



## The Lessons of Hannah

by Maggie Garrett

I have been surrounded by children with special needs my entire life, even from the day I was born. My cousin Hannah, born just four months before me, had a rare genetic disorder called Cornelia de Lange Syndrome, responsible for her signature small stature, joyfully over-arching eyebrows, and cute little button nose. The day she was born, our family was told that she wouldn't live past the first night, but Hannah, being the resilient girl that she was, proved the doctors wrong. She grew up to be a miraculous young lady who danced to her own music every second of the day. Hannah taught me so much about life and helping others, lessons that I would never have learned from anybody else. She also helped me discover my passion for working with children with special needs.

I find comfort in those who listen to my heart, not necessarily my words. In elementary school, I found one of my best friends who happened to be on the spectrum. We grew to be really close, to the point where others began recognizing our special bond. My music teacher, the music therapist for Camp Hollywood at the time, noticed my relationship with my friend and recommended that I volunteer at Camp Hollywood with her over the summer. I was really too young, but I loved camp from the very beginning! That's how I came to know about FOCUS.

While I loved volunteering, as I grew older, I was content with my Hannah Banana and I spent a lot of time with her. But I had to learn something: the love I had for her could be shared with others, too. In June of 2014, just three days before her seventeenth birthday, Hannah went to be with the angels. Although I

was heartbroken, I knew that I needed to share her love and keep her legacy alive, so I decided to get involved with FOCUS again this summer.



*Maggie and her cousin Hannah*

On my first day at camp, I was given a very special gift. As we led all the campers to their groups, I saw a familiar face. I knew I had seen him before, but I just couldn't put my finger on it. It finally hit me – I was seeing somebody else I knew very well: Hannah. My new little friend reminded me so much of Hannah: the same small stature, adorable eyebrows, and cute little button nose. Volunteers aren't allowed to know the medical diagnoses of campers, but it didn't matter, I was hooked! Before one of our activities, he was running around like the wild thing that he is, so I plopped myself down by the door to hold the fort down. Before I knew it, I had a little wild thing sitting in my lap. He looked up at me and gave me the biggest grin and I smiled right back. It's cheesy to say, but I think in that moment time froze. Moments later, he sprung out of my lap and continued to roam the gym, as if nothing had happened. That's when I remembered Hannah's favorite song. Whenever anyone sang "Head, Shoulders, Knees, and Toes," Hannah would absolutely lose herself in laughter and beg for you to sing it again and again. I decided to give it a shot with Christopher. Before the first line had even left my lips, he was back in my lap touching his head, his shoulders, his knees, and his toes as I sang each one. He showed me that same enormous grin that I had seen just moments before and he was gone again. Over the following couple

*(Continued on page 5)*

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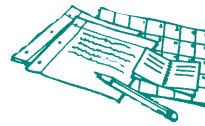
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**MISSION STATEMENT**

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 \$15 for families (waived if necessary) and \$30 for professionals.

**From the Editor***by Lucy Cusick*

"Summertime ... and the livin' is easy." Hmm. Whoever wrote that song wasn't the parent of a child with special needs! Our kiddos are out of school for the summer – and, while we love our kids to the moon and back, our kids often are easier when they have the structure that school provides. Each summer, the FOCUS phone rings relentlessly on the first day of summer, with parents asking about any openings at day camp!

FOCUS offers 11 weeks of day camp – a week of for parents to drop off the kids, knowing they will be safe for a few hours, hey, maybe they'll even have fun! The FOCUS staff is all over metro Atlanta – setting up in the wee hours of Monday; welcoming campers, counselors, and volunteers; making sure activities run smoothly; comforting campers who miss their mommies on Monday and comforting campers who are sad camp is over on Friday; re-packing camp and moving to a new location the next week. We do this for 6 weeks – pack, haul, unpack, enjoy camp, repeat.

It's so fun to be with your kids: sing, dance, cook, paint, eat lunch, and just enjoy them. Some kiddos are tougher than others; some parents have expectations that are greater than we can deliver; some weeks are more challenging than others. But at the end of summer, we are ready to celebrate, knowing we made summertime a little easier for the parents of over 300 kids.

*Join us on August 15 for SummerFest at Monday Night Brewing and raise a glass to FOCUS camps! Purchase your tickets at [www.focus-ga.org](http://www.focus-ga.org). ■*

**Upcoming Activities**

**Under the Stars Family Camps\***  
**August 7 – 9 at Camp Twin Lakes Rutledge**  
**October 2 – 4 at Camp Twin Lakes Will-A-Way**

\*Registration information was emailed in April. Some space still available, email [brian@focus-ga.org](mailto:brian@focus-ga.org) for information.

