



FOCUS

**Extraordinary Families
★ & Kool Kidz ★**

FOCUS

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My Sweet Myles

By Deidre Green

My son, Myles, is well-known for his pleasant personality and great sense of humor. He is very loving and compassionate, as most people expect from someone with Down Syndrome. There are, however, other aspects to his character. Myles has a strong-willed, stubborn, and non-compliant side that presents a big challenge for our family. Each day requires extraordinary patience and a lot of support!

By nature, I tend to tackle things honestly and directly. I have had to dig deep into my creativity pocket to keep my son active and focused. We relate best to each other when he is busy doing something he enjoys. So, we attend as many camps and workshops as fit into our schedule. One of the most rewarding things I have gotten him involved in, however, is Taekwondo. I was fortunate to be a part of the formation of the Special Needs Program at Tucker Taekwondo Center. There, he is fully engaged in the sport, learning discipline, and improving his fitness level. He responds well to Master Taylor's energetic blend of firm authority and fun.



Photo by Suchi Patton

appropriateness of his responses. At 9 years old, this sets him apart from his peers. Being in Taekwondo has not been the magic pill that makes him behave perfectly in all situations. What it has done, is show me what he can do under the right kind of direction. He is able to listen, focus, and follow directions. Knowing that he can do that in the dojang makes me confident that it will go with him elsewhere. In fact, I am already seeing that he is more manageable with other people.

- Independence is a big part of success for everyone. I
- want to make sure that Myles will be able to get a job. I
- know what the expectations are for most people with
- Down Syndrome. He could work for Publix; but, he
- could just as easily be a ball boy for the Braves or a
- water boy for the Falcons! I want him to develop the
- social confidence to explore his capabilities. Taekwondo
- is definitely helping me on that! As a parent, I have
- the responsibility to fully integrate him into society...
- and this program helps because it doesn't treat him as
- 'special.' He is a Martial Artist by his own efforts.
- I have dreams for him; but, Myles can't really
- conceptualize the future. What he knows is what he
- likes and desires today. He enjoys demonstrating
- and telling people about the sport he loves. Having a
- passion helps him articulate. He can do the kicks and
- explain each movement involved. He is very proud of
- what he can do and likes to show off his hard-earned
- muscles! I recently asked him what he was learning in
- Taekwondo. The list started with "Ai-ya!" and ended
- with "to follow directions". I cannot express how happy
- I am to have found a place where he can learn, have fun,
- and feel like he truly belongs. Surely this will translate
- into something positive for his future; and, that is what
- every parent wants. ■

With Down Syndrome, behavior can be very difficult to modulate. Myles cannot properly gauge the

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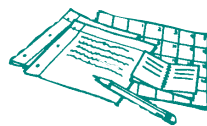
FOCUS offers emotional, informational, and physical support to families of children with disabilities or with ongoing medical conditions through a variety of programs such as support groups, respite care, and summer day camps. FOCUS networks parents who share common experiences and information with each other, providing a sense of community to families with children with disabilities.

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.

Families & Friends Give Back!

Building Bridges Therapy Services in Cumming organized a fund raiser for FOCUS on December 12. Vendors were invited to participate and give a portion of the sales to FOCUS! Vendors included Pampered Chef, Tastefully Simple, Tupperware, Stella & Dot, Premier Designs, Lia Sophia Jewelry, Celebrating Home, Darden's Delights, Discovery Toys, Fancy Beaus, and Custom Jewelry and Embroidery; Starbucks and Ippolito's donated refreshments. Thanks to all Building Bridges Therapy for organizing this event and to all the vendors and shoppers for their support!!



From the Editor

by Lucy Cusick

This year, my New Year's resolutions will NOT revolve around exercise, diet, or weight. I resolve to just be healthier, just because.

This year, I resolve to unplug. I resolve to turn my email off, unless I'm at work; okay, I'll check it only once or twice. I resolve to let my cell phone go to voice mail when I'm at Kroger. I resolve to realize that I do not have to be reachable at all times during the day (unless, of course, it's one of my kids calling!). I resolve to acknowledge that my Facebook Friends do not need to know where I am and what I am doing every day. I resolve to continue to resist a Blackberry, Smart Phone, and iPad. I resolve to continue to be think that tweets are a sound that birds make.

