

Miracle

by Tameche Brown

Our precocious little girl was born at 27 weeks, very unexpectedly. On April 28, 2008, while on my way to my 7 to 4 job, my car was hit head-on by an oncoming green truck. I'm not sure why I remember the color of the truck! My Honda CRV was completely crushed. The jaws of life were used to pull me and my almost 6-month pregnant belly out of the car. We were rushed to Kennestone Hospital. The doctors told my husband and me that the baby's heartbeat was dropping and there was bleeding on her brain. For the best chance of survival, she needed to be delivered in the next ten minutes. We had just enough time for a prayer and calls to my mother and brother before they whisked us away. Whew! I hadn't said this out loud for almost three years!! I was rushed in for an emergency C-section and emergency surgery on my life threatening injuries as well. Our Miracle didn't come into the world kicking and screaming; in fact, she didn't breathe for about ten minutes even though her heart beat was strong. And so began our 92-day journey in the NICU at Kennestone.

The nurses didn't say much to me or my husband about the prognosis of our little "Miracle." The story of our accident had traveled to the nurses and doctors in the NICU, which made them a little reluctant to add more to our plate. But I knew something was wrong after my initial visit in the NICU. After sitting with her for an hour, I asked my husband for a pad and pen. Mind you, I had a cast on my arm and leg, and I was in a wheelchair! I then asked to speak to the nurse assigned to our

daughter and told her that I wanted to know everything that she knew up to this point. She looked at me, paused for a second and said, "Okay, Mrs. Brown, if you are up for this, let me get my chart and we can get started." That day was long; I met with Miracle's nurse, cardiologist, primary care physician at the hospital, ophthalmologist, and the list goes on. I saw at least ten specialists that day. After an

exhausting day, we knew that our daughter's main diagnosis would most likely be cerebral palsy.



Before Miracle, my husband and I were always in a hurry. Rushing here and there, making last minute decisions, being the king and queen of procrastination. Our daughter has taught both of us to take time and smell the roses. We are no longer in a hurry about

anything in our lives. We've even given up our crowns of procrastination!! We now take one day at a time and enjoy that day. I've learned that our daughter is her own person and doesn't fit the mold of any four-year-old that I know. She's always smiling and laughing. She has perfected the art of wrapping daddy around her little finger (especially at bedtime!), which melts him every time!

This past year has been hard for us. Our daughter received her first wheelchair. Good, right?! We struggled because it was the first time we were forced to accept that she would

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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

Don't worry, be happy. Out of the mouths of ... ummmm ... fish. Big Mouth Billy Bass, a plaque that resembles a mounted game fish, wiggles its head and tail and sings "Don't Worry, Be Happy" by Bobby McFerrin. Designed to startle those passing by, most people are not as startled as they are annoyed. Having that song stuck in your head for a day is worse than the initial fright!

Don't worry, be happy. Really? Who came up with THAT? Big Mouth Billy Bass advises, "In every life, we have some trouble, but when you worry, you make it double. Don't worry, be happy." Don't we wish not worrying and attaining happiness was that easy? Certainly, as FOCUS parents, we've heard all the old adages about making the best of situations, lemonade from lemons and all that. We've been there, done that!

But, the subject of happiness continues to come back around. Recently, we posted this question on the FOCUS Facebook page: *In the future, my biggest hope is that my child is _____*. We had 50 responses. Twenty of those responses was one word: happy. So, in my ever-over-thinking brain, I started thinking about what makes us happy. We all have different answers for that: good health for our kids and ourselves, a happy marriage, financial security. But, sometimes even that doesn't really make us happy.

So, I googled happiness and had a gazillion hits. I surfed around on Psychology Today, found lots of catchy quotes, and discovered something called The Happiness Project (www.happiness-project.com). Pretty interesting. Created by Gretchen Rubin, who is also the author of *Happier at Home* and *The Happiness Project* which were both instant New York Times bestsellers. *The Happiness Project* offers daily happiness quotes, a monthly newsletter, a book club, and the opportunity to belong to a Happiness Project group. I poked around, ordered the books, and checked out some of Gretchen's articles. I think maybe she's onto something – maybe happiness isn't a state of mind as much as a way of life!