**FOCUS on Moms**  
**August 22, 2015**  
**At First Christian Atlanta**  
**4532 Lavista Rd, Tucker 30084**

Join FOCUS for a time of comfort, hope, fun, and chocolate! Watch for the email to register or contact [elizabeth@focus-ga.org](mailto:elizabeth@focus-ga.org) with questions!

**FOCUS Day at the Georgia Aquarium**  
**September 20, 2015**



Watch for an email from FOCUS on July 10 with the details about FOCUS Day at the Georgia Aquarium. Please let us know right away if you need a paper application mailed to you. Tickets are \$20 each and include admission to the aquarium, a brunch in the Oceans Ballroom, and parking.

FOCUS has 700 tickets, which is not enough tickets for everyone in FOCUS. As in past years, we will give preference to families who have never been to FOCUS Aquarium Day. Of course, you can always apply, but don't be mad if we don't have enough tickets!

*Watch for the email and follow the directions. If you have questions, call or email [joy@focus-ga.org](mailto:joy@focus-ga.org).*

## What We Are Is ... Sad ...

So ... goodbye is pretty hard to say, even when it should be a happy goodbye. Like most of the staff at FOCUS, Karen Greenfield first found FOCUS as a parent of a child with special needs. She and Bill moved to Atlanta with 13-year-old Katie and 10-year-old Kyle back in 1998. Bill traveled each week and Karen kept the home-fires burning, busy with two children, one with Sanfilippo Syndrome and many medical needs. Karen first attended Share Groups in Alpharetta – where we shared resources (the Internet was just making it to every house so you actually had to talk to other parents to find information!), drank lots of coffee, and cried and laughed (mostly) about our lives.

In August 2000, Karen registered Kyle for a week of Camp Hollywood and offered to lead the art activity. She already knew that our kiddos considered complicated art projects to be therapy, slapping on a little paint and being 'done!' She knew how to modify activities so they were easier and more fun!

In April 2001, Kyle died unexpectedly in his sleep and Karen and Bill embarked on a new journey as bereaved parents. Karen continued to stay in touch with FOCUS, as she found that helping other parents helped keep a connection with Kyle. She joined the FOCUS staff in August 2003 to coordinate respite and day camps. As all the FOCUS staff, she was cross-trained in all programs and was always willing to help at all FOCUS programs – she even donned a swimsuit and helped at FAST Fins!

Over the next 10 years, Extra Special Saturday grew from three to six locations each month. Camp Hollywood expanded from three locations to ten each summer. Karen fine-tuned a formula for day camp that is replicable and portable so we could offer a week of fun to children all over metro Atlanta. Karen rarely missed a beat, making sure that the children were always safe while in our care.

Karen (and Bill!) also loved helping at Teen and Young Adult events – monthly social outings, Camp Infinity, and OctoberFest. Karen always had a camera handy, quickly earning yet another duty of photographing most events. She then would spend hours editing and organizing the photos. Karen went the extra mile, from volunteering at fund raisers to helping with the ever-growing technology struggles of a small nonprofit.

Most importantly, though, Karen loved our kids – she worked hard to accept all kids, especially those with challenging behaviors. As a parent, she had been told

'no' and knew how hard it was to have 'that kid' who was too active and too difficult to include at a program.

So, we will all miss Karen, or "KG," for her dry wit and her big heart. She loved being 'in the trenches' with our kids, loving them for who they are and what they CAN do; she always allowed our kids time to just be kids; and she always knew to keep her toes out of the way of wheelchairs!



At Camp Hollywood, we close with a song called What-I-Am by Will.I.Am. It's the perfect song for how Karen loved our kids – and how much we will miss her:

*If what I am is what's in me  
Then I'll stay strong – that's who I'll be  
And I will always be the best "me" that I can be.  
There's only one me, I am it, have a dream I'll follow it  
It's up to me to try.  
Oh! I'm a keep my head up high  
Keep on reaching high, never gonna quit  
I'll be getting stronger.  
And nothing's gonna bring me down (no!)  
Never gonna stop, gotta go (go!).  
Because I know I'll keep getting stronger.*

*What I am is Thoughtful  
What I am is Musical  
What I am is Smart  
What I am is Brave  
What I am is Helpful  
What I am is Special*

So, what we are is Sad, as our very special KG retires. Florida now has a little more sunshine and a big piece of our hearts.