I resolve to go through the mail on my counter more than once a month. I resolve to keep a calendar that is detailed enough that I don't miss a commitment. I resolve to be careful and to not over-commit. I resolve to (gasp!) say no ... occasionally and only in the nicest of ways.

These resolutions I hereby make today, December 22, 2010. Check in with me on February 1 ... just call me on my cell. (Oops ... was that sarcasm?) ■

Spread the Word!

2011 is the year of spreading the word about FOCUS, especially to families with young children! Young children are vital to the growth of an organization! If you know a group that might like a guest speaker from FOCUS, if you are willing to take FOCUS brochures to the offices of professionals in your area, or if you have another idea on how to spread the word, please email Elizabeth@focus-ga.org.

Kool Kidz Closet – Great Deals Every Day!!

Times are tough – we all need a few bargains! Shop at the Kool Kidz Closet at the Village Terrace Shopping Center, 2500 Old Alabama Road in Roswell for gently used maternity clothes, children's clothing and toys. All sales directly benefit the Closet and FOCUS! The Closet is open for shopping on Tuesdays, Wednesdays, Fridays and Saturdays from 10 am to 2 pm.

The Closet accepts donations of gently used children's clothes, toys, books, and baby equipment. The Closet is also a wonderful place to volunteer! Email koolkidzcloset@focus-ga.org or call FOCUS for more information!

The Sounds of Katharine

By Elizabeth Hewell

POW! POW! Diagnosis Hydrocephalus

Hellpp. Prayer

Silence. No cry at birth. Lungs not developed

Squeek Squeek. Mobile incubator coming into our room for our first look at our baby girl

Sniff Sniff. Crying as Katharine is taken across the street to Scottish Rite

Silence. Overwhelmed by the realization that she is in need of soooooo much help

Ding. Elevator door opens and up to the 2nd floor of Scottish Rite

Click Click Click Click. Heels of my shoes as I walk down the long hallways to see my daughter

Splash splash. Wash your hands before entering the unit

Silence. I don't know which one is my baby.

Sniff Sniff. I am the first one to hold her. She is soooo tiny, helpless and beautiful

La la la la la. I sing and rock her for hours at a time

Beeeeeeeeeeep. Another child's pulse ox goes off

Swish Swish. Nurses to the child

Riiiiip Riiip. Diaper tabs of her diaper

Drip Drip. Feeding pump feeds my baby

Click Clack. Doors to ICU open and close over and over again

Ring Ring. Doctor calls at 6:30 am. Needs to perform another shunt revision (over 18 in 6 months)

Scraaatch Scratch. Consent for surgery. Sign my name, date, Katharine's DOB

Mur Mur Mur Mur. Prayer

Quiver Quiver. Diagnosis Epilepsy

HaHaHa. Laughter. Smiles and recognizes Dad and Mom

Splash Splash. Wash your hands

Buurrrrrpppp Ziiinnngg. Projectile vomits

Silence. Not thriving. Unable to eat

Sniffle Sniffle. Pray. We simply want to love her ... let us be wise with our decisions

Scraaaatch Scratch. Sign our name and date

Quiet. G-Tube and Fundo surgery

Flush Flush. G-Tube is plugged. Ginger ale or simply push??

Ha He Ha He. Laugh. Sometimes it is the only thing left to do

Hack Hack. Coughs a lot

Haannnnk Hannnnk. Breathing is sounding like a Goose call

Silence. She stopped breathing

WHY? Pray

Shhhhhhhhhhhhhhh. Aerosols

Thump Thump Thump. Chest Therapy

Silence. Trached at 3 months old and diagnosis Cerebral Palsy

Slurp Slurp. Suction Suction Suction Suction

Shhhhhhhhhhh. Aerosol

Thump Thump Thump. Chest Therapy every 4 hours

Silence. Shunt not working

Riiiiip Riiip. Surgical needle being open to tap her head for 2 months

Whhhaa Whhhaa. Cry – she does not like the pain. Even with a trach, I can still hear her cry

HELP. Pray

WHEW. Relief! Coming home after 6 months and 21 surgeries at Scottish Rite

Beep Beep... MMMMMM Oxygen at night...

Slurp Slurp. PICU in my little girl's room

Ding Dong. 12 hours nursing for 18 months – Prayer does work

La la la la Elmo's World. Elmo songs

I Love You, You Love Me. Barney songs

Once upon A Time. Reading her books

WOO WOO. Call 911 Allergic to milk

MA MA. Katharine starts to talk



(Continued on page 4)

Coming Up at FOCUS

Always check our website at www.focus-ga.org for updates!

