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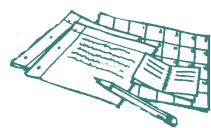
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MISSION STATEMENT

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.



From the Editor

by Lucy Cusick

This fall is filled with activity at FOCUS. The Extreme Home Modification Tour (September 15), FOCUS Day at the Georgia Aquarium (September 16 – yes, all 800 tickets are gone, sorry), FOCUS Day at Zoo Atlanta (October 27), FOCUS Fashion Show (November 11), Annual FOCUS / Lekotek Holiday Party (December 8). Mixed in with these big events are the usual programs such as Extra Special Saturday Respite and Parent Support (Share) Groups. In between, we continue to work to raise awareness about living with a child with special needs and to raise funds for our programs so that the cost is not passed on to our families.

As if that's not enough, we have another big event to announce: the FOCUS office is moving!! We have been in our current office for 5 years and our staff and programs have grown during that time. We found a nearby office that will accommodate our administrative needs and our desire to offer more informational workshops to families; we hear the need for more information on Medicaid waivers and IEPs. We recognize the need for parents of young children to learn to navigate the system. We see the need for more teen activities. We would love to offer classes on Wellness and nutrition...for parents!! This new office space will accommodate all of this, with room to grow. Yes, you'll have to drive to us....but we plan to make it worth the trip!!

We do have a wish list – actually, more of a 'must have' list. Gifts of money will be used for folding chairs and tables; we'd like to buy them so they'll match! We need a few desks, with computer returns so if your office has upgraded, we'd love to look through the storage closet. If you have time to help pack and unpack the last week in September, give us a call! The more the merrier, many hands make light work, and we all love to be needed. ■



Spin for Kids

A BIKE RIDE TO BENEFIT CAMP TWIN LAKES AND ITS PARTNERS

Sunday, October 28, 2007 Camp Twin Lakes Rutledge, Georgia

Join Camp Twin Lakes and its partners for a fundraising bike ride through the gentle rural hills of Morgan County and help send children with serious illnesses and life challenges to camp.

Go to www.spinforkids.org and register to ride for Team FOCUS.
 Funds raised will go towards the events that FOCUS offers at Camp Twin Lakes:
 Under the Stars and Camp Infinity. Join us for a fun day – call us at FOCUS with questions!!

Camp Hollywood: *Where Everyone's A Star*

FOCUS made stars for ten weeks all over metro Atlanta at Camp Hollywood! Campers made Razzleberry, Snazzleberry Fizz, created Bouncy Blubber, painted birdhouses, and sang "Take Me Out to the Ballgame." Campers, volunteers and counselors all had fun at Camp Hollywood!

We appreciate all the staff and volunteers for their energy and devotion to our campers. Thanks also to the churches that opened doors and hearts to FOCUS and to our families: Alpharetta Presbyterian, Cathedral of St. Philip, Embry Hills United Methodist, Heritage Hills Baptist, Hope House, Johns Creek United Methodist, Mt. Bethel United Methodist, and Summit Baptist.

Thanks also to the sponsors of Camp Hollywood: Alpharetta Presbyterian Church, Fulton County Human Services Department (F.R.E.S.H.), The Kroger Company, John Wieland Homes & Neighborhoods, Post Properties, Snapping Shoals EMC, Imlay Foundation, The James M. Cox Foundation, Variety of Georgia, and Mrs. Lenore Maslia, plus sponsors of "FORE FOCUS" and "For the Love of Children."



A Match Made at ... Camp Hollywood!
(Continued from front page)

condition, and they grieved for their daughter and her loss as they grieved for Evan. They continue to support causes that help families of children with special needs, always in memory of their precious Evan.

These two families might never have met; by 2005, Jordan was a teen and Evan had been gone for 10 years. But, stars crossed as FOCUS began looking for a new location for Camp Hollywood. Mr. Hal heard of our search and vouched for FOCUS at his church in Roswell. He offered to be the liaison between church and camp, to come to camp each day so he could help make camp work for the kids. He only had one request: he did not think he could work with the children. He choked up, saying that he just was afraid he would be too sad, remembering Evan, remembering their loss. Of course, I agreed with sympathy and understanding. We would love to have his help and certainly understood his limits.

