



Extraordinary Families
★ & Kool Kidz ★

FOCUS

Volume 28, Number 4

July/August 2011

FOCUS Celebrates 28 Years: 1983 – 2011



FOCUS in 1983

In August 1983, the first FOCUS newsletter was typed (yep, on a typewriter!) and xeroxed for distribution to the first FOCUS families. It was two pages long and written by FOCUS co-founders Susan Calhoun and Lynne Conboy. From that very first newsletter:

We are pleased to let you know that FOCUS is officially off the ground. We are excited about the potential for the organization and want you to be a part. Our purpose is to give emotional, physical and informational support. We are enclosing a brochure to give you more details. Having a chronically ill child in your home is a very unique experience. It definitely puts pressures on a family that are not faced by other families. At times, these pressures can seem almost insurmountable. We found that sharing the good, as well as the bad time with others experiencing the same thing, helped us cope with these pressures. One very important point we would like to stress is that YOU are very important to us. FOCUS is an idea, but it can only be as good as all of us make it. We have received lots of encouragement from parents, doctors, nurses, and other hospital staff who feel like there is a need for a support group like FOCUS, but now we really need parent involvement. And we need parents at every stage of handling a chronically ill child. Some of you may just be going through the initial acceptance while others may have been dealing with this for some time now. Still others may have resolved the problem either by a child improving or by the death of a child. We need parents at every stage so we can share with those who are going through something we have been through and to gain from those who have "been there" previously.

We have many plans for the upcoming months. We are hoping to have monthly gatherings where we will occasionally have a discussion leader. Some times we will simply get together to socialize and share with each other. Hopefully, we will even have get-togethers with our children. Also, we hope to offer support to families when their child is hospitalized. And we are going to work very hard to put together a list of resources for special needs children in Atlanta, including county programs, private clinics, etc.

FOCUS in 2011

FOCUS has indeed grown! We no longer own a typewriter. We moved from a living room to a basement in 1994 to official office space in 1999. We have computers ... and (gasp!) a website ... followed by (drum roll) email! FOCUS started with a handful of parents who saw a need and created a solution. Susan and Lynne banded together to support each other, knowing that if there were two families, then there must be more. Most grassroots organizations start this way; FOCUS not only started this way, it has thrived!

Of all the changes, our mission has never wavered, only expanded. Living room support groups led to workshops. Saturday respite care blossomed into summer day camp which led to overnight camps. Family activities multiplied and grew into family camp. Partnership with another nonprofit led to a merger that added more wonderful programs. In 2011, we reach almost 3,000 families in and around metro Atlanta.

Adding programs required more staff. We have hundreds of wonderful volunteers, but year-round programs require year-round staff for planning and growing. To prosper, FOCUS needed a staff to manage and maintain the 'business' side of the nonprofit world: a 'seasonal' staff for camps and swim teams; a board of advisors to advise and refer parents; and a board of directors to oversee and govern the entire organization.

We often hear from families "we don't really know what everyone does at FOCUS" so we thought an anniversary

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FOCUS Celebrates 28 Years

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issue introducing everyone might be fun! Do not be deceived by the number of employees – most work part-time!! We still need and love our many volunteers!!

So ... without further ado, here are the current “FOCUS girls,” in their own words, in the order that they came to FOCUS!

LUCY CUSICK

Executive Director (full time)



I came to FOCUS as a parent, and I came kicking and screaming. I did NOT want or need support; my child was NOT going to have ongoing special needs; by golly, I was going to “fix” him (don’t judge me, I was a new mom!!). I attended

my first Share Group in 1987, two years after Josh’s premature birth and subsequent diagnosis with cerebral palsy. I left that meeting, ready for the next one. I honestly did not know there were other parents out there who were as overwhelmed and scared as I was. While I know many parents think support groups are depressing, I find them comforting. It helped to talk to other moms who were a little ahead and to maybe help a mom who was a little behind me.

