



Comfort. Hope. Fun.

## Thankful for Olie

by Christopher Moore

I am thankful for many things today. But I'm particularly thankful for every hour of every day that I have had the opportunity to spend with Olie.

When we became aware of Olie's condition we did not know what to expect. I did, however, commit to accepting Olie for who he was, to not waste a single day with him, and to cherish every accomplishment he ever made – no matter how small. We heard it all from Olie's doctors: He won't live past 2 years old ... he will never sit up on his own ... his cognitive development will never exceed that of a one year old. Over the years, Olie kept surprising us and kept reminding us that some milestones are more important than others. At less than six months he survived his first surgery – a mandibular distraction to correct a recessed chin. This was the first time Olie was presented with the option to quit, but he struggled through a very rough 36 hours of recovery, and graced us with his beautiful smile for the first time days later.

Time after time – surgeries, hospitalizations, and ambulance rides – Olie was given the option to quit, and he always bounced back with his same exuberance. I do not have enough resources to give Olie everything he deserves. The WORLD does not have enough resources to give Olie everything he deserves. But somehow, this didn't mean anything to Olie. He still perks up every time I come home from work. He still shows off his toothy grin every time I pick him up.

What I finally came to realize is that Olie unconsciously made the same commitment



to me that I made to him. He has never blamed me for not being able to make his stomach work, or not being able to make him walk, or not being able to give him back that crucial part of his 22nd chromosome that I took for granted for much of my life. After almost every setback Olie bounced back with his same enthusiasm, charm, and love for his family and life. Never holding a grudge against me for not being able to help as much as I wish I could, or for even making him go through a procedure that we could only assume he wanted in the first place.

I doubt I'll ever meet a more perfect soul. Happy Thanksgiving, everyone! ■

*Christopher and Ashley have two children Oliver (5) and Owen (3). Olie is well-known for his extreme love of all things Mickey Mouse and his killer smile. Olie has Phelan-McDermid Syndrome and was recently diagnosed with leukemia. His family is concentrating on enjoying every moment, giving Olie and Owen even more love than ever.*



## From the Editor

by Lucy Cusick

This newsletter was so fun to put together – we mostly hear from moms but know that our dads have feelings too – they might just be less willing to share them!

We are in a time of sad good-byes and happy hellos here at FOCUS. This is the time of year when we are in and out, finishing up programs for this year, planning for next year – we might not feel the full effect until January. We hope you will send messages of love and appreciation to Elizabeth and Sonca for their years of comfort, hope, and fun! (Send to [inquiry@focus-ga.org](mailto:inquiry@focus-ga.org) and we'll forward to them!)

During this season of gratitude, take time to encourage someone. A note. A cookie. A comment. Hold a door. Smile. Our lives are crazy-busy, filled with tasks (many are truly life and death!) and chores (usually not so drastic). Take a moment and be great-full.

Hoping your holidays are filled with special memories, sweet smiles, and all things great.

### Sad Good-Byes ...

We say 'so long' to **Elizabeth Hewell** and **Sonca Pham** this month. It's tough to say goodbye to TWO staffers in one month – especially when our staff only had EIGHT to begin with!!

Most of us know Elizabeth as the Coordinator of Comfort, Hope, & Fun! She truly offered all three with hospital visits, support groups, workshops and conferences, summer camp supervision, and camp laundry queen! Elizabeth is the best party planner ever – from MVP events to Daddy Daughter Dances to staff birthday parties; she also orchestrated Climb for Kids, a tremendously successful fund raiser for FOCUS.



Elizabeth has worked for FOCUS during two seasons of her life: before her daughter Katharine's death in 2007 and after her death. Her story alone has helped numerous

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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](http://www.focus-ga.org). Annual subscriptions to the newsletter are \$25 for families (waived if necessary) and \$50 for professionals.

parents as they walked in the darkest shadows of life. Elizabeth and her husband Mark live by two simple words: No Regrets. Elizabeth is leaving to accept a position with a growing church. We will never regret the time Elizabeth shared with FOCUS and we know she will continue to touch hearts everywhere she goes.