Because of my need for instant gratification, I found the following article (*see page 3*) promising. I hope you do, too! And if you decide to start a Happiness Project Group, please send me an invitation!

FOCUS and Summer Time!

Summer Share Groups – FOCUS appreciates the parent volunteers who facilitate support groups throughout the school year. We know that summer is stressful, too, but we take a break in the summer while families are (hopefully) on vacation and children are out of school! The FOCUS staff is around, however, if you need an impromptu telephone share group!!

Extra Special Saturday – Extra Special Saturday takes a break in June, July & August while kids are having fun at Camp TEAM, Camp Hollywood, and Camp Infinity! Please take a moment to thank our wonderful caregivers and volunteers at each respite in May. Because of them, FOCUS continues to offer fun for the children (and a break for the parents!) in six locations each month!

Seven Tips for Making Yourself Happier IN THE NEXT HOUR.

By Gretchen Rubin from *The Happiness Project* (www.happiness-project.com)

You can make yourself happier – and this doesn't have to be a long-term ambition. You can start right now. In the next hour, check off as many of the following items as possible. Each of these accomplishments will lift your mood, as will the mere fact that you've tackled and achieved some concrete goals.

1. **Boost your energy:** Stand up and pace while you talk on the phone or, even better, take a brisk ten-minute walk outside. Research shows that when people move faster, their metabolism speeds up, and the activity and sunlight are good for your focus, your mood, and the retention of information. Plus, because of "emotional contagion," if you act energetic, you'll help the people around you feel energetic, too.
2. **Reach out to friends:** Make a lunch date or send an email to a friend you haven't seen in a while. Having warm, close bonds with other people is one of the keys to happiness, so take the time to stay in touch. Somewhat surprisingly, it turns out that socializing boosts the moods not only of extroverts, but also of introverts.
3. **Rid yourself of a nagging task:** Answer a difficult email, purchase something you need, or call to make that dentist's appointment. Crossing an irksome chore off your to-do list will give you a big rush of energy and cheer, and you'll be surprised that you procrastinated for so long.
4. **Create a calmer environment:** Clear some physical and mental space around your desk by sorting papers, pitching junk, stowing supplies, sending out quick responses, filing, or even just making your piles neater. A large stack of little tasks can feel overwhelming, but often just a few minutes of work can make a sizeable dent. Try to get in the habit of using the "one minute rule" – i.e., never postpone any task that can be completed in less than one minute. An uncluttered environment will contribute to a more serene mood.
5. **Lay the groundwork for some future fun:** Order a book you've been wanting to read (not something you think you should read) or plan a weekend excursion to a museum, hiking trail, sporting event, gardening store, movie theater –

whatever sounds like fun. Studies show that having fun on a regular basis is a pillar of happiness, and anticipation is an important part of that pleasure. Try to involve friends or family, as well; people enjoy almost all activities more when they're with other people than when they're alone.

6. **Do a good deed:** Make an email introduction of two people who could help each other, or set up a blind date, or shoot someone a piece of useful information or gratifying praise. Do good, feel good – this really works. Also, although we often believe that we act because of the way we feel, in fact, we often feel because of the way we act. When you act in a friendly way, you'll strengthen your feelings of friendliness for other people.
7. **Act happy:** Put a smile on your face right now, and keep smiling. Research shows that even an artificially induced smile has a positive influence on your emotions – turns out that just going through the motion of happiness brightens your mood. And if you're smiling, other people will perceive you as being friendlier and more approachable.

Some people worry that wanting to be happier is a selfish goal. To the contrary. Studies show that happier people are more sociable, likeable, healthy, and productive – and they're more inclined to help other people. So in working to boost your own happiness, you're benefiting others as well.