As I learned ‘the system,’ I discovered that parenting a child with special needs involved lots of decisions. Push walking or give in and use a wheelchair? Special education vs. inclusion? Eat in or take out? I discovered that I am not a black-and-white person. I love gray. I love options. So, Josh did walk with a walker, but never all that well. As an adult, he uses his power chair; but he weight bears good enough to be independent at home. While I believe in inclusion, I do not believe inclusion is the best for everyone. I do believe that you ‘start at the top’ and work your way from there. Josh was fully included all through school, but, as an adult, he enjoys social and recreational activities with his peers with disabilities. As for food? If it’s fixed for me, I don’t care what it is!!

In 1992, I started working a few hours a week for FOCUS, visiting families in the hospital, calling new parents, and facilitating a support group. In August 1994, Susan Calhoun resigned for health reasons and the board of directors asked me to become the executive director. Honestly, the timing was not great; Josh was in school, but Jessica was still in preschool.

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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.

Nevertheless, I was ready to work again after being a mostly stay-at-home mom for 5 years. So, the FOCUS office moved from the Calhoun’s living room to the Cusick’s basement. The office consisted of one computer (that I really didn’t know how to use), a desk and filing cabinet, a copier, and a fax machine. After a few years, we needed our basement back and FOCUS needed more space, so we moved to an office park and into our first office! There were three of us by then, all part-time, but we were proud of that little office!!

I have learned a lot about the nonprofit world over the years. I wear many hats at FOCUS and do a little of everything, from changing diapers to troubleshooting computer problems to hauling and moving Camp Hollywood. My biggest job is the responsibility I feel when the kids are in the care of FOCUS. I am known for walking around a program, constantly counting kids!

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FOCUS Fund Raisers

Mark your calendars NOW for these FUN fund raisers!
Info on all fund raisers at
www.focus-ga.org

SummerFest at SweetWater Brewery Saturday, August 6, 2011

Celebrate summer with FOCUS.
Enjoy brewery tours & tastings,
food by Willy's Mexicana Grill, music,
and a few surprises!
Contact annie@focus-ga.org for
more information.

E*TRADE Financial Presents The 2nd Annual Run the Farm for FOCUS A 10K and 5K Trail Run 1 Mile Family Walk Cedargate Farms in Newnan Saturday, September 24, 2011

Hosted by Phil & Ann Beegle

Run or walk the trails of
beautiful Cedargate Farms
and support FOCUS programs!
For more information,
email runthefarm@focus-ga.org

Camp Twin Lakes 6th Annual Spin for Kids October 22 – Mountain Bike Ride October 23 – Traditional Road Bike Ride

Camp Twin Lakes plans this awesome
event. Ride or support TEAM FOCUS and
support the programs FOCUS will offer at
Camp Twin Lakes in 2012. For the past two
years, TEAM FOCUS was the #1 partner,
raising over \$20,000 for
Under the Stars and Camp Infinity!!
Help us keep our winning streak!!
Call FOCUS or email lucy@focus-ga.org
for all the spinning info!!

Looking Back at the fun at FOCUS!!

May 1 FOCUS Day at Six Flags Over Georgia

Thanks to the Forrest & Frances
Lattner Foundation, over 900 people
enjoyed a day of coasters & chicken!!



May 7 Swim Meet for the FAST Fins Swim Teams

Swimmers from seven
FAST Fins Teams
participated!



June 16 FOCUS at the Gwinnett Braves game



FOCUS Celebrates 28 Years

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When we have a new parent call to join FOCUS, my heart aches a little for them. While their lives will be rich and full, it will also have many difficulties and heartache. My platform to new families is that this life can be so hard – you must take breaks (respite, camp, mom’s day off!), have fun (family activities and family camp!), plan ahead (home modification tour!), and pace yourself – but this life has such joy. One smile says it all.

JOY TROTTI

Associate Director (part time)

I attended my first share group in 1992 as a mom to toddler Rachel Trotti, who had red hair and multiple health and developmental challenges. Soon after, Lucy recruited me to join the board, and I stayed after Rachel died in 1994. Five years later, Lucy came recruiting again – this time for the position of associate director.



Over the years at FOCUS, I’ve had various program and administrative responsibilities. Now my favorite jobs are planning Under the Stars Family Camp and family activities such as Six Flags and Aquarium Days. In my ‘spare’ time, I write grants and develop the annual report, as well as being a human resources department of one! Working at FOCUS is truly a dream job for me - I love the children, families and staff.