Sonca Pham began with FOCUS as a college student at Kennesaw State University. Sonca had little experience with children with special needs when she began an internship as a summer camp



counselor, but she quickly learned that quick feet and a little love go a long way! Sonca coordinated Extra Special Saturday respite and was a favorite counselor at Camp Hollywood, Camp TEAM, and Camp Infinity. Sonca writes that “there’s no such thing as a disability, but rather one’s ability to do something differently.” She is moving on to a full-time job but will take a piece of us with her because “love is bigger than the trouble that we’ll ever see.”

... and Happy Hellos



We welcome back to FOCUS **Annie Garrett** as our Program Director! Many of you already know ‘our Annie’ from her years of volunteering (1998 to 2004) and working (2005 to 2012) at FOCUS. Annie spent the last four years as a Camp Director at Camp Twin Lakes and is now returning to manage (and grow!) the programs at FOCUS. We are thrilled to have her back! ■

**Supper & Support at CHOA**

FOCUS now offers support groups for the NICU & TICU at CHOA campuses of Scottish Rite and Egleston!! Contact joy@focus-ga.org for more information!

**What Is It Like?**

*By Dallas Crum*

**H**ey everybody! I was asked recently to answer a few questions about what it is like to be a parent of two special needs kids. I thought a lot about sharing this. Here you go.

1) What is the hardest part about being a parent of a specially-abled child? The unknown. Will my daughter be able to have a relationship and get married? Will my wife and I ever be empty nesters? Will our daughter live that long? What kind of future does my son have? Will he be able to support himself one day? Will he be accepted socially? Will our marriage make it through this? Will I make it through this? No answers. Knowing more than the doctors you see. Endless therapy, unique diets, financial strain, countless visits to every type of “specialist” and every type of doctor you can think of. IEPs. Fighting to get your child the coverage and services they need with insurance, the school system, Medicaid, doctors, therapy providers, etc...



2) What in your life makes it easier – how you relieve stress, how you cope, etc? What makes it easier? There is no “what makes it easier.” What I do have that keeps me going? Faith, Love, Hope, Alcohol (just kidding, ha ... ) I love those kids. No matter what the outcome for them and our family is, I wouldn’t trade it or who they are. This is my family.

3) If a younger couple was coming to you for advice on how to parent a specially-abled child, what would be some important advice you’d give? Well... I’m still pretty young I think, BUT... I would tell them, it’s ok to cry, it’s ok to talk about what could have been or what may never be, It’s ok to wonder how in the world you are going to take another step. I would tell them you will have doubts, you will question why, you will have unanswerable questions. You may doubt God, your faith. I wish I could end with a high five and a, “don’t worry! It will get better.” The only problem with that is that it’s bull (in my opinion!). Try not to listen to people who mean well but say things that hurt, things that cause more confusion and mixed emotions. They don’t understand ... they are saying the cliché phrases that should never be said.

I can say though: whatever the outcome, it’s worth it. Even if I don’t get to see my baby girl grow up and get married, I will never trade a moment I am blessed to spend with her. Even if my son doesn’t progress to a level that he can function independently, he is my son and he is enough, no matter who he is. ■

*Dallas is the proud dad of Ethan (4) who has mild autism and Riley (2) who has Trisomy 9 mosaic. However, Dallas and his wife Faith think they are both more adorable than specially-abled – and we agree!*

# Stark Reality – Sanity Is Relative

By Will Stark

Although I would hope that those who read my posts would have a better idea of the type of life I lead ... yet some seem to be confused.