Feel happier yet? ■

Workshops at FOCUS

**Friday, May 3 at 10 am
at the FOCUS office.**

An overview on the Katie Beckett/
Deeming Waiver by Debbie Dobbs.
Please RSVP to elizabeth@focus-ga.org

**Friday, May 10 at 10 am
at the FOCUS office.**

An overview of the NOW/Comp Waivers
by Heidi Moore.
Please RSVP to elizabeth@focus-ga.org

Coming Up at FOCUS!

Always check www.focus-ga.org for details!

May 5

FOCUS Day at Six Flags Over Georgia

More than 900 tickets were pre-sold on-line!
Sorry, no more tickets are available.

May 11

FAST Fins Intramural Meet

Mountain View Aquatics Center
Come cheer on our swimmers and check out
our FAST Fins program!

FOCUS Day Camps

For information on day camps,
please contact FOCUS at inquiry@focus-ga.org.
Registration closes for day camps on May 11. Hurry!

- **May 28 to May 31.** Camp TEAM is a traditional outdoor day camp experience, offered at Mercer University in Chamblee for campers ages 7 to 13. Camp TEAM is full!
- **June 3 to July 12.** Camp Hollywood is a mostly indoor day camp where campers enjoy arts, crafts, cooking, science, music, and recreation based on the themes of popular children's movies. Some locations of Camp Hollywood have openings – apply quickly!

June 22, 2013

Daddy-Daughter Dance & Dessert

at Mt. Bethel United Methodist Church.
This fabulous event is for FOCUS girls and
their dads, granddads, or special man.
Watch FOCUS emails for more information!

Under the Stars Family Camps

August 9 – 11 at Camp Twin Lakes, Rutledge
October 5 – 6 at Camp Twin Lakes, Will-A-Way

We're having "FOCUS Camp Fever," a spinoff of Saturday Night Fever, at Under the Stars this year!
Applications went out by email on April 19.
We anticipate family camps filling up quickly,
but encourage families to apply online
since cancellations always occur!!

From our Facebook Page ...

Technology abounds for our kiddos – what technology makes the biggest difference in your life ... and why??

- iPad-FaceTime, so I can see my nonverbal girl and make sure she is good...
- The desk top computer. It's in his room, used as a friend and yep, a sitter! It gives "us" hours of quiet time! Thank goodness!
- Teaching Bran to spell because he loves to google stuff. Just have to watch WHAT he googles. Lol.
- Her communication device of course! She has an Eco2 made by PRC and it has enabled her to tell us what she is thinking in that pretty little head of hers.
- His iPod helps him calm down from sensory overload.
- A tobii ATI communication device!!
- We have a Nabi android tablet. Not as good as iPad because you can't get that many apps on it. It keeps our son happy and not crying sometimes. It is only around \$140.
- I would say the internet in general so I can connect with other special needs families & ask for their advice. For my daughter, her feeding pump. It has been a godsend.
- The iPad. Gross motor skills work just fine on the iPad. Thanks posthumously Steve Jobs!
- Dynavox Maestro is great for our girl...can't imagine our life without it...
- Paul says the light bulb... (*Everybody loves a wise guy!*)
- Wii, Wii U and Nintendo are big winners in our house!



<http://tinyurl.com/focusgeorgia>

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Memorials

In memory of Gavin Leong
 by Paige Hill
 In memory of Hal Davies by
 Sara Burkes
 Sally & John Catabiano
 Lucy & Wayne Cusick
 Lousie & Guenther Hecht
 Sally Hildebrant
 Stuart & Dorene Krackow

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Honorariums

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 Emmett & Nancy Hart Foundation
 In honor of Toni & Saxon Dasher by
 Dena & Greg Jones
 In honor of The Kostopoulos Family
 by Betty & Demus Jones
 In honor of Anna Kostopoulos
 by Les & Mary Alice George

The Liam Vilensky Camp Scholarship Fund



FOCUS offers summer camps for children, teens, and young adults with disabilities: 11 weeks of day camps and 1 week of overnight camps. FOCUS camps offer the specialized attention our campers need, so each camp has a nurse to provide medication, G-tube feedings, and to manage emergencies; we also have a very low counselor to camper ratio. Counselors are experienced special educators. Volunteers are wonderful teens and young adults with a heart for service.