I understood his request ... but I forgot to tell the camp director! On the first day of camp, registration was chaotic, as always. In the confusion, Mr. Hal was assigned to Group 4, the older group of teens, to help as necessary with that group. After registration calmed down, I started looking for Mr. Hal, checking to make

sure that he was ok. When I discovered the mistake, I went to him, told him I needed him at registration, that we needed a vacuum, that we needed a mop ... trying to convince him to come out in the hall. "No," he said, "I'm helping Jordan. If I leave, who will help her?"

And so it was. Jordan and Mr. Hal became the talk of Camp Hollywood in 2005 and every Camp Hollywood since. Mr. Hal helps Jordan in every class – they bowl, they sing, they paint. Mr. Hal feeds Jordan each day, making sure she drinks or eats all that her mom says she needs. He pushes her wheelchair, greets her each day, and when Jordan seizes, Mr. Hal sits and holds her hand, gently calling her name until the seizure ends.

And there's more. Mr. Hal goes to Jordan's Miracle League games and birthday parties. He came to the FOCUS fashion show to cheer her on. He attended her graduation party. When they are together, you might catch them share a smile, or maybe even holding hands.

Friendship such as theirs is not found everyday...but our lives are not everyday. Miracles and friendships are everywhere at FOCUS – just ask Mr. Hal and Jordan. ■

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 two 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 September 15 and October 20 and April 15. I would like to be on the waiting list for November 17 and December 1. 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 2007

- Acworth** at Summit Baptist Church • 4310 Moon Station Ln.
- September 8, 10 am to 2 pm
 - October 6, 4 to 8 pm
 - November 10, 10 am to 2 pm
 - December 1, 10 am to 2 pm

- Alpharetta** at Alpharetta Presbyterian Church
180 Academy Street
- September 29, 10 am to 2 pm
 - October 27, 4 to 8 pm
 - November 17, 10 am to 2 pm
 - December 15, 10 am to 2 pm

- Chamblee** at Embry Hills United Methodist Church
3304 Henderson Mill Road
- September 8, 10 am to 2 pm
 - October 6, 4 to 8 pm
 - November 3, 10 am to 2 pm

- Conyers** at Heritage Hills Baptist Church • 2987 Highway 212
- September 29, 10 am to 2 pm
 - October 27, 4 pm to 8 pm
 - November 17, 10 am to 2 pm

- Cumming** at Christ the King Lutheran
1125 Bettis-Tribble Gap Road
- October 6, 10 am to 2 pm
 - November 3, 10 am to 2 pm
 - December 1, 10 am to 2 pm

- Marietta** at Mt. Bethel United Methodist Church
4385 Lower Roswell Road
- September 15, 10 am to 2 pm
 - October 20, 4 pm to 8 pm
 - November 17, 10 am to 2 pm
 - December 1, 10 am to 2 pm

- Snellville** at Snellville United Methodist Church
2428 Main Street
- October 20, 4 pm to 8 pm
 - December 15, 10 am to 2 pm

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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FOCUS





A Match Made ... at Camp Hollywood!

By Lucy Cusick

There are many stories that represent FOCUS, stories of friendships, laughter, and shared times. Some make you laugh, some cry, some shake your head in awe. I'd like to share one of many FOCUS stories as we begin our 25th Year of Support.

Jordan Aldredge was born in 1987 to Mike and Christy Aldredge. Their second child, Jordan appeared healthy, breezing through her two-month checkup with ease. A month later, Jordan's older sister broke her arm; Christy vividly remembers thinking that that broken arm was so terrible, just the worst thing that could ever happen. She changed her mind the very next weekend, Easter weekend, when Jordan had a seizure. After a battery of tests, Jordan was diagnosed with lissencephaly; she was one of the first children with this diagnosis in Atlanta. Lissencephaly means 'smooth brain' and causes developmental delays, cognitive delays, physical disabilities, and a host of medical issues. Mike and Christy were devastated when they were told that Jordan's life expectancy was only 5 years. Christy says now that she jumped every time Jordan sneezed, afraid that this was the moment that Jordan was dying. (Jordan is now almost 21 years old!) While Jordan is delayed in all areas, the most concerning is her seizure disorder. The Aldredges found FOCUS early and were involved in share groups and family activities. Jordan is now a regular at Camp Hollywood in Alpharetta; she is just delightful - all smiles when she is happy and communicates with her facial expressions.