Most 57 year olds are looking to retirement. Their kids have grown and left the house. Due to seniority many are settled in their jobs and are making a comfortable income. They are looking forward to getting up in the morning and wondering what they will do that day. They have visions of drinking their morning coffee and then jumping into the car and heading to the mountains to watch the leaves change, walking endlessly thru knick-knack shops in small towns or hopping from one fall festival to the next. They might get a lawn service or a house cleaning service so they are not held back from being free to do whatever.

When we first decided to adopt 23 years ago, we embraced the fact that we were making a life-long commitment. For most families, the future plans for their kids involve morals, wise social choices, good grades, college, independence, marriage, and grand-kids. Wow, now that's a list! With our three birth children those were our hopes, dreams, and goals. But with the adopted children we found some were not applicable and others needed to be greatly modified along with the expected goal. Our older children are grown up, with good morals, and good grades. Two pursued college and are teachers, two have children of their own, and one is living here right now helping me. But our special children, although they have grown up, are not always socially accepted, not fully independent or able to make wise choices. This means they will most likely be living with me (Lord willing) until one of us has passed on.

Seems some have the impression that my life is like being retired. I drink my coffee, ride my motorcycle, talk about the mountains, and just have fun. But my days consist of waking, bathing, dressing, medicating, feeding, socializing, entertaining, feeding, cleaning up after, keeping the peace, feeding, dressing, and putting



the kids back to bed. This is aside from the typical cleaning, laundry, dishes, sanitizing, yard work, home repair, shopping, doctors' visits, and miscellaneous errands. In all this I do (for sanity's sake) find some time to get away, even if it's just an hour every other day, to try and clear my head for the next wave.

This is not a cry of "woe is me." I knew

this was to be my life. There was no blind eye, denial, or misinterpreting our future when we started. We thought and prayed long and hard before we headed down this road. So my life is one I asked for ... and love. I love my kids. I love being Mr. Mom. I love all those who donated to make this last couple of years possible. I do not wish my life were different ... other than Cheryl still being a part of it. I am happy.

For those who have wondered about a woman in my life ... have them read this first. If they still want to meet me then have them get a doctor's note proving sanity from a psychiatrist. If they pass both of those tests they also need to love coffee. No one in their right mind would want to be a part of this at this stage of life.

I am not in my right mind ... but I love my kids and it's all I know.

I love to make people smile ... it helps me cope. ■

*This excerpt of Stark Reality is a Facebook memory from October 2014. Will has three biological children and five living children he and his wife Cheryl adopted: Melody (25), Johnathan (22), and Jacob (17), all with Down Syndrome and other conditions, and Natalie (24) and Katie (17), with other diagnoses and challenges. Will lost his best friend and wife when Cheryl died suddenly in 2011 and he became Mr. Mom and a single dad. He works at FODAC and continues to make people smile and to keep Dunkin' Donuts in business with his coffee addiction!*

# Choosing Tyler

By Aaron Campagnone

It has been almost exactly 17 years since I first met Tyler. A few weeks before Thanksgiving 1999, I got a call out of the blue from a good friend, Karyn, who I had a crush on for years. Turns out Karyn was now a single mom and had just moved back to the area.

We talked a LOT on the phone over the next few weeks and finally agreed to meet and have dinner the Monday after Thanksgiving. She had already told me her two-month old son had Down Syndrome. At that point, I didn't really know that much about Downs, but it was just dinner!

I don't remember specifics from that dinner. I know it was a Mexican restaurant, and I know it was cold because Tyler was hidden under a fluffy blanket in his car seat/carrier. What I do remember was seeing this incredibly cute, smiling, loving little baby boy. Oh, I also remember saying goodnight, giving Karyn a very platonic hug, and thinking that I was going to do everything in my power to marry that woman and be a father to that little boy! It was not "love at first sight" (at least not with Karyn J) since I had known Karyn for years at that point. But I knew that my life had changed that night.

Being an engineer and a computer geek, I spent the next few weeks alternating time between talking on the phone with Karyn and researching Down Syndrome on the internet. I didn't educate myself about Tyler to see if it was something I could handle, I did it because I had decided that I wanted to be in his life, and, just like any other parent or friend, wanted to know more about him!

