



## Never Give Up

by Maddy Stanley

First of all, I'm not looking for any sympathy whatsoever, this is what I want people to understand about me. I was born with a neurological disability that affects the left side of my body. It is called schizencephaly. Most people have never heard of it because it's a very rare disorder. However there's a similar disorder called Cerebral Palsy. I just say that I have that because it's more common. When I was one year old, I had a brain scan. My doctor told my mom and dad that I would not be able to walk or talk at all. Just imagine if you got the news that your child would never walk or talk! It was devastating to my parents.

The odds really were stacked up against me, and it was going to be a hard, long, tough battle to fight. But, look at me now! After years and years of physical, speech and occupational therapy, I am talking, walking, and using the left side of my body the best I can. I always used to (and still say) to myself, don't give up because you are halfway through this battle. In addition to being self-motivated, I have many supporters like my family and friends. They all make me want to be the best that I possibly can!

Everybody learns how to walk at an early age. For some it comes so naturally, but for those few like me it doesn't. My disability made everyday things much harder than they should be. Going from the doctor saying that I couldn't walk, to learning to walk, was a great accomplishment at two years old. I didn't walk the way all the other kids walked, but I was fine with that. I was just thankful that I could!

Because I didn't give up, I, I swim with the Georgia Blaze Paralympics swim team and danced in my high school's talent show. The Paralympics swim team is a big deal. If I

continue to work hard and not give up, I could go to the Paralympics! I have to go to swim practice and work really hard at it. It is the same with dancing in my high school talent show. I had to work hard. I'm a hip-hop dancer and I wanted to try out for the talent show. My parents said I would not make it. I worked hard and did not give up at all. I made the talent show, and I realized that having a positive attitude and not giving up would open many doors!



Talking also did not come to me very easily at all, so my parents taught me sign language at an early age. When I was still hungry I was able to do the sign for more and thank you. Then I started to take speech therapy which was helpful. Even though it's still a little hard to talk, I am doing the best I can. I'm just thankful for the time and effort that my parents and therapists put into helping me with my talking. My parents say to me, "You talk too much," or, "Stop talking." My friends even joke around saying, "You are going talk our ears off." I knew it would not be easy to pronounce some of the words and sounds, but just look at how much I have accomplished! I'm not giving up anytime soon. I will continue to do the best I can.

I had to overcome many things and always will say, "Never give up." People may doubt you, but if you doubt yourself, you most likely will give up. My whole life I've been working hard to overcome my challenges. I proved my doctor wrong. I am not only walking and talking but I am swimming, dancing, and not shutting up! Keep pushing on – it's worth it – trust me. If I can do all these things, you can too! I'm not giving up anytime soon because I am willing to push myself the extra mile to get where I need to go. Wherever that is, I will be successful and proud of all my hard work. ■

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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*

Spring always brings new families to FOCUS – between the annual education conference, adapted swim team, and the promise of Six Flags Day and summer camp, the phone starts ringing around February 1 and doesn't really stop until ... well, until around December!! So, the office is really bustling right now – planning camp activities, advertising for volunteers, preparing for the onslaught of mail ... and getting ready for our annual dinner, dance, and silent auction! Never a dull moment in the life of a nonprofit!

Planning FOCUS activities can be tricky – we reach 3,000 families – and every family has an 'expectation.' And, guess what? Not every expectation is the same!! So, our best program keeps a child safe and as entertained as possible! We strive to do 'better,' but, at the end of the day, we want every child to be safe and sound when parents return!!

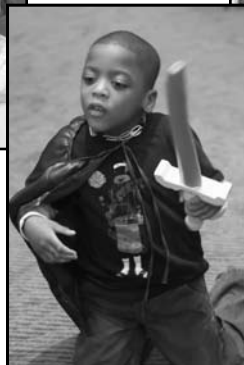
When my Josh was young, I was the pickiest of parents. If I didn't like the care he received, I just wouldn't take him back; It took me a long time to realize that Josh also needed to learn to NOT be waited on the moment he decided he needed something. Waiting is a lesson learned by all children – and because he was my only child, he didn't have to wait much at home. Just because he was the center of my world didn't mean he was the center of the universe!!!