FAST (FOCUS Adapted Swim Team) Fins

Register now – Season begins February 11

Fast Fins concentrates on learning and developing swim strokes, improving stamina, developing team skills, building self confidence, and increasing fitness. Participants must be able to swim one lap of the pool with minimal flotation and to follow directions. Coach to swimmer ratio is 1:4.

Download a registration form at www.focus-ga.org or call FOCUS with questions.

January 29, 2011

FOCUS Annual Education Conference Dunwoody United Methodist Church

Life as a parent of a child with special needs is often uncertain – you just never know what a new day has in store. Join us for Life Is ... An iPod Shuffle! We'll learn a lot and laugh a little. Brochures will be mailed to those families without e-mail addresses on file. Otherwise, we will e-mail them in early January. Call FOCUS if you don't get one.

February 26, 2011

Understanding the Transition Process

Sponsored by the InterAgency Transition Council and FOCUS at Mercer University Atlanta. Learn about services for young adults with disabilities as they exit high school. Topics will include SSI, guardianship, waivers, work & college options and more! Brochure on-line soon at www.focus-ga.org or call FOCUS!

February 26, 2011

28th Annual For the Love of Children Dinner, Dance & Silent Auction

Join us for an evening of Cabaret & Cabernet! Call FOCUS for sponsorship packages, ticket information, or to contribute to the silent auction.

April 27

FORE FOCUS Golf Classic at Bear's Best

May 1*

FOCUS Day at Six Flags Over Georgia

May

Camp TEAM

June & July*

Camp Hollywood

August 12-14*

Under the Stars Family Camp at Camp Twin Lakes

* Registration information will be available soon.

The Sounds of Katharine
(Continued from page 3)

Slurp Slurp. Suction Suction Suction
Suction

Thump Thump Thump, Shhhhhhhhh,
YAAAAA. No oxygen needed at night

Hurray Hurray. Trach out after 18 months.
Let's go to Disney!!

HaHaHeHeYooHoHo. Laughter and over
stimulated to see Barney

Beep beep. Feeding pump messed up, or
maybe it was me. Formula all over bed

Swishhhhhh. Enema

Riiiiip Riiip. BIG Diaper change

Aaaaaah. Katie Becket/Deeming Waiver
Renewal.

Chaching, chaching. Buying Girl Scout
cookies for IEP meeting.

Katharine talks. Bye Bye. Read a Book. I
want Mommie. LMNOP (alphabet). Peek
A Boo

YAAAAAY. Van with ramp

Creeeeek. Lock the wheelchair in van

Ding Dong. Therapy 3 days a week

Honk, honk. School bus for special
education preschool

Gurgle Gurgle. Not breathing correctly.
Diastat not working

WOO WOO. Slam. Close the door of the
ambulance door

MMMMM. No brain activity on MRI

Scraaaaatch Scratch. Do not resuscitate

Switch. All machines turned off

Silence.

The sounds of Katharine started on October 27, 1997 and suddenly ended on March 10, 2007. Our home and lives became silent of all the sounds of Katharine. This past November, as I entered my first FOCUS event, I was suddenly aware of her sounds again. The sounds of your children have been a comfort to me and have brought back sweet memories of Katharine. I am thrilled to be back serving the families of FOCUS.

Thank You

Many thanks for all contributions to FOCUS. This list is through December 20, 2010. All later donations will be listed in the next FOCUS newsletter.

Corporate/Foundation

LM Aero Club for Camp Hollywood
The Forrest & Frances Lattner Foundation for Family Activities
Alpharetta First UMC Women's Consignment
Cobb County Friendship Club
DeKalb School Employees Foundation
EZ Agape Foundation
GoodSearch
IBM Employee Services Center
Kiwanis Foundation of Atlanta
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The Billi Marcus Foundation
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Northlake Kiwanis Club
Philoptochos Greek Orthodox Cathedral of Atlanta
Plum District
Kaye B. Smith Foundation
Speedway Children's Charities
Toshi Designs We Are One
Tupperware Fundraiser
Uber Trade

SHOP TIL YOU DROP EVENT

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Lisa Buxbaum
Betsy & David Glass
Age Magerfleisch
Lauren Reid
Lucy Sommer
Starbucks in Cumming
Ippolito's in Alpharetta