In parenting Rachel, and now Rebekah for 16 years, James and I try to be purposeful about raising a child to become a responsible adult. This saying sums up our approach: *There are only two lasting gifts we can give our children – one is roots, the other, wings.*



PATTY VASTAKIS

Office Manager (part time)

Like many of the other FOCUS girls, I volunteered for FOCUS before I came on as a staff member. My sister Anna found FOCUS after the premature birth of her son, Nick, in 1989. Our big Greek family surrounded Anna and her family after Nick’s birth, but we never really knew what to say or do. FOCUS helped her find resources and information after Nick was diagnosed with cerebral palsy; Anna was a regular at the Northlake Share Group and found that she liked helping other parents. I volunteered with her at the very first FOCUS fashion show, helped at the dinner dance, and was then recruited as the office manager. Funny, my biggest fear about working at FOCUS was that I wouldn’t have enough to do.....that’s a

laugh! Our programs have grown so much that my desk is never completely clean!

My job at FOCUS is more than just a desk job; I also love going to programs (mostly family activities, family camp, and fund raisers) and meeting the families that I’ve talked to on the phone and read about in the newsletter. Our family continues to support FOCUS, out of gratitude for helping my sister and out of admiration for the wonderful children and families.

KAREN GREENFIELD

Respite and Day Camp Coordinator (part time)



My family moved to the metro area in 1997. At that time, we had a nine year old son, Kyle, who had Sanfilippo, a degenerative genetic syndrome. Kyle brought us in contact with FOCUS; I first became involved through Share Groups, sharing our daily struggles at the monthly group. We then learned about FOCUS respite and Camp Hollywood.

Kyle died in 2001, but I continued to be involved with FOCUS and began working in 2003. I love playing with the children and watching them grow up. I have learned many lessons at Extra Special Saturday Respite and Camp Hollywood: to love our children for who they are and what they CAN do; to not confuse disability for bad behavior (sometimes there is a difference!); and to allow children time to be just kids. I am so thankful for the opportunity to work with our wonderful children!



ANGIE WEILAND

Parent Support Coordinator (part time)

Our son, Bret, is 15 years old and severely physically and cognitively delayed. He was born that way, without any rhyme or reason. Talk about being thrown into a “new world” – I sure was!

Bret’s paraprofessional at preschool introduced us to FOCUS. She worked for FOCUS at one of the respites and convinced me to bring Bret one Saturday. I had not left Bret with anybody except his school teachers until that day. From that day on, I have been truly grateful for FOCUS. I loved respite and Bret had a great time!! He was well cared for and treated like a typical little boy – that was the first lesson I learned from FOCUS. Treat him like he is typical – have fun and enjoy your time together.

Several years later, I began to work for FOCUS a few hours a week. I was eager to share my knowledge and

experiences with other parents that have children with special needs. I have come to believe that there are good days and bad days. Everybody is allowed a bad day, but you must get up the next day and start all over. I also have learned that there are a lot of ignorant people in the world. I try not to have my feelings hurt by these people – they don't mean any harm; I just try to educate them. I also believe that there is a place and time for therapy. When you are at home with your child, you don't always need to be "working" with him/her. You should also enjoy "playtime." A doctor also warned me about doing too much; burnout and exhaustion is common among parents – and kids!! In fact, when Lucy called to ask (tell) me to write about my connection with FOCUS, I was on the phone, cancelling a long-awaited speech evaluation. I decided that Bret is too busy during school to manage yet another therapy. He has been in speech therapy for years, and we all need a break.

At FOCUS, I coordinate the share groups, the annual conference, the monthly workshops, and FAST Fins swim teams. I help at other programs, including Camp Infinity, Camp Hollywood, and Extra Special Saturday respite. It's great to see our children accomplish a goal – but it's even better to see them have fun!

So, enjoy your child. Give him/her the best opportunities to have a wonderful life, but don't forget to let him/her have fun, too!

CELIA LAWTON

*Community Involvement Coordinator
(part time)*



It has been several years now since my children attended their first FOCUS program, but I remember that day as clearly as if it were yesterday. My husband, Frank, and I were taking our twin boys (Kirk and Scott) to Extra Special Saturday so that we might enjoy a few brief hours of respite. The kids had been diagnosed with autism at age three, which resulted in numerous challenges for us, including but not limited to: boundless energy, sensory integration dysfunction, social skills limitations, and so on. We were so nervous that day! We really needed a break, but we were also skeptical that a group of people unfamiliar to our family would truly be able to care for our kids.