Learning patience, asking for help, and watching the activity around you are all good skills to living real life. Josh learned to wait his turn, to watch his friends for a cue about how to act (or react), and to just plain not get every single thing he wanted! I'm not sure who had to be taught – me or him. Regardless, the lesson was learned and he (and I) enjoyed many opportunities together (and apart!).

Happy Summer Planning, FOCUS families!! We hope to see you out and about! ■

**Looking Back ...****MVP Valentine's Party**

Over 125 children and families enjoyed the 6<sup>th</sup> annual MVP Valentine Party at the Greek Orthodox Cathedral on February 5. Children enjoyed dress-up, arts and crafts, photos and autographs with princesses from Fleetwood Dance Theater and superheroes from Hero Alliance, and entertainment by Atlanta's own Queen Glitter. A special thanks to the Greek Orthodox Cathedral for the use of the beautiful church, to the Philoptochos Ladies Auxiliary for providing the delicious desserts, to Marie Reynolds for her face-painting ability, and to Natalie Howell for her photography talent.



## Turn the Nightmare of Family Game Night into a Sweet Dream

by Celia Lawton

Family Game Night has always been an extremely painful experience for my family – my husband, twin boys with autism, and me. When my kids were very young, they had absolutely no interest in playing games. They preferred, instead, to perseverate on letters and numbers, draw pictures on our walls, and generally run amuck throughout our house.



As their cognitive and reasoning abilities strengthened with age, they still did not like games for a variety of different reasons including: the inability to stay on task for the entire length of the game, as well as the inevitable meltdown that would occur when either one of them would lose. In the midst of these meltdowns, my husband and I would race to the TV in search of a video that might distract the losing child, overcome the meltdown, and generally reduce the amount of interaction that any of us might have to have with each other.

But one day, a special needs teacher at school introduced my kids to a game called Sleeping Queens. I am not affiliated with this game in any way, nor do I get any benefit from sharing it with you other than the hope that your kids might enjoy playing it as much as mine have over the years.

The rules of the game are easy to follow. That's because a six-year old girl thought of the concept one night when she could not fall asleep. There are several queens in the deck that are asleep and must be awakened. The most common way to wake them is to discard matching pairs of number cards, or to discard number cards that form simple math equations ( $1+2=3$ ). Once a queen has been awakened, the player gets to keep that queen. But beware, there are a variety of special cards mixed in the deck such as Kings, Dragons, Knights, and Potions that wake, protect, steal, and "re-sleep" the queens, respectively! The first player to collect a pre-determined number of queens (or a pre-determined number of points associated with the queens) is the winner.

The cards in this game are very engaging, which is the main reason why my kids enjoy playing it. After all, who wouldn't like a Tie-Dye King, a Cookie King, or a Pancake Queen? And here's another reason why this game is so popular in my household – it only takes about 15 minutes to play it from start to finish. So children, in general, are able to stay interested throughout. Finally, as a parent, I found that I could improve the odds of a child's winning through the cards that I selected to play, which often thwarted many a meltdown that might have occurred. Nevertheless, don't be mistaken that Sleeping Queens appeals only to the very young. There are numerous scenarios that occur throughout the game to make it interesting and challenging for players of any age.

So if the thought of family game night leaves you tossing and turning in bed at night, give Sleeping Queens a try. And maybe, just maybe, your family will fall under its sweet spell! (For more information, visit [www.gamewright.com](http://www.gamewright.com).) ■

## Looking Back ...

### FOCUS Education Conference

FOCUS families enjoyed another day of information, networking, and laughter at the 25<sup>th</sup> annual FOCUS Education Conference. Keynote speakers Julie Tennant and Derrick Tennant shared their story and their life slogan "I Love My Life!" Workshops on IEPs, Wills & Trusts, SSI, Managing Behavior, Grief, Marriage, Siblings and Quick, Healthy Meals were all popular! Thanks to Dunwoody United Methodist Church for hosting us, Chick-fil-A for donating lunch, the Backdraft Quartet of the Stone Mountain Chorus for entertaining us, and all the speakers and exhibitors for giving us their time.





