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MISSION STATEMENT

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.

Fund Raising Season is Upon Us!

Does your family / child enjoy FOCUS events? It's time to raise money for all the programs FOCUS offers; each program is offered to families at no cost, or at a much reduced rate; FOCUS covers the rest.

We have two annual fundraisers. At each one we have a silent auction and/or a raffle. We need items for both – new toys, gift items, gift certificates. January is a great sale month – if you find a great buy, please consider donating it to FOCUS!

- Saturday, March 15, For the Love of Children,™ the 25th annual dinner, dance, and silent auction. This year, we welcome Clark & Lane Howard as our honorary chairpersons!
- Wednesday, May 7, FORE FOCUS Golf Classic at Bear's Best. A great day of golf fore a good cause!!



From the Editor

by Lucy Cusick

It's that time of year again – time to make your New Year's resolutions! I have a theory about New Year's resolutions ... I don't usually make them. Instead, I make Monday, Tuesday, Wednesday (you get the idea) resolutions; I take Sunday off.

If you Google 'New Year's resolutions,' you'll find 359,000 hits. The first ten hits are interesting; the other 358,990 are fairly repetitive ... not that I looked at them all. According to www.wilstar.com, making New Year's resolutions dates back to early Babylonians. But the Babylonians weren't interested in losing weight or quitting smoking. Their most popular resolution was to return borrowed farm equipment!

www.usa.gov lists these favorite resolutions: lose weight, pay off debt, save money, get a better job, get fit, eat right, get a better education, drink less alcohol, quit smoking, reduce stress (overall and at work), take a trip, and volunteer to help others.

www.associatecontent.com offered a new twist to resolutions, including send a card once a week to someone who needs a lift; donate one item a month to charity (help others and clean the clutter); donate 2 hours a month to charity. Most advice includes trying to make the resolution a habit so that after 30 days, you don't have to consider it a resolution; Oprah calls that a 'lifestyle change.' In the special needs world, it's called 'behavior modification.'

I've noticed that most resolutions involve being 'better.' Eat better, pay better, be a better person. As the parent of a special needs child, my resolutions included helping Josh 'be' better – walk better, talk better, act better. I wonder if poor Josh ever felt better? At 22, he now must make his own resolutions; I'll offer assistance for 30 days to see if it becomes a lifestyle change.

As 2007 ends and 2008 begins, I resolve to only try to better myself. Maybe that will, in turn, help make everyone better. Oh, and I'll return any borrowed farm equipment. ■

Yadiel*(Continued from front page)*

found comfort and support (as well as yummy biscuits) at the FOCUS DeKalb Share Group. Meski has taken advantage of the Chamblee Extra Special Saturday Respite and has "enjoyed a little me time." Meski has also volunteered some of her precious time at the FOCUS office stuffing envelopes for FOCUS! Yadiel is taking a few steps with a walker and saying a few words. He says "No!" and "Why?" a bit too often for a tired single mother, but those words are music to

her ears! She works hard for her children and continues to fight for everything her two boys need.

Meski has mastered her third land...the land of special needs families...and has found herself a nice little niche. It is her home and although it is not the "American Dream" she envisioned for herself and family, she is happy and proud of the life she has given her sons. ■

Extra Special Saturday Registration Guidelines

To register your child, call FOCUS with your child's name and age and the location for which you wish to register. For Acworth, Alpharetta and Marietta locations: please choose three months to register and two months to be on the waiting list. 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 at Mt. Bethel Daycare on January 12, February 23 and April 19. I would like to be on the waiting list for March 8 and May 10. 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."*

For all other locations, please register as usual. If you are registering your child for the first time and would like to talk with someone, indicate that on your message.