Every FOCUS camp is offered to at a reduced rate. For instance, the fee to parents for FOCUS Camp Hollywood is \$145 per week; the actual cost to FOCUS is \$350 per week. FOCUS grants and fund raisers cover the \$205 difference.

FOCUS also offers scholarships to campers, based on the financial need of parents. This means that campers who qualify receive more help with their camp fees. In 2012, we awarded over \$5,000 in scholarships to Camp Hollywood, over and above the scholarship that each camper receives.

Liam Vilensky attended FOCUS camps loved camp – especially FOCUS Family Camps and Camp Hollywood. After her death in 2010, her grandparents established the Liam Vilensky Camp Scholarship Fund to support FOCUS camps and campers.

To support the Liam Vilensky Camp Scholarship Fund, please make checks payable to FOCUS and note 'Scholarship Fund' on your check or donate online at www.focus-ga.org.

Volunteer for FOCUS!!

FOCUS offers many volunteer opportunities – from helping at summer day camps to offering a helping hand in the office! Our small paid staff depends heavily on volunteers at all the programs we offer! So that everyone has a good experience, we do have a few guidelines:

- Volunteers must be at least 14 years old to volunteer with FOCUS children. Safety for all children is our first concern, and this age restriction is for the safety of FOCUS children AND volunteers! For projects for children under age 14, or for information on collecting items FOCUS needs, please contact FOCUS.
- Volunteers who are 18 years or older must complete a Volunteer Disclosure and Consent Release of Information so FOCUS can perform a background check. Background checks must be done annually and take about three business days. Background checks require volunteers to give their social security

number; we take all precautions with this information by keeping it under lock & key at the FOCUS office.

- Volunteering is....well....voluntary!! We need volunteers who respect, accept, and love our children! We need volunteers to be role models AND to be silly! Please come to FOCUS with lots of energy and know that YOU might help a child have an awesome experience!
- FOCUS welcomes school clubs, scout troupes or church groups. But, please be willing to help where you are needed – which might not be with your best friend. We also ask that you leave your cell phone in your pocket and concentrate on having fun with your camper!
- If you register to volunteer, please know that we count on you!! If you register and then cannot attend, please contact volunteer@focus-ga.org as soon as possible! ■

Miracle

(Continued from page 1)

need assistance with mobility. We cried and had a pity party for a couple of days, until Miracle showed us that she had no time for pity parties!! Her physical therapist recommended a chair that Miracle could push herself – and, boy, did she! She took off! She no longer had to wait on mom and dad – she could push herself, go to her toy box, and even open a door by herself!!

The life changing "Get over it, Mom and Dad" came when we took her to school the first time in her wheelchair. We got her out of the car and Miracle took off! She knew exactly how to get to her class and that she needed to knock on the door to get in. Our daughter once again taught us that she wants to be independent and that sometimes a different path is needed to accomplish this!

I'm learning not to get angry anymore when people ask "What's wrong with your daughter?" Instead, I try to educate individuals that Miracle is a person who loves music, dancing and The Wiggles ... and that she happens to have cerebral palsy. It is hard sometimes when I am reminded of the things she cannot do, or she doesn't get invited to the birthday parties or play groups with typical kids, but those are the days I reach for my hidden stash of chocolates, smile and say "Okay, what's next?" Each day we struggle to find positive moments to remind ourselves

how far we've come. When we find those moments, we relish them!

We got involved in FOCUS shortly after Miracle came home and started on the 'specialty appointments.' Kathie Teta, neurology nurse practitioner, gave us a brochure. It took a couple of days to make the call ... I had to summon up the courage to admit that I needed help! When I called, I spoke with Karen Greenfield, who not only took my information, but asked me how I was doing and actually waited for me to respond! That made my day – someone really cared about me!!