How wonderful it was to come back not only to happy kids, but also to happy FOCUS employees and volunteers! From that moment on, we were hooked on FOCUS, and we began to participate in more and more programs. Some programs were designed primarily for the kids, some were designed especially for us as parents, and some were designed for our family as a whole. All of them have been outstanding.

Our children are fourteen now, and incredibly, will be

starting high school in August. Looking back, I am convinced that we have been able to get to this point, in part, because of our association with FOCUS. The programs, the support, and our relationships with other parents have made our family stronger and wiser.

In addition to my family's direct participation in FOCUS programs, I also have been the FOCUS grant writer for many years now. I am passionate about all the things that FOCUS does to support special families, and I communicate the uniqueness of our programs to charitable-giving organizations in an effort to obtain funding support from them.

So, pardon me while I do my job for a minute! Did you know that every FOCUS program is subsidized? That means that the "per person" fee FOCUS charges is less than the "per person" cost. For instance, those coveted Aquarium Day tickets we all battle for? Parents pay \$15 per ticket for admission, brunch, and parking. FOCUS pays \$45 per ticket. FOCUS must raise \$30 per person to cover the cost of Aquarium Day. Last year, we had 800 people at Aquarium Day. That's \$24,000! Most families don't understand that FOCUS underwrites every activity to keep the cost as low as possible to parents.

You might not realize it, but you can help FOCUS in our grant seeking process – just by giving us the name and contact information for any person or company that participates in charitable giving. So the next time you are at work, or attending religious services, or mingling at a family reunion/class reunion – please keep FOCUS in mind! Tell them about FOCUS – and tell us about them!! If we are a good match, I'll work hard to submit a funding request to that organization so that FOCUS can continue to offer wonderful programs to your family.

KAREN DAVIS

Program Assistant (part time)



While at Hannah's neurologist back in 1995, I commented to him that there must be other parents going through this same thing as we were and surely there must be a support group out there for us "walking wounded."

Like magic, he pulled out a FOCUS brochure! I waited for several weeks and then after getting some more bad news from Hannah's pediatrician, I finally got up enough courage to go to a meeting. It was by far one of the best things I ever did. I left that meeting with the absolute knowledge that "everything would be okay." All of these other women were sitting around laughing (can you imagine?) and having a good time (really? I hadn't had a good time in months!) while talking about some of the

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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.

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In honor of Amari Smith by Nita Stephens
In honor of Alexandra Kaye's High School Graduation by Shannon Nesbit, Director of Music Ministries at McKendree UMC

In honor of Mitchell Rowe's 13th Birthday by
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Thanks to the family of Liam Vilensky for establishing the Liam Vilensky Camp Scholarship Fund. This fund will support the many

camp programs offered by FOCUS: day camps, overnight camps, and family camps. All FOCUS camps offer the medical care and modifications necessary for campers with disabilities, as well as the fun of just being a kid.

FOCUS Celebrates 28 Years

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serious challenges of raising a child with special needs. I saw that we could still have a wonderful, fun and fulfilling life. Life did not have to be all gloom and doom.

We also learned to get involved in the classroom, to partner and help, to actually see the potential of our kids. There is nothing like walking into a special needs class room and seeing all these bright beautiful faces that are busy learning how to read, hang up their bags, go through the lunch line independently, etc. It helped me understand that our kids can learn to be independent, that they can be capable of daily tasks, how important it was to stop babying and doing things for my daughter (which I still struggle with!). It was also very eye opening to see that the entire world did not revolve around my Hannah!!! (But don't tell her that!!)

I started working for FOCUS in 2007. My job changes on a daily basis, usually helping with the event du jour!! I primarily assist with preparing for our big family activities, talking to new parents on the phone, helping with fund raisers, and trying to keep the resource database current. Until I came to FOCUS, I had no idea all of the 'behind the scenes' work that was involved; I guess I just thought these big events just happened!! Now I know that magic wands are not involved, only hard work and lots of love. I am proud to be a FOCUS girl and a FOCUS mom!