*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!!***

EXTRA SPECIAL SATURDAY RESPITE SCHEDULE 2008

Acworth at Summit Baptist Church,
4310 Moon Station Lane

- January 12, 10 am to 2 pm
- February 2, 10 am to 2 pm
- March 1, 10 am to 2 pm
- April 5, 10 am to 2 pm
- May 3, 10 am to 2 pm

Alpharetta at Alpharetta
Presbyterian Church, 180 Academy
Street

- January 26, 10 am to 2 pm
- February 16, 10 am to 2 pm
- March 29, 10 am to 2 pm
- April 26, 4 to 8 pm
- May 17, 10 am to 2 pm

Chamblee at Embry Hills United
Methodist Church, 3304 Henderson
Mill Road

- January 12, 10 am to 2 pm
- February 2, 10 am to 2 pm
- March 1, 10 am to 2 pm
- April 5, 10 am to 2 pm
- May 3, 10 am to 2 pm

Conyers at Heritage Hills Baptist
Church, 2987 Highway 212

- January 12, 10 am to 2 pm
- No February ESS
- March 29, 10 am to 2 pm
- No April ESS
- No May ESS

Cumming at Christ the King
Lutheran, 1125 Bettis-Tribble Gap
Road

- No January ESS
- February 2, 10 am to 2 pm
- March 1, 10 am to 2 pm
- No April ESS
- May 3, 10 am to 2 pm

Mableton at First Baptist Church,
5385 Main Street

- January 26, 10 am to 2 pm
- March 15, 10 am to 2 pm
- May 3, 10 am to 2 pm

Marietta at Mt. Bethel United
Methodist Daycare, 615 Woodlawn

- January 12, 10 am to 2 pm
- February 23, 10 am to 2 pm
- March 8, 10 am to 2 pm
- April 19, 4 to 8 pm
- May 10, 10 am to 2 pm

Snellville at Snellville United
Methodist Church, 2428 Main
Street

- No January ESS
- February 23, 10 am to 2 pm
- No March ESS
- April 19, 10 am to 2 pm
- No May ESS

Equipment That Works!

Minivans are terrific for many purposes; they can carry up to 7 people and haul all kinds of cargo. Minivans can also be fitted with a wheelchair lift or ramp system; most of the time, however, a van loses at least one seat when these are added. What happens when you have a large family, thus needing all the seats in the van OR when your child uses a walker? The walker can fold up into the back of the van, but the van is a little too high to lift a teen or young adult into the van?

The Kostopoulos family found a seat to replace a captain's chair in their Toyota Sienna minivan for their 18-year-old Nick who uses a walker. The van is too high for him to get into the van and he's too heavy to

lift!! The Turning Automotive Seating (TAS) by Bruno was the perfect answer for the Kostopoulos family. According to the Bruno website (<http://www.bruno.com/bruno-turning-automotive-seating.html>), the TAS is a "system that provides easy access to an automotive seat. For higher vehicles, this is accomplished by seat rotating, coming out of the vehicle and down toward the ground."

They ordered the TAS through Mobility Express who replaced one captain's chair with the TAS. This seat retails for about \$4500. If added to a new van within a year, a rebate of \$1,000 is available; you must confirm the rebate with Toyota.



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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UNDER
STRESS

FOCUS

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Yadiel

By Meskerem Tizazu, as told to Stephanie Shapiro

Meskerem Tizazu (Meski to her friends, family, and FOCUS) had already experienced navigating through a foreign country when she moved to the United States from Ethiopia 10 years ago. She and her husband settled down in Virginia to begin their family and soon were the proud parents of a healthy baby boy, Nathan. Life was as she expected and dreamed. Meski was living the "American Dream." How could she have possibly thought her life would be any different when she became pregnant with their second child soon after?

Life did become different, drastically different. Two weeks before her due date, Meski was in a car accident. Within seconds, her life began a new journey, in another foreign land. Upon collision, Meski's placenta separated and an emergency c-section was performed. It was unclear how long her son, Yadiel had been deprived of oxygen, but doctors assured her that after his 14-day stay in the NICU that her little baby boy was fine. Meski remembers the doctor reassuring her that "all is well." Meski's motherly instincts told her otherwise.

Over the next few months, Meski poured over Nathan's baby videos, convinced that Yadiel was not developing properly. "He doesn't hold his head up," she pleaded to the pediatrician. "All children develop at different rates," she was told, "you cannot compare your boys."

