

An Open Letter to My Child's Therapists

by Melanie Durity

I am the mom of a child with special needs. Our oldest child, Gwendolyn, has mitochondrial disease; she has significant developmental delays and requires lots of medical care. We have been on this journey for more than 8 years, and I am finally ready to confess: *I do not want to be a therapist when I grow up!*

Now I know this is shocking. I know moms out there who, after watching their children in therapy and learning from therapists, have gone back to school to become therapists. I think that is fantastic! However, that's NOT me. God did not create me with the gifts or desire to be a therapist. But, there are some things I really appreciate about the therapists who have worked with Gwendolyn:

- 1. Creativity:** Wow, Gwendolyn's therapists are talented and creative. Special needs kids are like puzzles -- really, really hard puzzles. Now, I love a good puzzle, but it's frustrating if it is too hard. Over the years, her therapists have found things that she CAN do and things that we CAN work on with her. Creative therapists ask the right questions, create the right atmosphere, and arrange the pieces in new ways so that we are closer to solving the Gwendolyn puzzle.
- 2. Communicate with me:** I love when a therapist is very specific with me, especially when there is something a therapist feels is critically important for me to be doing with Gwendolyn during the week. Her therapists explain why this item is critically important and demonstrate exactly what I need to do. Also, they do not give me too many of these "to dos" per week.



- 3. Understand they are part of Gwendolyn's "team:":** I love when a therapist says, "What things are they working on at school?" or, "What things is she working on at home?" or, "What is the occupational therapist working on?" It is great when the "left hand" knows what the "right hand" is doing. I believe the sky-is-the-limit for my daughter when this kind of brainstorming/reinforcement occurs.

4. Give grace: Through the years, Gwendolyn's therapists have shown us so much grace! They bear with us when she or I have bad days. They understand that sometimes there are more important things than therapy: ordering her medical supplies, making her food and medicines, caring for my husband and other children. They have understood these time constraints. They have loved us through the hard days.

I want Gwendolyn's therapists to have some expectations of me too. I want them to know that:

- I am listening
- I will be on time
- I want to know what is going on in therapy so that I can assist at home
- I love them and am very thankful for them
- I support them in caring for my daughter

During this journey, I have been impressed with the therapists with whom we have come in contact. Gwendolyn's current therapists, both private and school therapists, are truly God-sent. They are my heroes. They do their job without hope of monetary rewards. They look for the best in Gwendolyn.

I am thankful for ALL of you! ■

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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*

I am feeling particularly amazed today, as I arrange all the heartfelt articles in this newsletter. I love selecting the photos for the Looking Back section; I am blown away by the generosity of our sponsors and donors. I may be in the spirit of Thanksgiving a little early, but I am amazed by the support of some friends for almost the entire 30 years of FOCUS.

I am amazed by the volunteers who show up at every FOCUS event. We see all ages: middle school, high school, college, twenty-somethings, middle age, and grandparents. They come in with energy and enthusiasm; they love on our kids, pamper our families, and bring new ideas to the table.

I am amazed by the FOCUS staff. They leave their own families at night and on the weekends to work FOCUS programs. Check out the calendar (www.focus-ga.org) and you'll see that almost every weekend in September and October had multiple events. Every event had at least one FOCUS staffer there. They work weeks to plan, the weekend to manage, and the week after to unpack and re-organize for the next event! They pore over evaluations and make notes for adjustments for the next year – and they treasure the sweet notes from families.

I am amazed by our children – all of them, siblings and extra-special ones, too. Our children with disabilities endure hours of therapies and doctor visits; they work hard to perform a task that we just do, without even thinking. And they rarely complain; in fact, they often smile, even after painful procedures. Siblings are often required to tag along to all these medical appointments; they are the extra hands and eyes a parent needs at trying times. They grow up with more knowledge and compassion than other children their own age.

I am amazed by our parents – they learn to be tough and loving at the same time. They learn to live with a broken heart and put on a happy face. They adjust, re-adjust, and re-re-adjust their lives and dreams. They love fiercely and unconditionally.