# My Heart Flip Flops

by Cindy Lutenbacher

*FOCUS mom Cindy Lutenbacher is a college teacher and single-mom of two daughters through adoption. We'd like to share some tender excerpts of Cindy's yet-to-be-published book about Nikki, who has special needs, and her older sister, Rocio.*

Dear Nikki,

When I think of you as a tiny one, a rookie to this world, it's hard for me to know how much fun you were having. It's hard to remember the delights of your days, for the terrors of your nights were so profound. I remember that you loved the indoor swing ... Rocio holding and snuggling you in the corner of the couch ... and music. I suppose that anyone reading these words could easily see you as pretty doggoned ordinary. Not ordinary to me, for my heart flipped and flopped and wrapped itself around your black eyes and your throaty squawks and your fiddle-fern puffs of hair and your sweet-salty smell that fills my nose even now as I type these fragrance-free words.

But it's your nights that I recall most vividly, for they were all but unbearable. Beginning at about 7:30 p.m., you cried. You cried. You cried. And it seemed that nothing could truly comfort, console. I remember rocking you in Grandma Sis' rocker... buckling you in your car seat and setting you atop the dryer. I tried music. I tried the tummy upset meds that the pediatrician prescribed. I tried everything that anyone, anywhere, suggested. Nothing worked with any consistency. Nothing. Those three months, I don't know how you survived. Or me, either. I remember driving to Morehouse those days, with a mantra as companion: stay on the road, stay on the road, stay on the road.

But mostly, I remember feeling helpless before your sorrow or your pain. I could not find the way to ease your suffering, but, no matter what, I would be with you in your agony. I would simply be there with you. Toward the end of October, perhaps you heard me, and we both began to minutely inch our way toward sleep. Or perhaps I had nothing at all to do with your eventual tiptoe toward the land of Nod.

You're still a lousy sleeper. And I still don't know if who I am or what I am is the mother you need. But I keep trying to listen and learn. You're one heck of a teacher, kiddo.

All my love, always,  
Mom

Dear Nik,

Today, my heart is remembering you six years ago, when you were fifteen months old. I am surprised by the pain therein, for I thought these astounding six years had healed it all. Six years ago at just this time, Ruby, your amazing and gifted teacher in the baby room at the child development center asked me to come have a private talk.

I had known that your developmental itinerary was different from Sissa's, with her whippersnapper dispatch. Certain milestones were lurking, such as the fact that at six months, you could not hold up your head while on the floor. Your range of sounds produced seemed really limited. But I was determined not to compare you to Sissa. I wanted you to have your own timetable, your own gifts, your own life.

Whew, buddy, was I right. And also wrong, for that determination kept me in denial.

"Something's going on, Cindy," she said, and held my hand. We held each other and cried together. My denial had burst, and fear for you took its place in my heart. But that fear was only born of love, my sweetheart, for I only wanted then and still want now for you to grow and have a life of purpose and joy. Anything else is gravy.

All my love, always,  
Mom

Dear Nikki,

Today, I find that I am wishing for you courage. Courage to hold onto yourself with all your might. Courage to just be you, no matter how "lame" anyone thinks is your love of books or your efforts to sing or your delight in dogs or the difficulties you have in grabbing hold of conceptual and logical matters. Every scrap of you, every flyspeck of you, every quirk and quark is magnificent. Don't you ever, ever forget it.

It seems to me that too many folks want to make us be something other than what we are. I know I did, when I first began to take in the reality that you were having to struggle extra hard to learn things. My sweetheart, I'd be lying if I said otherwise. That autumn, I wanted with all my soul for your abilities to be "normal." I wanted you to be not who you are.

I remember those first few weeks after Ruby and I talked... as a numb fog, for my fear for you and for your future was so great. I was dazed and frightened, utterly adrift and devoid of knowledge about whatever was going on for you. Trying to wrap my brain and heart around your needs was completely unfamiliar terrain for me.