She did compare, though, and knew by his lack of muscle tone and tight little fists that something wasn't right. Smart and unyielding, Meski continued to question; one day her pediatrician was on vacation and Meski leapt at the opportunity. She took her son in to the office and met with another pediatrician within the same practice. And her instincts were confirmed. That pediatrician validated her concerns and ordered an MRI immediately. Memories of the car accident, the emergency c-section, the 14 day stay in the NICU rushed back. Yadiel had moderate to significant brain atrophy and was diagnosed with cerebral

palsy due to traumatic brain injury. Finally, someone believed her. Finally her son could get some help. Therapies began immediately.

When your child has special needs, so does the entire family. Meski quit her job to stay home with Yadiel and pursue his growing medical and therapeutic needs, but financially the family could not continue to live in Virginia. In 2005, Meski moved to Atlanta with her two young children; her husband was to follow when a job transfer became available. He never moved, however, and they were divorced soon after. Meski now faced the challenge of being a single mother, alone in a large city with no family around to help her. Many people would fall apart under such circumstances, but not Meski. She held her head up, smiled, pushed forward and created a life for herself and family in Tucker.

Today, Meski works part time as a dental assistant and has a wonderful neighbor who helps with her sons. She has
(Continued on page 7)



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Visit our web site at www.focus-ga.org for information and upcoming events!

Thank You

Many thanks for all contributions to FOCUS. We work diligently to use all contributions to help families of children with disabilities or ongoing medical needs.

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*Plus a special thanks to all
who placed ads in the program,
attended the show, and/or
volunteered for the show!*

FOCUS 2008

Get Organized & Mark Your Calendars Now!

February 9

FOCUS Annual Education Conference

Join us for a day of "Jeopardy!" at
Dunwoody United Methodist Church.
Brochures mailed separately.

March 15

25th Annual "For the Love of Children"
Dinner, Dance and Silent Auction
Honorary Chairpersons:
Clark & Lane Howard

May 4*

FOCUS Day at Six Flags Over Georgia

May 7

"FORE FOCUS" Golf Classic at Bear's Best

June 2 – July 11*

Camp Hollywood –
exact dates still being determined

August 15-17*

Under the Stars Family Weekend
at Camp Twin Lakes

* *Registration information will
be mailed by March 1 for these
events.*



LOOKING BACK!

Visit our website for information on upcoming events.

FOCUS Day at ZooAtlanta

FOCUS families enjoyed a relaxing day at ZooAtlanta on October 27 in the Ford Eco Center. This new location was a big hit – larger, warmer, and with a play area! Thanks to the Jr. League of Gwinnett & North Fulton and FOCUS fund raisers for sponsoring this popular event.



“FOCUS on Fashion”

The eighth annual fashion show, starring FOCUS children and the professionals who care for them, held at Georgia Shakespeare on November 11 was a fashionable success! Guests enjoyed entertainment by Fleetwood Dance Theater and Dance for Fun, music by pianist and composer Christopher Cannon, and our beautiful children showing off the latest fashions by Belk. The fashion show showcased our FOCUS children (and their special professionals) and highlighted the programs that FOCUS offers children with disabilities or medical needs and their families. Many, many thanks to all the models, sponsors, and volunteers who make this event so special to FOCUS. For a complete list of sponsors and contributors, please see the contributor list on page 5.



Annual FOCUS /Lekotek Holiday Party

Over 90 families from all over metro Atlanta gathered at Eastminster Presbyterian in Stone Mountain and enjoyed lunch, arts & crafts, and the Real Santa Claus on December 8. This annual event is the perfect way to celebrate another year – thanks to all who came, helped, contributed (see contributor list) to this festive event!

Special Education Corner

By Jean Estes

Parent Question:

We had to take our son out of school because he has had pneumonia twice in six weeks. The school system will provide a tutor three hours per week, but will not provide any other services. His IEP says he's supposed to get PT, OT and speech. Is the three hours of tutoring per week all that the school system is required to provide to our son?