Not far away, in 1989, another young couple, David and Anne Moroz, welcomed Evan, their first baby boy. They were settling into parenthood when they found thirteen-day-old Evan in his crib not breathing. He was resuscitated and spent time in intensive care. Evan never had a diagnosis, but most medical professionals attributed his resulting medical issues to interrupted sudden infant death syndrome (SIDS). Evan needed a tracheostomy, a J-tube, and later a G-tube. As a registered nurse, Anne learned the ongoing care that Evan needed, and she, David and their families accepted and loved Evan for all his abilities. At age 4, however, Evan died very suddenly, probably due to unknown cardiac complications. Anne and David remember and miss him every day. Anne now works with many parents of children with special needs as a nurse at Northside Hospital, giving them hope and advice to help them on their journey.



Evan's grandparents, Mr. Hal and Mrs. Shirley Davies, were a huge support to Anne and David. Mrs. Shirley saw them daily; Mr. Hal traveled with work and worried about and loved them as he worked. They loved Evan without

(Continued on page 7)

Inside This Issue

-
- Contributions*page 3
- Equipment That Works*page 4
- Coming Up at FOCUS*page 5
- Extra Special Saturday*.....page 8
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Visit our web site at www.focus-ga.org for information and upcoming events!

Equipment That Works – Breathing a Little Easier

By Stephanie Shapiro

Our handsome two-year-old son Jake came into this world with a long list of complications. After a healthy full-term pregnancy, he was born by an emergency C-section with the umbilical cord tightly wrapped around his neck. There was no heartbeat. They called him a 'blue baby.' During the trauma at birth, Jake had also aspirated meconium. His lungs were severely infected and weak. To further Jake's issues, he was later diagnosed with mitochondrial disease and a seizure disorder. We had been through all this before. Jake's sister Hannah, 18 months older, also has mitochondrial disease and seizures. The difference was that Jake's lungs were incredibly delicate and sensitive due to his additional issues at birth. Jake's low muscle tone, non-ambulatory status, and delicate respiratory system led to many doctor's appointments, ER visits and hospitalizations due to respiratory complications and pneumonia.

My husband and I spent countless nights staying up with Jake taking turns "cupping" his lungs (also known as chest percussion therapy or CPT). I likened it to repetitively beating on his back in hopes of breaking up the mucus and phlegm that inevitably found a home in his lungs. There were many sleepless nights when all we did was hold him in our arms trying to break up the colony of infection spreading through his little chest. Jake did not have the strength and muscle tone to cough up the build-up that grew within him. It broke my heart to hear him rattling with every breath, and I counted the days until the next doctor's visit or chest X-ray. I felt as though nothing we did alleviated his discomfort: therapies, massages, and breathing treatments. Every time he was hospitalized for upper respiratory issues, I feared it would be too much for his little body to take. In February, Jake was hospitalized again. In less than two years, it was his eighth hospital stay. I was afraid we were going to lose him.

Soon after that, we were introduced to an AMAZING and life-saving therapy system called simply THE VEST. The Vest Airway Clearance system is an easy-to-use airway clearance device consisting of an inflatable vest connected by two tubes to a small air-pulse generator. When worn, the air-pulse generator rapidly inflates and deflates the vest, gently compressing and releasing the chest wall up to 20 times per second. This process, called high-frequency chest wall oscillation, creates mini-coughs that dislodge mucus from the bronchial walls, increase mobilization, and move it along toward central airways. The action

also works to thin thick secretions, making them easier to clear. Once the mucus has moved from the smaller to larger airways, coughing or suctioning can easily remove it. In addition, the therapy opens the lungs so well that we can do his breathing treatments at the same time making them twice as effective. Unlike manual chest percussion therapy, The Vest system treatment does not require special positioning or breathing techniques. The process may sound uncomfortable, but it is so gentle it feels like a massage. Jake has even worn his vest in his crib and has slept during his therapy sessions!