Yep, today is a realization that I am living an amazing life, working alongside amazing people, for amazing children and their amazing families. In the spirit of Thanksgiving, thank you all for your amazing partnership. ■

Katie Gives Back!

Katie Parsons gives back to FOCUS in a unique way! She designed and created Duct Tape Wallets and sold them for \$1 each and gave the proceeds to FOCUS!! Katie marketed her wallets very creatively – she made and wore a Duct Tape Dress to the Daddy Daughter Dessert Dance!! Thanks, Katie, for giving back!



Special Events for Medically Fragile Families are ongoing. Please call FOCUS or email elizabeth@focus-ga.org if our child is homebound, hospitalized frequently, has a tracheostomy or a G-tube, or is at significant medical risk.

Teen/Young Adult Activities are ongoing. Please call FOCUS or email patrick@focus-ga.org for information on monthly social outings and other events for teens and young adults who enjoy socializing but require only a 1:8 ratio.

Finding Comfort Through FOCUS

by Rick Roberts

When your children are sick, you feel bad and comfort them as best you can. You tell them they will feel better soon. And, usually within a few days, they are back to their normal activities. But, when it comes to a special needs child, that outlook is much different, especially for our family. We have become accustomed to our monthly hospital runs to Scottish Rite with our son, who has cerebral palsy and uncontrolled seizures. That tide turned recently for us after the scariest seizure ever and the helplessness feeling that came with it. On his way home from school, he had a seizure; the bus aid and bus driver did not recognize that he was seizing. Sometimes even we don't know recognize a seizure until he's fully clonic tonic.

Luckily, Matthew's nurse Anthony was working that day. (Matthew has the GAPP Waiver, which provides nursing services for medically fragile children. Anthony is a law student at Emory & a part-time cage fighter. All asides, but interesting!) Anthony recognized that Matthew was seizing and administered the anti-seizure medication. Matthew then went into full arrest. Anthony started CPR and administered oxygen to our son and called 911 ... not easy things to do all at one! As a parent, it's taken me almost 9 years to become a proficient at all of this! I've had one class in CPR, my wife Sue has taken it twice. We're not highly experienced in life-saving techniques!

Sue calls, frantic ... something about Matthew in full cardiac arrest, waiting on ambulance transfer (which, come to find out, was the same day of the funeral for the Roswell Fire Chief. Another aside, but interesting). Time froze; I heard the words, but I could not respond. I quickly left work and rushed to the hospital.

By the time I arrived, Matthew was breathing and the seizure activity seemed to have stopped. As a precaution, the emergency room doctor wanted to admit him to the intensive care unit. Dads, if you have been in the intensive care unit, you know what I am talking about. The process is very regimented: you follow your child upstairs to the Unit, then you are told that you need to wait in the waiting area as your child is evaluated. The nurse comes to get you when they are ready for you. So there you sit, and wait for what seems to be forever. You become concerned about why it's taking so long, is he seizing again, do they have another emergency to tend to, etc. Finally, a nurse walks into the waiting room and says she is looking for the parents of Matthew. You jump up and follow her like puppies. We see our son, peacefully sleeping, take a deep breath, and exhale slowly. Wow.

Our first visitor was usually Rosemary, the FOCUS hospital volunteer. She showed up like "Radar O'Reilly" from MASH ... how did she even know we are here?? She must have kept chocolate in her purse!! Rosemary watched Matthew grow up, always bringing a cheery hello (or leaving a quiet note, if we were sleeping!). Going to the hospital is never fun ... but we lost a little ray of sunshine when Rosemary died last November.

During this particular hospital stay, we learned of another little boy about the same age as Matthew, and we noticed he was visited by Rosemary, too!! My wife immediately called the other mom and they chatted like long lost friends. The mom insisted that we stop by to visit when we took Matthew out for a little ride to see the fish or to the play room. So, we did – and we traded information on treatments, diets, and doctors.