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Memorials

In memory of Jack Raker by John McAllister
In memory of Ilana Hayes by Calanit Hayes
In memory of Kelly Graham Eanes by Jan Pittman
In memory of Michael Marland by Meg Marland
In memory of Emily Larkin by Jean Morgan
In memory of Ronald Seitler by Frank, Celia, Kirk & Scott Lawton
In memory of Liam Vilensky by Dana Cohen
Jane Radman
Richard Wolownik

Honorarium

In honor of the Kanne Family by Joseph Schwartzel
Cathi & Ronald Gramling
In honor of Jane & Jim Wells by Nancy & Tom Chewing
Corbin & Thomas Rankin
In honor of Bret Weiland for Hanukah by the Chimberoff family
In honor of Greg & Golfo Pappas by Tom, Carolyn & Tommy McBride
In honor of Pete & Pauline Giannakopoulos by Victoria & Lee Livaditis

In honor of Rebecca Holbrook by Mr. & Mrs. Alfred Holbrook
In honor of Dr. Tom Mahon on his retirement by Dr. Kim & Mary C. Sutherland
In honor of Amari Smith by Nita Stephens
In honor of Devin Terrell's 12th Birthday by Brian Johnston
In honor of Joy Trotti by Irene Constantinides
In honor of Benjamin Keesee by Mary & Robert Keesee
In honor of Zoe Ozga by Joan & John Donofrio
In honor of Sammie Leiter by Judy Bowman
In honor of Damian Caputo by Veronica Caputo
In honor of Mathew Wyatt Ladd by Jill Mahaffey
In honor of Lucy Cusick by Jane Ayres & Jim Smith
In honor of Joy Meenan by Kate Orecchio
In honor of Susan Calhoun by Doug & Susan Klee
In honor of Drs. Cooley, Miller, Lyon, Snitzer, Taylor, Lloyd, Walsh, Lantis, Suchder & Kogen, all of whom took such wonderful care of Liam and our whole family by Rachel, Asher & Meitav Vilensky
In honor of Ryan Benedikt, by Rosemary and Thomas Devine

FOCUS ON FASHION

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Fifth Third Bank
Darlene & Bill Walton
Kool Kidz Therapy Services
The Chase Family

(Continued on back page)

Looking Back ...

FOCUS on Fashion

The 11th annual fashion show, starring FOCUS children and the professionals who care for them, held at Oglethorpe University on November 6 was a fashionable success!!

Guests enjoyed performances by Fleetwood Dance Theater and Dance for Fun, music by pianist Christopher Cannon, and our beautiful children showing off the latest fashions from Belk. A special thanks to the doctors, nurses, therapists, and teachers who modeled with the children and to Shayr Guthrie and Patrick Cusick for emceeing another wonderful show. For a complete list of sponsors, please see the contributor list on page 5.



Annual FOCUS/Lekotek Holiday Party

The annual FOCUS / Lekotek Holiday Party was another grand affair. Families from all over metro Atlanta gathered at Eastminster Presbyterian Church in Stone Mountain for lunch, arts and crafts, the Secret Santa Shop and visits with Santa Claus. This annual event is a perfect way to begin the holiday season. Many thanks to Eastminster Presbyterian for their hospitality, Santa Eddy for his Santa love, Zesto for the yummy fried chicken, to the Northlake Kiwanis for their support, to the FAA for donating WebKins, to Lekotek for their help, and to all the volunteers who helped at this festive event!



MVP Holiday Party

Medically fragile children and their families enjoyed a family photo opportunity at FOCUS in late November. Thanks to Tripod Photography for donating a photo to each family, Dinner A'Fare Northlake for the surprise meal, and Santa Ed for his patience!!