I was hooked! I attend the 5 & Under Share Group and loved meeting other moms. When Elizabeth asked me to be the parent coordinator for the 5 & Under Share Group, I happily agreed. I see myself in many of the moms who come to share group each month. I love being able to offer insight and resources, which is something that I'm truly passionate about.

To me, life is not about finding the perfect solution, but instead about how each person can navigate their individual journeys successfully. Sharing my fears and emotions hopefully helps others understand that they

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"There is Nothing Like a Daddy's Love"

by Sean Durity

I see my daughter, Gwendolyn, standing at the top of a staircase. She is dressed in a flowing white gown. Her strawberry blonde hair is swept up into teasing tresses. The aroma of fresh flowers drifts down to me, the loving father with a heart about to burst. It is her wedding day, and she is about to descend the stairs one last time before leaving her mother and me to start her new life and marriage. Except that it won't ever happen that way.

Gwendolyn has a mitochondrial disease. She can't stand or walk. She can't say, "I do." Dresses are not wheelchair-friendly, especially if she wants to pull her legs up. She is nine years old, and it is likely that she won't live to marriageable age. That's the brutal reality I've had to mourn. But, even as I have let that dream die, I have discovered something greater from the heart of that dream -- there is nothing like a Daddy's love.

I can't fix her. I am not going to discover the cure for mitochondrial diseases, no matter how many internet articles I read or doctors I meet. I can't figure out what will motivate her to do something new. I have no idea what tomorrow might bring for our family. But that's OK. There are times when Gwendolyn will only calm down if I take her in my arms and hold her close, just the way she likes. She snuggles into my left shoulder. At night, she needs me to sing her a hymn or two and whisper, "Daddy loves you" before she goes to sleep. Sometimes when I come home she just smiles and giggles. On fall Sundays, there is no place she would rather be than watching a Steelers game with me. I can bathe her, change her, brush her hair, and make her do her therapy. I can navigate a wheelchair, make her daily

food, start her feeding pump, and administer her medications. I'm Daddy, after all. And there is nothing like a Daddy's love.

My wife is tired. The daily grind is exhausting. I have a full-time job that pays the bills but demands my energy. Our other children need Dad, too.

I don't know how we will pay for a wheelchair van or home modifications. I still don't have that special needs trust in place. Our vacations are tougher, if we can take them. Life could be easier, right? But I am here to stay, for my children and my wife. They need me because there is nothing like a Daddy's love.

My strength is gone; my faith wonders. I stop to think about the most important things in life. Does God really care about what is happening to us? Then I realize I can climb into my Heavenly Father's lap. He comforts me when no one else can. Even though I am broken seemingly beyond repair, He CAN fix my deepest needs. He provides our shelter, food, clothing, medicine, jobs, caring doctors and therapists, a fantastic church, and even occasional respite! If I stop to listen, through all the doubts and fears and questions, I can hear Him. He sings over me and whispers, "I love you."

There is nothing like a Daddy's love. ■



Miracle

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are not alone; even though our children might have different diagnoses, our journeys tend to be very similar.

We got involved pretty quickly – attended the annual education conference, the home modification tour, Six Flags Day, and MVP events for medically fragile children. This past August, we decided to try Under the Stars Family Camp!! This was a stretch for us – packing everything we would need for two nights away from home AND sharing a cabin with strangers! Well, Joy at FOCUS matched us with the perfect family! Todd, Traci, and Emma Brun were the perfect cabinmates – and

Miracle and Emma are now BFFs!! They love hanging out together – in fact, they go to the same Extra Special Saturday respite location. They enjoy their girl time, while we can relax and rejuvenate, knowing they are in great hands!

If you are new at FOCUS, I encourage you to get involved!! Check out their programs, help them fund raise, become part of the FOCUS family. You'll find Comfort, Hope, and Fun for all! ■

FOCUS Fund Raisers

Support FOCUS fund raisers AND the programs FOCUS offers by attending FOCUS fund raisers ... and bring friends! Proceeds go to FOCUS programs which are offered at a reduced (or no!) cost to children and families!