Just one of the many sweet notes we received when parents learned Karen planned to retire: *You met our little one when she was just a small chocolate drop and it was my first time dropping her off at respite. You greeted me with such a huge smile and asked me my name. You looked at your list and said "This must be Miss Miracle. Welcome to respite." At that time Miracle was in a Kid Kart and I was holding on tight to the handle but then something happened. Miracle smiled at you and I let her go. You have always remembered her name whenever we are at a FOCUS function and that goes a long way with me. We will miss you terribly and want you to know that Florida has some great weather and you deserve some extra sunshine. Love, Tameche, Miracle and Paul* ■



# Nine Ways to Be a Good Friend to Moms with Kids in the Hospital

By Marjan Holbrook

I've spent some miserable days at a children's hospital with my daughter, but thanks to amazing people, I also have warm memories from those days. Here's a guide to help you become a friend to a mom who's going to be spending nights tossing and turning on an uncomfortable sofa/bed-thing in a chilly hospital room.

**1. Don't assume someone else is going to do it.** The saddest memory I carry is my husband, stepson, and I watching my daughter almost die in the PICU with no one else there. Those were the worst days of our lives, yet everyone assumed someone else was taking care of us. My family does not live in this state, and it took a few days to get flights and other things in order.

As soon as word got out we were alone, people surrounded us with non-stop support and love. Every person who came said, "I'm sorry, I thought so-and-so would be here." Don't assume someone's church, synagogue, or in-laws are taking care of them. Take action because you may be the only one. The first person who came to see my daughter at the hospital was not anyone related to us; it was her bus driver.

**2. Tell them it's OK to ask for what they need.** I used to say you don't have to bring anything, but then I realized they'll bring something anyway. During one of our stays at the hospital, my friend, Heather, called me and asked me what I wanted. I said, "Nothing, thank you." After I got off the phone, I thought I might as well tell her what I wanted. I wanted miso soup, the cheap powder type that you mix with a cup of hot water, the perfect PICU pick-me-up. She brought me miso soup. It's been years since I've seen Heather, but to this day, every time I eat a bowl of Miso soup, I say, "Thank you, Heather, for the miso soup."

**3. Take care of the "other kid."** When moms are in the hospital with a sick child, they need to figure out what to do with their kids who aren't in the hospital. Don't wait for moms to ask if you can help take care of their other children. I can concentrate on the child who is hospitalized when I know my other child is having a good time with friends. You can also help out by dropping off a few things to keep the other child busy.

**4. Feed them.** Our hospital is Children's Healthcare of Atlanta. The food is surprisingly good, and more importantly, they serve Starbucks in the lobby. However, it's so nice to get food from the outside. Consider bringing healthy snacks or smaller meals. When I was on

bed rest during pregnancy and several times while my daughter was hospitalized, my mother cooked my favorite Persian dishes. We would all sit down and eat as a family in the hospital. I remember overhearing two nurses talking and one saying our family is awesome. It made me feel so good to know that even though my child has so much going against her, what people see is that she has a family who loves her.

**5. Be yourself and tell them a good story.** During one of our stays, my sweet friend, Nilu, came with dinner from one of her favorite trendy restaurants. We sat on the couch/bed-thing, ate, and talked about the ending of her previous relationship and her super sexy boots. We cried and laughed together. After she left, I cried once more thinking of the unfairness of someone as good as her ever being treated badly and the unfairness of me having to wear my ugly (yet comfortable) CrossFit shoes instead of those super sexy boots. I was startled when one of my daughter's monitors started beeping (oh, that awful beeping), but felt peace come over me. You see, my friend's heartache and sexy boots gave me a break from the reality of being in the hospital. Yes, I want you to care about me, but please allow me to care for you too.

**6. Unless you are a medical doctor,** refrain from giving medical advice or questioning the parent's judgment. I have friends who are doctors and I rely on them to educate me. I have some other friends who are not doctors but come to the hospital and say things like, "Did you really need to take her to the ER? It's just a growth spurt, right? Maybe it's because she is allergic to gluten." My response is, "Thank you, I will look into that." What I'm thinking: Is this chick for real? My daughter is 9 years old; she was diagnosed with CP and mitochondrial disease at age 2. That means I've been Googling this for seven years. So please, non-doctor friend, stop with the medical advice and judgment.