Comfort is the foundation that FOCUS was built on, and we are glad that we are a part of the FOCUS family. (And, of course, the chocolate helps!) ■

FOCUS HOSPITAL VOLUNTEERS

Our Rosemary is now passing out chocolate in heaven (probably at bedtime!) to many children she visited here on earth! We at FOCUS continue to miss her cheery updates – and her gifts of holiday baklava.

Winter is a good time to introduce (and re-introduce) our current hospital visitors. The FOCUS staff is grateful for their time and compassion that they give to our children and families:

Visits to CHOA at Egleston

Ann & John Schramm: Ann and I do not have a FOCUS child, but looked this life squarely in the face at one time. Because of this experience, we became interested in helping those who have the reality of life with a special needs kid. When we moved to Atlanta from New Orleans in 2000, Ann found FOCUS and began visiting Egleston as a volunteer. While attending Emory Business School, I jumped in to help Ann by making the Egleston rounds before class.

While we do our best to help the FOCUS families at Egleston, we can assure you that we receive more than we supply during these visits. We are continually blown away by the strength and cheerfulness of the families and the kids while dealing with the pain, stress, boredom and uncertainty associated with recurring hospitalizations. It's both humbling and a source of great satisfaction for us to provide any comfort, hope (and chocolate!) during the hospitalization experience.

(Continued on page 7)

Looking Back at the Fun ...

3rd Annual Run the Farm for FOCUS 5K Trail Run & 1 mile Family Walk

Runners and walkers hit the trails at beautiful Cedargate Farms in Newnan on September 29. Participants enjoyed the early morning exercise, breakfast, and awards! Thanks to the sponsors, contributors, and volunteers for their support and to Phil & Ann Beegle for their generosity and willingness to share their lovely farm!



TEAM FOCUS Supports FOCUS Programs in Spin for Kids

TEAM FOCUS once again rocked in Spin for Kids and raised money for Under the Stars 1, Under the Stars 2, Camp Infinity, and OctoberFest. The spinning efforts of TEAM FOCUS will help keep the cost of these programs affordable to FOCUS families. A special thanks to everyone who rode, raised money, and donated!



FOCUS Family Activities & Family Camp & Moms Day Off!

FOCUS had a wonderfully busy fall: FOCUS Days at the Georgia Aquarium and ZooAtlanta and Under the Stars 2. Our families tell us that they love these events because they love being one of a crowd instead of standing out in a crowd and because of the special treatment they receive!!



Daddy-Daughter Dessert Dance
The inaugural daddy-daughter dessert dance on September 8 was a definite success!! Daughters enjoyed a special date with their special dad, grandfather or uncle, feasted on yummy sweets, had face painting creations to match their dresses by Marie Reynolds, and took to the dance floor to the music of DJ Tony Washington. A very special afternoon was had by all!

Under the Stars 2 Family Camp filled Camp Twin Lakes Will-A-Way this year to capacity!! Families loved the cooler weather, as well as the bonfire, hayride, and other camp activities!



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Judy & Ken Hammett

In memory of Steven Winokur,
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on the anniversary of their
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SPIN FOR KIDS

Thanks to the riders of TEAM
FOCUS and to those who donated
to Camp Twin Lakes on behalf of
TEAM FOCUS in Spin for Kids.
Proceeds will be used in 2013 at
FOCUS programs at Camp Twin
Lakes – we are thankful for your
support!



Moms Day Off on the Houseboat was a wonderful day of food, conversation, pampering by Mary Kay, and more food! Thanks to Mr. & Mrs. Bagwell and to Captain Jeff for their generosity and continued support!