May 8, 2013

13th Annual

E*TRADE FINANCIAL FORE FOCUS Golf Classic

at Bear's Best Atlanta.
Golf for fun and "fore" FOCUS!!

September 21, 2013

"Take On the Night," a glowing 5K experience!

FOCUS receives 10% of the registration proceeds –
run OR volunteer for this unique event!!
www.takeonthenight.com

August 17, 2013

4th Annual

SummerFest at SweetWater Brewery

Cheers to summer
and FOCUS camps!
Enjoy brewery tours
& tastings, Willy's
Mexicana Grill,
cornhole tournament
and music!



October 19 & 20, 2013

Spin for Kids

Dr. Robert Bruce is team captain this year for TEAM FOCUS in Spin for Kids!! Dr. Bruce rides every year to support FOCUS programs Camp Infinity and Family Camp Under the Stars, all offered at Camp Twin Lakes. He also volunteers his time as a counselor! All funds raised by TEAM FOCUS go directly to FOCUS programs at Camp Twin Lakes – ride or support TEAM FOCUS and help more kids go to camp!



Contact lucy@focus-ga.org for more information about any of these events.

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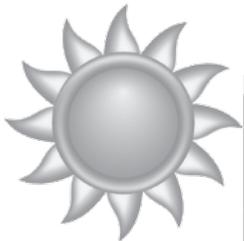
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MAY 2013



Sun	Mon	Tue	Wed	Thu	Fri	Sat
Visit www.focus-ga.org for the most current information about FOCUS activities.			1	2	3 Deeming Waiver Swim: 4pm - Swim Summit 4:30pm - MTV Swim 5:45pm - MTV Swim	4 Respite: 10am - Acworth 10am - Chamblee 10am - Cumming 10am - Marietta 10am - MJCCA Swim 11am - MJCCA Swim
5 Six Flags Day Swim: 3:30pm - Cumming 5:30pm - J Creek 5:30pm - Roswell	6	7 Share Group: 10am - 5 & Under	8 Fore FOCUS Golf	9	10 NOW/COMP Share Group: 10am - Cumming 4pm - Swim Summit 4:30pm - MTV Swim 5:45pm - MTV Swim	11 Intra-Squad Swim
12	13 Share Group: 9:30am - Gwinnett	14 Share Group: 10am - Med. Fragile	15	16 Share Group: 9:30am - Conyers	17	18 T/YA Group New Share Group! Respite: 10am - Alpharetta
19	20	21	22	23	24	25
26	27	28 Camp TEAM	29	30	31	

JUNE 2013



Sun	Mon	Tue	Wed	Thu	Fri	Sat
						1
2	3 Camp Hollywood 10am - Lawrencevill 10am - Alpharetta	4	5	6	7	8
9	10 Camp Hollywood 10am - McDonough 10am - Johns Creek	11	12	13	14	15
16	17 Camp Hollywood 10am - Acworth 10am - Marietta	18	19	20	21	22 Dads & Daughters
23	24 Camp Hollywood 10am - Marietta 10am - Buckhead	25	26	27	28	29
30	Visit www.focus-ga.org for the most current information about FOCUS activities.					

Share Group Calendar by Location!

Please call (770) 234-9111 or e-mail (elizabeth@focus-ga.org)
to RSVP and for reminders, directions, or further information.

5 & Under – 10:00 am

This group is especially for parents of
children with special needs who are 5 years
old and younger.

FOCUS Office
3825 Presidential Parkway
Suite 103, Atlanta 30340
May 7

Conyers – 9:30am

Chick-fil-A
1610 Hwy 138 SE
Conyers 30013
May 16



Grayson – 10am

McDonalds
1881 Grayson Hwy
Grayson, GA 30017
May 18

Gwinnett – 9:30am

Chick-fil-A
Hwy 124 (Scenic Hwy)
May 13

Medically Fragile – 10am

Kimberly Forester's home
in Alpharetta
RSVP to Elizabeth@focus-ga.org
for directions and reservations.
May 14