Our Vest System was purchased through Hill-Rom after a prescription for the device was faxed by our pediatrician's office. The system is typically fully covered by insurance. Ours was initially denied, but Hill-Rom quickly appealed and, sure enough, our insurance company realized how much they could save in fewer hospitalizations due to this preventative and effective therapy system.

Since the Vest, Jake has had clear-lung check-ups and has even increased his muscle-tone and level of alertness. His tolerance to physical activity has increased so much so that we have been able to increase his physical therapy and set long-term goals we never imagined before. I finally see a light at the end of the tunnel we have been navigating for years. The Vest has been a gift to not only Jake, but to my entire family. Jake is happy, breathing well and we can all rest peacefully at night. I only wish we had found it sooner!! ■



Coming Up at FOCUS

3rd Annual Extreme Home Modification Tour

Saturday, September 15
10 am to 1 pm

Have you considered making changes to your home to allow your child with disabilities better access, more independence, or for easier care giving?? Come see how other FOCUS parents have modified their homes. You MUST RSVP by calling FOCUS or emailing angie@focus-ga.org to receive the directions & further information on each home.

Teen & Young Adult (T/YA) Groups

Saturday, September 29, 4 - 7 pm
Saturday, October 20 4 - 7 pm
Saturday, November 17, 4 - 7 pm

We've not determined what we'll do, but we've blocked off the dates! (The times may change a little, especially if we are going to the movies.) We'll post the activity on the website as soon as we know. This group is especially for teens and young adults who want a place to hang out, will stay with the group and require no on-site medical staff.

Register by calling FOCUS or emailing lucy@focus-ga.org.



Atlanta Parent Magazine's Family Block Party 2007

Saturday, October 13, 2007
Mercer University – Atlanta Campus
One beneficiary is FOCUS
Go to www.focus-ga.org for further info!

EDUCATION CORNER, by Jean Estes

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 to FOCUS for Jean to angie@focus-ga.org or call 770-234-9111. She will choose one or two questions for each newsletter.

Mom's Day Off!

Saturday, October 20, 2007
11 am – 3 pm

It's the day FOCUS moms eagerly anticipate – Mom's Day Off!! We'll enjoy a fall day on the lake – bring a dish to share, a six pack of your favorite non-alcoholic beverage and join us for a relaxing day on the lake. Directions will be sent only to those who RSVP by calling or emailing angie@focus-ga.org by October 12.

6th Annual FOCUS Day at ZooAtlanta

Saturday, October 27
Lunch at the Ford Conservation Room & Eco Hall
Provided by FOCUS – New Location this year!!

Zoo Day Details:

- You must purchase tickets in advance from FOCUS for your immediate family only. Children (3 and over) and Adults are \$10 each. Children under 3 are free. Lunch will be in the Ford Conservation Room and Eco Hall (11:30 am to 1 pm) is included!! But come EARLY to get good parking!!!
- Tickets must be used on October 27, rain or shine.
- Make a day of it! Zoo hours are 9:30 am to 3:30 pm because "Boo in the Zoo Day" is a special evening event on October 27 this year. Go to www.zooatlanta.org for more information.
- October is the perfect time to visit the zoo – cool enough for the animals to appear, warm enough to be comfortable.
- Families with Zoo membership can attend for only \$5 per person (3 and over).
- For tickets, please send your name, address, and phone number with a check for the number of tickets you need by October 12 (so we'll have time to mail the tickets to you). Please include a self-addressed, stamped envelope. We'll mail all the tickets and updated zoo information on October 19.

LOOKING BACK!

Visit our website for information on upcoming events.

9th Annual Under the Stars Family Weekend – FOCUS Is A Blast!

Ten things I learned from FOCUS Under the Stars Family Fun Weekend 2007

*By Kim Denson, with apologies to those who did not attend.
Some of these refer to the weekend and you just had to be there!!*

1. It is okay to have 'ice cream and cake' before a meal!!
2. The FOCUS staff is really very organized angels in disguise.
3. Any food is good when you are not the one cooking it.
4. I really can relax away from the comforts and routines of home.
5. Cookies and milk at 9:00 pm really do help you sleep!
6. There is more than one way to "Walk It Out!"
7. Respite travels!!
8. We could share a cabin with another family that we didn't know and actually LOVE them!!
9. "Melt-downs" aren't so bad ... when you are among your FOCUS Family.
10. That I will not miss another one – FOCUS is a BLAST!