I only began to arise after a chance conversation with a friend in the parking lot at the GSU child development center. Her older son has cerebral palsy, and she told me of Babies Can't Wait... Thus began a couple of years of testing and terror. Babies Can't Wait did its own basic "milestones"



type testing and qualified you for therapies – speech, occupational, and physical. I studied milestone chart after milestone chart to try to figure out where you were. I kept copious notes... and made vast lists of ideas of activities to do to help you develop. I began a journey that most parents of children with special needs know all too well because keeping track of everything is vital ... and nearly impossible for most of us. Hiking the special needs paper trail is a full-time job. I learned about the demands of the blessing-curse Katie Beckett waiver, which requires us to document everything from the make and year of my car to the dates and data of every evaluation and test...

I think I was insane with it all. I knew that the earliest years would be the best ones to try to help you along, and I was afraid to waste them. I was also just one little person, trying to be fair to Ro in terms of mother-energy, trying to hold onto a job I loved amid the dementia of tenure-track demands. I was so afraid for you, and I still hear that trepid voice, even now, sliding unbidden and unwelcome into my thoughts. I was forty-seven when you were born. When you're forty-seven, I'll be ninety-four, or dead. What if you can't make it on your own? What will happen to you, then?

I love you, Nik. And because I do, I will give that Fear a name, so that I can give it a good talking to every now and again of a Friday morning. Let's call her Gertrude.

Love with all my heart,  
Mom

*[Cindy has dinner with a friend, Junee, whom she had not seen in more than twenty-five years].*

June: "Cindy, did you know Nikki had special needs when you adopted her?"

Cindy: "No. If I had known, I would have said no. And that would have been a huge mistake. I would have been afraid that I wasn't up to it. But – and the cards are still out on whether or not I'm the good thing for Nikki – I know that she's right for me. My life is unbearably so much more than it ever could have been without her."

And we drank to that.

Dear Ro,

I am so grateful for your honest answer to my question about whether you feel that I love you less since Nikki joined the family. Your honesty can make a great difference in you and me being able to better work things out between us. Thanks, babe.

I love you so much that I can't even hold in my brain the thought of how much. (I know, I know... considering my brain, that may not be saying all that much, but it's the best I've got...)

I really hate it that there's ever been even a moment when you may have felt less loved or that I love Nikki more. I may not know much, but of two things I am absolutely certain: that I love each of you with everything I am, and that I love each of you equally with each other.

All I can think of right now is to keep working toward having more time with just you...to keep working to help you and Nikki be okay and loving with each other...to keep working so that you and Nikki have what you need inside your hearts and inside your minds to be able to be fully alive in this world. And I pray that these things are enough.

I love you, my dearest Ro.  
Mom

Dear Nik,

Your [early] years were split between GSU's child development center and Menden, and oh, my sweetheart, you were bathed in love by magnificent women who loved you deliriously, who worked every moment to understand you and help you, who listened to the Nikki within the Nikki. You learned your letters and numbers, and most of all, you seemed happy.

At the end of your kindergarten year, the upshot of the IEP meeting was that your abilities fit better with an LD (Learning Disabilities) class... and that year was a sheer nightmare for you with classmates who teased and ostracized you and teachers who didn't protect you or even see you very well.

So I learn, dear Teacher Nikki, that I need to be in close touch with your school days and your encounters and your growing. I learn that you are vulnerable now, but may be even more vulnerable as the differences between you and your classmates grow larger. I learn, daily, how colossally rich is my life because of you and Sissa. I try to learn that I am enough. Not great, but enough.

And I hope that last one is true.

I love you.  
Mom

*(Continued on page 8)*

## Coming Up at FOCUS

Always check the (new and improved) FOCUS website at [www.focus-ga.org](http://www.focus-ga.org) for more details! And, do you LIKE FOCUS on Facebook?? Check it out at <http://tinyurl.com/focusgeorgia>

### May 6\*

FOCUS Day at Six Flags Over Georgia

### May 29 – June 1\*

Camp TEAM at Mercer University in Chamblee

### June & July\*

Camp Hollywood

*\*Brochures and applications to these activities were mailed to active FOCUS Families by bulk mail on February 27. Families are encouraged to apply since these programs are very popular and space is limited!!*