The title says "Choosing Tyler," but really, he chose me! From the cute little smile he would give me when I picked him up to the "sad face" he would make when he was about to start crying, he was the one doing the choosing. Karyn and I dated for almost two years and eventually were married in 2001. We then began to seriously work on getting Tyler's biological father to allow me to adopt.

It took three years, but in 2004, I was able to adopt Tyler. In the judge's chambers, on adoption day, the judge sat me down and explained that if I agreed to the adoption, I would legally become Tyler's father. He said that if



something happened between Karyn and me, I would be legally responsible for child support for Tyler. I looked right back at him and said that I fully understood, but that would only be if I did NOT get custody! He just smiled and said that he was now sure I was aware of the importance of the proceeding, that I was making a good decision, and that I was, in his opinion, qualified to be Tyler's Father.

The last 12 years have not always been easy, but I can honestly say they have always been fulfilling. I am so blessed to have Tyler in my life and am proud when people refer to him as my son! ■

*Aaron and Karyn chose to have more children and now have three boys total! Thus far, no child support has been needed!!*

## 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](http://www.focus-ga.org) for the age requirements or email [volunteer@focus-ga.org](mailto:volunteer@focus-ga.org).

# Thank You

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 In honor of Keith Watkins & Mandy Lusk's Wedding by Gloria & John Ebert

*Thanks to ALL who donated to FOCUS Climbs for Kids and the SUPER BOWLathon! These events are successful because of YOU!*

## Save the Dates in 2017!!

### January 21

FOCUS Annual Education  
 Conference at Dunwoody  
 United Methodist Church

### February 25

For the Love of Children Gala  
 at the Thalia N. Carlos  
 Hellenic Center

# Looking Back at the Fun!



### FOCUS on Moms (August) and Mom's Day Off (October)

Two opportunities for moms to enjoy a little comfort, hope, and FUN! Thanks to First Christian Church of Atlanta, the Junior League of Atlanta, and the presenters who volunteered for FOCUS on Moms and to Tommy Bagwell for his support of Mom's Day Off!



**FOCUS Climbs for Kids** on September 18 was another fantastic event! Families, kiddos, and friends conquered their fears, faced the wall, and raised \$15,000 for FOCUS!



**OctoberFest** overnight retreat for teens and young adults – such fun! No parents!



**FOCUS Day at Zoo Atlanta** in November – A lovely day with the animals – and other FOCUS families!



Fragile Kids Foundation and FOCUS joined together for **The Super Bowl** in November. This event was right down our alley – such fun with our friends, families, and supporters! Congratulations to Katherine Lucier and Team Phantom Strikers for raising over \$1,000 for The Super Bowl!

**Brownies, Bingo, and Boogie** on Columbus Day was a fun way to spend a day off of school! Thanks to the volunteers from Aspen Insurance for helping – they are experts at the Chicken Dance!



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

was another weekend of champions, Olympic style! Families enjoyed the first cool weekend with arts & crafts, archery, boating, climbing wall, and hanging out with the FOCUS families.

*(Continued on page 8)*

**Looking Back at the Fun!**

*(Continued from page 7)*



**MVP BooBQue,** hosted by the Knights of Columbus and Holy Cross Catholic Church was a bootiful day with lunch, games, and music therapy for our medically fragile children and their families.



**FAST FINS Swim Meet**  
in October – eight teams, one pool, great fun!

**Ongoing at FOCUS**

**MVP Events for Medically Fragile Families**

For more information, email [joy@focus-ga.org](mailto:joy@focus-ga.org)

**Teen/Young Adult Activities for ages 13 to 29**

Please email [brian@focus-ga.org](mailto: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](mailto:lucy@focus-ga.org) if you want to get involved at FOCUS but can't figure out how to start!!

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