Thanks so much for a fabulous weekend!! I REALLY did enjoy myself. I loved our cabin-mates so much. I learned this weekend to be more patient with my son after watching how she managed her son. We always can learn from other families, and I appreciate that opportunity!!



CAMP INFINITY

There are not many overnight camp opportunities in Georgia for teens with physical and/or cognitive disabilities so FOCUS, Kool Kidz Foundation, and Camp Twin Lakes came together to plan an overnight camp: Camp Infinity!! For the pilot week of Camp Infinity, we selected teens from FOCUS and Kool Kidz whose needs we felt we could manage for four nights. We had a great week of high ropes, zip lining, climbing wall, swimming, dive-in movie, and archery. Three organizations are better than one – and we had the Infinite Fun to prove it!!!

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.

Fulton County Human Services Department (F.R.E.S.H.) for Camp Hollywood

Corporate/Foundation

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Individual Contributions

Lemonade Stand by Avery Denson, Natalie

Young & Erin Moore
(see photo)

Jesse & Janis Chastain
Mrs. Lenore Maslia
Christopher & Cynthia
Mathis

John & Catherine Oubre
Ryan & Lauren Reavis
Josephine Ross
Rosemary Saunders
Darin & Kathleen Shelp
Whitney & Keri Webb



Honorariums

In honor of Alice Ann Fell by HE & Jean Puder
In honor of John DeLuca by Eula Catrett

Memorials

In memory of Cade Sherwood by Rusty Townsend
In memory of Laurel W. Ziemer by Melinda & Mark Ziemer
In memory of Dan Dunwoody, Dr. Henry Warnock & Charles C. Hertwig III by Mr. & Mrs. W.P. Thompson

Microscopes Are For Science – Not For Children with Special Needs

The first useful microscope was invented in the Netherlands in the early 1600's. Since that time the microscope has developed into a powerful tool that is used in a variety of disciplines. For example, microscopes allow us to view and study the microorganisms that make people sick. They are employed by security personnel to reveal the presence of material that is suspicious in origin, and they are even used by historians to detect the age and composition of historical artifacts.

There is a different microscope, however, that is often used with special children. This microscope is not a piece of equipment, but rather it is the tendency to scrutinize the actions of children with disabilities more closely than the actions of children who are considered typically developing. Trickier still, is the fact that most people do not even realize that they are using their "human microscopes" for this purpose.

Consider the following scenario that happened one day to my child. My special child was participating in a mainstream class, when an "incident" occurred with another typically developing child. The child claimed that my son had made some sort of physical contact with him. However, the teacher and my child's paraprofessional observed nothing unusual during the instruction. Furthermore, there was nothing to indicate that the child was distressed and the child did not say anything to either of the adults in the room at the time of the occurrence. It was only later, while at home, that the child mentioned the situation to his parents. The parents then called the school to complain. Administration interviewed both the teacher and the paraprofessional and they verified that they had observed nothing. Still, my child was taken to the principal's office to discuss how to interact "appropriately" with others.

This incident was minor, and probably would have not elevated to the parent level and certainly not to the school's administration, had it involved two typical children. I feel as if my child's behavior is constantly scrutinized, that his every move is observed, recorded, and reported. Don't get me wrong; I work diligently to help my child learn 'appropriate' social behavior. New situations (like a new school year and a new teacher) are difficult for him. I use social stories to re-direct, explain, and re-explain. But my child is a child, after all. Like other kids, he misbehaves and manipulates. And he should be punished, for infractions that are serious. But ... not for every little childish misdemeanor. Every once in a while it is ok to look the other way, to distract or re-direct without blowing every action out of proportion. Perhaps without the microscope, he could be viewed as member of one large class of kids, and the whole situation would be kept in perspective.

Special children deserve to be treated as normally as possible. When we make an effort to treat them that way, we might be surprised to discover that in many cases special kids do exactly the same things that typically developing children do. ■