EXTRA SPECIAL SATURDAY RESPITE SCHEDULE 2011

Acworth at Summit Baptist Church, 4310 Moon Station Lane
(You may register for three months, choose wait list for two months)

- January 8, 10 am to 2 pm
- February 5, 10 am to 2 pm
- March 5, 10 am to 2 pm
- April 2, 10 am to 2 pm
- May 7, 10 am to 2 pm

Alpharetta at Alpharetta Presbyterian Church, 180 Academy Street
(You may register for three months, choose wait list for two months)

- January 22, 10 am to 2 pm
- February 19, 10 am to 2 pm
- March 26, 10 am to 2 pm
- April 30, 10 am to 2 pm
- May 14, 10 am to 2 pm

Chamblee at Embury Hills United Methodist Church, 3304 Henderson Mill Rd.
(You may register for three months, choose wait list for two months)

- January 8, 10 am to 2 pm
- February 5, 10 am to 2 pm
- March 5, 10 am to 2 pm
- April 2, 10 am to 2 pm
- May 7, 10 am to 2 pm

Cumming at Christ the King Lutheran, 1125 Bettis-Tribble Gap Rd.
(You may register for all dates)

- February 5, 10 am to 2 pm
- March 5, 10 am to 2 pm
- May 7, 10 am to 2 pm

Johns Creek at Johns Creek United Methodist Church, 11180 Medlock Bridge Rd.

(You may register for all dates ... but only one FOCUS ESS a month!)

- February 5, 10 am to 2 pm
- March 5, 10 am to 2 pm

Grayson at Grayson United Methodist Church, 555 Grayson Parkway
(You may register for all dates)

- February 12, 10 am to 2 pm
- April 16, 10 am to 2 pm

Marietta at Mt. Bethel United Methodist Daycare, 615 Woodlawn Rd.
(You may register for three months, choose wait list for two months)

- January 22, 10 am to 2 pm
- February 12, 10 am to 2 pm
- March 12, 10 am to 2 pm
- April 16, 10 am to 2 pm
- May 14, 10 am to 2 pm

Newnan at Cornerstone United Methodist, 2956 Sharpsburg-McCullum Rd.
(You may register for all dates)

- February 12, 10 am to 2 pm
- March 26, 10 am to 2 pm
- April 16, 10 am to 2 pm

- To register your child, email karen@focus-ga.org OR call FOCUS with your child's name and age and the location for which you wish to register. Please note the registration restrictions of each location. If you are registering your child for the first time and would like to talk with someone, indicate that on your message. Not to insult anyone's intelligence, but here's an example of how to register, using the FOCUS voicemail. Call 770-234-9111, select extension 4.

"I would like to register Betty and Jack Smith for respite in Acworth on February 5, April 2, and May 7. I would like to be on the wait list for January 8 and March 5. Betty is 5 years old and has cerebral palsy; Jack is 3 years old and has no extra needs. I can be reached at 770-000-0000 if you need to call me about this reservation."

Parents will receive a reminder email from Karen Greenfield the Monday or Tuesday before each respite date, requesting that you confirm your plans to attend. Important: If you do not receive that email, you might not be on the respite list so call or email Karen to find out. Do not come to respite and hope for the best; we carefully plan our staff and volunteers based on the number of children we expect and do not want to disappoint anyone!! If your child is sick on the day of respite, please call FOCUS and let us know; we might be able to add a child from the waiting list!!

*Please bring lunch, extra clothes & diapers, and any medication (**must be in prescription bottle, with correct dosage on label**). We look forward to sharing an Extra Special Saturday with your child - enjoy your time off!! Register soon since locations fill up quickly!!*

Contributions
(Continued from page 5)

Denim Sponsors

- Building Bridges Therapy
- Floortime Atlanta
- Child Neurology Associates
- Darden’s Delights
- Fred Glass Family
- Allison & Kenneth Johnson
- Fleetwood Dance Theatre

FOCUS on Fashion Donations

- Pamela Adley
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- Deborah Maslia & J. Paul Whitehead
- Kathy McMillon
- Julie Rawls Moore
- Dina Norris
- Vicky & John Patronis
- Suzanne & Curt Smith

Equipment (and Clothing!) That Works!!

Kathleen Stover has designed an ingenious smock for individuals with eating or drooling issues. The smock is made from a ‘regular’ shirt; the shirt is altered so it can easily slip overhead and is lined with terrycloth for absorption. The neatest aspect is that the individual looks like he/she is just wearing a shirt!! Check them out at www.adaptationsbykathleen.vpweb.com or call Kathleen at 404-547-1826.



Parent Surveys

In November, we sent a survey for FOCUS families to complete. The results were very interesting – and, of course, sparked even more questions!! Look for more surveys in the upcoming months; we’ll keep them brief, but know that your input is important to us!

FOCUS is a nonprofit organization that provides emotional, informational and physical support to families of children with disabilities or ongoing medical conditions.

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