Important Life Lessons

by Katie Greenfield

Of all the lessons I have learned in my life, the most important were taught to me by my younger brother Kyle. Kyle was born on May 15, 1988 with a rare degenerative disease called mucopolysaccharidoses (MPS). People with MPS are missing an enzyme that breaks down complex sugars. Consequently, these sugars are stored in the brain and body causing loss of cognitive and physical abilities. Generally children with MPS have a life expectancy of only ten to twelve years. Kyle's diagnosis was devastating to all the people who were close to our family. Little did we know that Kyle would be the happiest child anyone had ever known. Kyle showed us all that, in spite of life's difficulties, it is still possible to keep a positive attitude and smile through all the hard times. He reminded us all that we could not take our time here on earth for granted and must live life to the fullest. Who knew such a young child could teach us so much?

Growing up with a brother who had special needs taught me another very important life lesson: to be accepting of everyone, no matter their differences. Kyle was always accepting of everyone. He greeted every person he met with a smile and a hug. I learned at a very early age that not everyone looks or acts the same, but that does not mean that you should treat them any differently. Kyle was a great example of this. Because of his disease, Kyle did not look the same as other children. He developed facial hair at a very young age and had exaggerated facial features. People would often stop and stare because they were curious and did not understand. I made it my goal to make others aware of his illness and to let them know that even though Kyle may look or act differently, he was still just the same as we were.

You should always find joy in the little things in life. This is yet another lesson my brother reminded me of on a daily basis. Kyle had fun no matter where we were or what we were doing. He always made the best out of situations. He gained such excitement from small things that we may just look at as a part of a day to day routine. Kyle's favorite meal was a cheeseburger and fries, and his favorite place to eat was McDonald's. The look of excitement stretched across his face when we would walk in to that restaurant was a reminder that even just a simple thing can brighten someone's day, that the little things really count for the most.

Kyle taught me that, through the good times and the bad, it is possible to keep a positive attitude. No matter what, he always had a smile on his face. When he was eight years old, Kyle lost the ability to speak and control his body movements, but that did not slow him down.

He required extra help getting through his daily routine, and my family and I were always by his side. Kyle was a member of a t-ball team, and although he could not hit the ball or round the bases on his own, that did not stop him. Kyle would swing the bat with my father's help and hold Dad's hands as he ran from base to base with the biggest grin on his face. These actions helped teach my family and me a valuable lesson: attitude is everything. The strength that he exuded helped us all to be stronger. His perseverance taught us to never give up, no matter what life throws in your direction.

When Kyle passed away at the age of twelve, I learned the most difficult lesson of my life. I learned that you should always take full advantage of your time here on earth. It is important to live each day as if it was your last, and Kyle did this whole heartedly. He was never afraid to try new things. To this day, I still strive to be more like him in this aspect. From his passing I also learned that you should never take your family and friends for granted. Spend as much time as possible with the people you love. You never know when they could leave you forever.

Without knowing it, Kyle taught every person he encountered important life lessons. He showed us all that it is possible to be accepting of everyone, even if they are different. He taught us unconditional love. Kyle proved to us that keeping a smile on your face and a positive attitude through the good times and the bad can help you make it through. He taught us that even when life is hard, leaning on your friends and family will help. Kyle also helped us see that sometimes the little things in life can bring the most joy. Kyle was a great example of living life to the fullest, and I am eternally grateful for all the lessons he taught me.

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 for the age requirements or email volunteer@focus-ga.org.

FOCUS Hospital Volunteers

(Continued from page 3)

Jen Angier: I have loved being a FOCUS volunteer at Under the Stars Family Camp and FOCUS on Fashion for almost ten years now. I volunteered to visit families in the hospital after Rosemary's death. I enjoy bringing a smile and feeling a sense of relief when I walk in the door of a hospitalized child and their family. The extra love FOCUS provides to families through this program is contagious – spreading love, compassion to them knowing they are not alone. I think Rosemary is looking down and smiling on all of us!

Visits to CHOA at Scottish Rite

Lauren Seidl: (Lauren is on vacation so we can rave about her without her permission!) Lauren serves on the board of directors at FOCUS and is otherwise known as "James' mom!" James has therapy every Monday at Scottish Rite so after Rosemary's death, she offered to give up her hour of knitting to visit FOCUS children and parents. After a year of visits, she now recognizes the 'repeat' families and prepares for her visits by shopping for special treats: a hairbow, a particular candy, a cup of soup. She especially likes giving the Mary Kay Pampering With A Purpose roll up bags for moms – she reports that moms love the bag better than chocolate!