**7. Once they are home, give them space.** Visitors in the hospital are great. Being in a hospital with your child can get boring and sharing the TV with your kid means no reruns of "Sex and the City." Visitors break up the day and make you feel like a part of the world. When you come home from the hospital, you need time and space to enjoy your bed, your pantry and

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# She's Going to Be Like Me

By Hillary Key

"Why are you so upset?" Bennett asked, looking back and forth from Jeff's face to mine. "I thought you were going to say you had a miscarriage."

Jeff and I looked at each other, then he broke the silence. "Bennett, you always know what to say, buddy."

But we were upset. How could we explain our obvious pained expressions to our son? How would we explain that we were crushed by the news we had received hours earlier? The perinatologist had said it while looking at my ultrasound during a checkup – "I don't like what I see."



*Bennett, now 15, and Lacey, now 2, modeled in the 2014 FOCUS on Fashion Show, stealing the show with their big smiles!*

And there it was, up on screen. Bennett's baby sister had a brain malformation, the same as his – Joubert Syndrome. Joubert Syndrome again.

We had been on this journey for nearly 13 years. The realities of it had not just reached out and struck us from an ultrasound, they were strangling us. How would I explain our pain without affecting how he sees himself?

No one is perfect, but in our biased estimation, Bennett is pretty close. He loves big. He loves God though he is wise enough to question. He loves people without limit, never judging them, though he is keenly aware of misgivings. And at 12, he had braved challenges that would topple most men.

So, Bennett, fresh off the school bus, still in his power chair, was staring up at me, waiting for an answer to his question. I grabbed a stool and sat in front of him. How would I hold myself together? I knew better than to think I could, so I said a quick prayer, and started with what he already knew. It went something like this.

"You know how you are awesome and that you make our day every day? And that you are a joy to us, and we love you so very much? Do you remember how we have told you about the problems you had breathing as a baby? And you

understand the challenges that can come with JS. We are not upset about who she is. We love her already. We are upset about her medically. Does that make sense?"

Thankfully it did, I imagine it made sense to him in a deeper way than we will ever understand. He had that pensive look on his face he gets when he is processing something important. So I went into the family room to do something – what, I don't remember. I was in a fog that would take some time to come out of. After a moment, Bennett followed.

"I'm not upset," he said.

"Ok. Why not?"

"Because she's going to be like me."

She was, in fact, an answer to Bennett's prayers. He had prayed persistently for a sibling. Later during my pregnancy, he would add to a pre-meal blessing, "And God, heal the baby with an awesome life."

So we decided to be like Bennett, and pray for God to heal the baby with an awesome life. We knew, that no matter what, she would be awesome. We just wanted her to breathe, to live, and to know how much we love her. ■

## *The Lessons of Hannah*

*(Continued from page 1)*

of days, Christopher and I enjoyed games, swimming, and dancing like there was no tomorrow.

I wholeheartedly believe that everything happens for a reason. For a while, I was completely lost as to why Hannah had been taken from us, but something came to light this summer. I was forced to realize that the love I have for her can be spread to others even when she's not here to spread that love herself. The gift she illuminated in me will continue to help others. Meeting Christopher and volunteering with FOCUS have been truly humbling experiences that made me realize why I'm here. Working with children with special needs will always be a passion, and I realize, now more than ever, that I am willing and able to continue spreading the love that was first shared with me through Hannah Ashley. ■



*Maggie and Christopher*

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Smith – and son Trevor –  
and all the sponsors, golfers,  
and donors for supporting  
our annual golf tournament  
on May 12!



## Nine Ways to Be a Good Friend

(Continued from page 4)

your shower, and to shave your legs. Sometimes our kids come home with new medical devices, and we need time to adjust to our new normal. Meals are great, but I often dread having to get out of my pajamas or entertain a friend who's dropping off a meal. I'm thankful, really thankful, but please let me figure out the date before a long visit.

**8. When it comes to helping, think outside the box.** Twelve years ago, my husband and I were married at a small church in Pennsylvania. Once, after an emergency surgery, I was too weak to sit up and eat, and one of the older church members happened to be visiting someone else. She came in the room and spoon-fed me. Another member came to my house after my emergency C-section and cleaned and organized my entire kitchen. No one waited for someone else to send them directions on how to serve others; they just did it.