ANNIE GARRETT
*Teen/Young Adult & Volunteer
Coordinator (full time)*

So I admit it ... the way I got involved in FOCUS is kind of lame. My mom MADE me!! When I was about 13 years old

she told me that I couldn't spend another summer sitting on the couch. I knew a little bit about FOCUS because I've known the Cusicks forever. Josh and I went to school together from 5th grade up!! So I decided to volunteer for a week of Camp Hollywood. From then on, Camp Hollywood was my very favorite week of the summer. And here I am ... 12 years later! After graduating from Furman University in 2008, I was fortunate enough to come home to work with the amazing ladies of FOCUS (my 'other moms'!!). Since then, I have been coordinating Teen & Young Adult programs as well as FOCUS' volunteer needs ... and doing a little bit of whatever else is going on at the time!

FOCUS has brought me so many gifts. Through my work with FOCUS, I have met countless amazing children and families. Every year I get to spend my birthday with 80+ AWESOME FOCUS families at Under the Stars Family

Camp! I cannot imagine my summers without FOCUS day & overnight camps. The FOCUS Teens & Young Adults are some of my favorite people on this planet. I am SO lucky I get to hang out with them once a month, and I literally cannot wait to go to Camp Infinity with them every year.

So what have I learned from FOCUS? No one can be more loving and accepting than a child, especially a 'FOCUS child.' Never underestimate these amazing children OR families. Keep your toes out of the way of wheelchairs (just kidding ... sort of). And sometimes your mom does have pretty good advice (but don't tell her I said that!).

MICHELLE THOMPSON
Manager of Kool Kidz Closet (part time)



I have a special place in my heart for adults and children with special needs. My sister Cindy was born with Down Syndrome and I helped care for her throughout her life. I marveled at her accomplishments and her love of the simple joys of life. Cindy lived with me and my family for the last few years of her life; she died two years ago, and I still miss her greatly. Through my sister and her friends, I learned to see the beauty in all people and to admire people for their abilities while being respectful of their disabilities.

I started working for FOCUS last year as the manager of the Kool Kidz Closet. The Closet is a thrift store for children's clothes and toys; it is also a job-site for community-based instruction students and teens and young adults with disabilities. We actually employ a few teens each summer, teaching them job skills. The kids are so excited about their first 'real' job! While I am rarely in the FOCUS office, I am at the Closet on Tuesdays, Wednesdays, and Fridays! Stop in and shop!!

ELIZABETH HEWELL
Program Assistant (part time)



I have been married for over 19 years to my wise and handsome husband Mark. We have two children together; Stephen is 15 (and learning how to drive ... ahhh!) and Katharine is in heaven waiting on us. Our story with FOCUS started when our daughter Katharine was born.

She had hydrocephalous, epilepsy, developmental delay, and was medically fragile. We were in the hospital when a nurse told us about FOCUS. I contacted them and Joy came to visit. She brought Katharine a Beanie Baby white duck and chocolate for me; most importantly, she listened.

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FOCUS Celebrates 28 Years

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I was hooked. After that visit, we became an active part of the FOCUS family: from share groups to Six Flags day to Camp Hollywood, FOCUS became a bigger part of our lives. We finally realized we were not alone.

I started working for FOCUS when Katharine was in preschool. This gave me an opportunity to encourage, educate, and listen to other families that needed support. I departed from FOCUS for a short time and then returned this past winter. I am again surrounded by families that need hope for the future, a place to vent, someone to listen, a day of fun, and wisdom from someone that has lived from birth to death with a child with special needs. I have enjoyed coming back into this group of strong, powerful, and grateful parents. Your children are amazing and they have truly made an impact on my life and others that care for them.

At FOCUS, I coordinate the events for medically fragile children and their families (known at FOCUS as MVP Events), the hospital visitation program, and the

bereavement group. I also help with other programs such as Camp Hollywood, Extra Special Saturday respite, and family activities.

Mark and I have adopted into our lives around two simple words: **no regrets**. We took Katharine everywhere we went, we love our children to the fullest; we made decisions that were right and some that were wrong, and we learned to simply let go and enjoy life. ■

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