Vickie Mabry: My family found FOCUS very early in our journey as parents when our youngest daughter Eve was born prematurely in 1989 and suffered a severe brain bleed at birth. Today she is a healthy (knock on wood) young woman with multiple disabilities and loads of personality. Eve reminds us daily of how lucky we are and, yes, how challenging it can be to have a character like her in our family. Over the years, we've spent a lot of time by her bedside at Scottish Rite, and I remember well the quick cheery visits from FOCUS' band of merry volunteers. I work close to Scottish Rite and can make visits at lunchtime. When I called to offer to volunteer, Rosemary had just died ... I guess it was a God thing!

Sarah Provow: I am blessed to be a hospital visitor for FOCUS, while continuing to volunteer at Extra Special Saturday respite in Alpharetta for many years. If I have the opportunity to put a smile on one mom or dad's face, or get just one tiny grin from a child, then I feel honored to have been able to spend just a moment with them. It is a mere moment in their busy doctor and test filled days, but to me it is often a moment frozen in time as I continue to hold that family close to my heart. And, I also love to be the bearer of chocolate, a temporary delight for many!

FOCUS Staff Joy, Elizabeth & Lucy visit children and families, when volunteers are unavailable or when the children are more critically ill. All three have parented a child with multiple disabilities and spent weeks in the hospital, more than once. Elizabeth and Joy have each lost a daughter, so they have walked the journey of bereavement. Hospital visits are always a good personal reality check and to remember to be grateful for home, health, and, um, chocolate! ■



Pampering with a Purpose

FOCUS moms continue to be showered with love by the Mary Kay Pampering With a Purpose (PWAP) roll up bags that were donated in August. In fact, we hear about moms trying to schedule a hospitalization just to receive one of these awesome bags (not really)! A huge shout out to Jen Dicello and her Mary Kay friends and to PWAP for the awesome donation and the ongoing love!

Support the ongoing Pampering With A Purpose campaign by Shopping on Thursday December 6 from 5:30 to 9:30 pm at a Holiday Extravaganza at the Gwinnett Environmental & Heritage Center in Buford. Thirty local small business owners will set up shop to help you with all your holiday gifts! For a flyer to share, email lucy@focus-ga.org.



Coming Up at FOCUS

Always check out the calendar at www.focus-ga.org for a complete list of programs!

November 3
Extreme Home
Modification Tour

November 4
FOCUS on Fashion

November 10
FOCUS Day at
ZooAtlanta

December 2
Snacks with Santa for
Medically Fragile Children

*Check the calendar for Extra
 Special Saturday respite and
 other on-going programs!*

Saturday, December 8
Annual FOCUS & Lekotek Holiday Party
 11:30 am to 2 pm
Eastminster Presbyterian Church
5801 Hugh Howell Road, Stone Mountain

Join FOCUS & Lekotek for food, fun, arts, crafts, caricatures and music. FOCUS will provide the fried chicken and Lekotek will provide the drinks and paper goods. If your name begins with:

- A-N Please bring a vegetable or side dish
- O-T Please bring a dessert
- U-Z Please bring bread

For easy clean-up, please bring food for 10 or more people in a disposable dish with a disposable serving utensil. Call FOCUS or email angie@focus-ga.org by December 1 and register the number

of adults and children attending. Santa brings each child a small gift so we need an accurate count; while bringing a grandparent or out-of-town cousin is permissible, please limit attendees to immediate family since we have limited space and Santa's workshop is pretty busy this time of year!!

Directions to Eastminster Presbyterian:
 Take I-285 to 78 East. Take Exit 7 (Hugh Howell Road) and go up the hill to the second church on the left. Families should enter the church through Founders Hall – follow signs & look for balloons!

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