### August 10 – 12\*\*

Under the Stars Family Camp 1 at  
Camp Twin Lakes Rutledge

### October 6 – 7\*\*

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

*\*\*Brochures and applications for both Under the Stars Family Camps will be EMAILED to all active families with email addresses on April 13. If you would like a paper brochure, call FOCUS by April 1!!*

## Workshops at FOCUS

Tuesday, March 27 at 10 am at FOCUS office.  
An overview of NOW/ COMP waivers  
by Heidi Moore

Friday, April 20 at 10 am at FOCUS office.  
An overview on Katie Beckett Deeming Waivers  
by Debbie Dobbs

Friday, April 27 at 10 am at FOCUS office.  
An overview of SSI / SSDI by Larry Christensen



*Happy Sweet 16 to Emily Powell,  
with thanks for requesting that gifts be made  
to FOCUS in honor of her special day!!  
(See contribution page for list of donors).*

## Special Events at FOCUS

29<sup>th</sup> Annual

### For the Love of Children

*Dinner, Dance, and Silent Auction*  
March 17, 2012

FOCUS celebrates 29 years of supporting  
Atlanta children and families, honoring Read Davis  
for his commitment to FOCUS.

12<sup>th</sup> Annual

### E\*TRADE Financial FORE FOCUS Golf Classic

May 9, 2012  
Bear's Best Atlanta

### SummerFest at SweetWater Brewery

August 18, 2012

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

### Run the Farm for FOCUS

#### 5 & 10K trail run & 1 mile family walk

September 29, 2012

Cedargate Farms in Newnan  
Go to [www.georgiarunner.com](http://www.georgiarunner.com) to register.

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The Forrest & Frances Lattner Foundation for Family Activities  
Kiwanis Club of Suwanee for Camp Hollywood

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Ashley Harrison  
Leroy, Linda & Nick Horst  
Kelly Wilkinson

In honor of Katie Preuss on her birthday  
Lisa and Adam Laarhoven



*My Heart Flip Flops*

*(Continued from page 5)*

Dear Nikki,  
"With Nikki, it's her way or no way."  
"Stubborn."  
"Like a mule."

I guess you've heard all these things, yeah, babe? Teachers and therapists and even I have said them. Well ... what can I say? These statements are you ... oh, yes they are. If you want to wear your boots in the morning, and I say, "Let's see if it's still raining," you throw a connotation. If you want to eat noodles first instead of whatever protein and vegetable I have fixed, you scream... All, regardless of the fact that I have never, ever given in when you act out.

Screaming is your favorite resistance perhaps because, foolishly, I let you know that it annoys the blinking stew out of me. Thanks to Sissa's smarts when you were about three or four, I've learned a different way that works most of the time; it's called the end run. When I first started trying to potty train you, we'd go to the bathroom constantly, and just as constantly, you resisted. But one time, Sissa took over and invented the "spy game." You and she had to sneak into the bathroom in order to avoid being caught by the "spies," whoever they were. You loved it and went willingly. Part of its joy was that you delighted – and still do – in any attention that Sissa gives

you. And part of the deal was – and is – that you simply love play-pretend. You love surprises.

So, now, when you oppose whatever and everyever, I try to quickly invent a scene in which you and I are the players. Hey, Nik, watch out for the looney birds!!! They're trying to eat our ears!!! Quick! Run!! Or a game that we can play. C'mon, let's speed-walk. Race ya! Or I use a silly voice to let an inanimate object speak, like that toilet. Or I tickle you. All of these engage your imagination and physicality, and they distract you from that land called NO.

All along, I've tried to understand what your resistance is about, what is its source. When you were about two... sometimes you would just completely shut down, turn lumpish, check out of the scene. ... I hypothesized that you would disappear when you couldn't quite understand requests of you. And I always wonder if it is a matter of fear... Or is it about power? Resisting is a very sure way to see your impact, for the grownups have to react. From one perch on the branch, your resistance could be seen as a power struggle. From another, you might be simply using a proven, verifiable strategy to know that you truly and fully exist.

My dearest little darling, you are here. You are here. You are here.

Love, always,  
Mom ■

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