Jean Estes answers:

No, three hours of academic tutoring is not all that he should be getting. According to the State Rules, specifically 160-4-2-.31 and 160-4-7-.07, your son's IEP team must consider the medical information as they review his IEP to change his placement to a hospital/homebound, and they must determine the other services which are necessary for him. If he was receiving speech, PT and OT, his medical condition does not change his eligibility for those services. It could cause a need for any one of them to be stopped temporarily (for example orthopedic surgery could cause PT to be stopped until the student healed). If the homebound student can still benefit from and participate in speech, PT and OT, the IEP committee should provide for those services to be given in addition to the services provided by the teacher. In addition, all homebound services are to be given by appropriately certified staff. If there is any question about what is appropriate and what the student can endure, the physician should put in writing that the student can continue to receive therapy(ies). ■

Jean Estes is an attorney in private practice representing children with special needs and their parents in their quest to obtain appropriate services in Georgia schools. Jean has worked with families for over 23 years and is the mom of a 14-year-old student with disabilities. Send your questions for Jean to angie@focus-ga.org or call 770-234-9111.

Trusting My Instincts

By Roger Brown

In 1997, my daughter almost died because of a plaque on the doctor's wall. Victoria was 10 years old at the time. She is non-verbal, epileptic and takes a variety of seizure meds.

Our story started when my wife and I took Victoria to the ENT to be treated for a sinus infection. The doctor prescribed an antibiotic. Over the next couple days, Victoria got progressively worse – lethargic to the point where all she would do is sit and stare. I knew the antibiotic wasn't working, because I had taken so many antibiotics myself.

I called the doctor and spoke with him personally. He told me to continue with the antibiotic. When I questioned him, he laughed and insisted that he was "board certified," with a plaque to prove it. I needed to relax and give the antibiotic a chance to work and I needed to listen to him. His attitude felt very condescending and I really didn't think he was listening to me. That really ticked me off, but I didn't have a better plan, so I did nothing.

The next day, Victoria was even worse. We called her neurologist and the office recommended Dr. Ann White, a pediatric ear, nose and throat specialist in Atlanta. Dr. White took one look at Victoria and said "Something is wrong and I don't know what it is, but we need to get her to Scottish Rite immediately."

I loaded Victoria back in her car seat and drove her to the E.R. – by this time, she was so listless she could hardly hold her head up. After blood work and 4 hours of waiting and analysis, the E.R. doc told me that Victoria's white cell count was dangerously low. The antibiotic that had been prescribed was interacting with one of her seizure meds with catastrophic consequences. They said she was hours away from death.

The seizure meds and antibiotic were stopped. We spent a night in the hospital and the next day Victoria came out of the fog – it was amazing how quickly she turned around.

I tell you all this to make you aware of what we found out about the dynamics of the patient/doctor relationship in medical problem solving, not to condemn the doctors involved – that solves nothing.

The reason this story is important is because it gave me the confidence to be a strong advocate for my children. Even though we may not be as articulate as the physicians, we, as parents have an intuitive feel for when something's just not right or a recommended solution is off the mark.

Often times physicians don't have a clue, but they will offer a remedy nonetheless, because that's what they are trained to do. The physicians involved in our story all had Victoria's best interests at heart. The problem is doctors are used to being the smartest folks in the room and therefore commanding credibility and respect. At our own risk, do we dare confuse their confidence and eloquence with problem solving ability?

... we, as parents, have an intuitive feel for when something's just not right or a recommended solution is off the mark ...

My wife and I learned these lessons:

- Politely speak up if it doesn't seem right – even if you can't explain why.
- Don't be afraid to suggest alternatives and boldly act on your instincts.

I have seen doctors change their minds midway through a session too many times in response to my suggestions, to think otherwise now. Physicians certainly have more information from years of training and experience in the field. Knowledge does not directly translate into problem solving, which requires listening and an open mind. Smart doctors consult and collaborate, rather than dictate.

Have confidence in your own sense of when a diagnosis or course of therapy is right or wrong and politely stand up for your child – even if you can't explain your reasons. ■