**9. Know that it does take more effort to keep a friend who's a "hospital mom."** I've missed out on being friends with some pretty cool people because they couldn't stay in a relationship with someone who might not call them back for hours or days (OK, sometimes months). It doesn't surprise me that the women who've stayed in my life are the strong ones who want to raise others up. ■

# Looking Back ...

## 007 Dance for Teens & Young Adults



Thanks to Hayley Tucker and the Lovett School for their support of the first ever Teen & Young Adult 007 Dance in April! Lovett Seniors choose a project the spring of their senior year – and Hayley chose FOCUS!! Teens & Young Adults danced for hours, taking quick breaks for yummy snacks before hitting the dance floor again! Thanks to the Haley and the volunteers from Lovett for making this evening an event to remember!



## Six Flags Day

May 3 was sunny and pleasant, perfect for almost 900 FOCUS peeps to enjoy FOCUS Six Flags Day! Everyone reported thrills, chills, and no spills – thanks to Coca-Cola, the Cox Foundation, and FOCUS fund raisers for supporting this annual event!



## Lego Land for FOCUS MVPs

Kiddos who are medically fragile need smaller crowds to decrease the chance of catching colds and other creeping crud. In May, FOCUS MVPs enjoyed a Sunday morning in Lego Land at Phipps Plaza.

## Camp TEAM (Together Everyone Achieves More)



Mercer University in Atlanta once again allowed FOCUS Camp TEAM to enjoy a week of camp on their beautiful campus! Campers had a blast – swimming, golfing, playing tennis, dancing to Lil' Vibes, and playing soccer with the Atlanta Silverbacks!!



## Teen & Young Adult Fun

FOCUS teens and young adults gather monthly for social activities – baseball, dance parties, and drum circles, oh my! For more info, email [brian@focus-ga.org](mailto:brian@focus-ga.org)



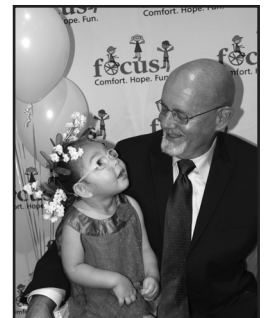
## FAST Fins Spring Meet

All 8 FOCUS FAST Fins teams showed off their form at the spring meet at Mountain View Aquatic Center in Marietta. Thanks to all the coaches and volunteers who make swim team a ... swimming ... success!!



## Daddy-Daughter Dance & Dessert

FOCUS girls and their favorite dudes enjoyed a royal ball, fit for princesses!! DJ Tony Washington played everyone's favorite songs – many thanks to Mt. Bethel UMC for opening their doors to FOCUS for this annual event.



## Fund Raising at FOCUS

Like it or not, fund raising is a part of every nonprofit. While FOCUS does have fees for some programs, here are some basic facts about fund raising at FOCUS:

Fees charged at FOCUS do NOT cover the cost of the event:

- Tickets for FOCUS Aquarium Day cost FOCUS \$55 each. Parents pay \$20 each. FOCUS fund raisers cover the additional \$30. Multiply that by 700 and you have the amount we pay the Aquarium each year!
- Camp Hollywood costs \$350 per camper. The most parents pay is \$150 per camper; some parents qualify for more scholarships. FOCUS Fund Raisers and grants cover the remaining \$200 (or more, depending on the level of scholarship).
- FOCUS on Moms, Share Groups, MVP Events are all FREE! FOCUS covers the cost so parents can enjoy the FUN!!

So, you get the idea – FOCUS has to write grants and raise money to keep FOCUS programs affordable. Here are three events you can help us with!

**Saturday, August 15, 2015**  
**6<sup>th</sup> Annual SummerFest**  
**at Monday Night Brewing**  
**670 Trabert Avenue, NW, Atlanta 30318**

Cheers to another great summer of FOCUS Camps! Enjoy Willy’s Mexicana Grill food truck, music, cornhole tournament, and free brewery tastings and tours. And, no whining, we’ll have wine, too! Go to [www.focus-ga.org](http://www.focus-ga.org) to purchase a ticket.

**Sunday, September 27, 2015**  
**FOCUS Climbs for Kids**  
**Stone Summit Climbing & Fitness Center**  
**3701 Presidential Parkway, Atlanta 30340**

TEAMS NOW FORMING! FOCUS kiddos of all ages and abilities climb with a FOCUS friend or volunteer from the community. Catalyst Sports will be on hand to assist all abilities! Email [elizabeth@focus-ga.org](mailto:elizabeth@focus-ga.org).

**Sunday, October 18, 2015**  
**Spin for Kids – Cycle for TEAM FOCUS**

The money TEAM FOCUS raises in Spin for Kids supports the programs FOCUS offers at Camp Twin Lakes! Email [lucy@focus-ga.org](mailto:lucy@focus-ga.org).

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