foundations and corporations to keep the cost of programs low to families. Here are a few easy ways to support FOCUS – **spread the word to friends and family!**

**Amazon Smile** – Name FOCUS as your beneficiary (listed as Families Of Children Under Stress, Inc.)

**Kroger** – Register for community awards (#37957).

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