March/ April 2013

Volume 30 Number 2



It's Not Easy Being Green — or —

The Technology Perils of a Small Nonprofit

We at FOCUS try really hard not to burden the parents of our children, who are already under enormous stress, with the problems of managing a nonprofit. We try to make programs affordable and registration easy; we are always refining the registration process to make it easy for parents but yet to make sure that we get the information we need. Many nonprofits have already 'gone green' with paperless applications. We're trying to catch up!!

In 2012, we went electronic with registration for Under the Stars Family Camps 1 and 2. It went well – we saved a few trees and the cost of postage and printing. So, for 2013, those applications will again be e-mailed to families on April 15. Contact Joy at joy@focus-ga.org or at 770-234-9111 if you have questions about registering for Under the Stars Family Camps or need a paper application.

Electronic registration for Camp Hollywood and Camp TEAM is our new attempt at being green. Rather than printing thousands of brochures and applications, and paying postage to mail them, they will fly through cyberspace at the click of a key! The trick now is for parents to follow the instructions carefully so that FOCUS gets the info we need to safely care for the campers! Please be patient with us while we muddle through the technology; I'm sure we'll make a few mistakes. We hope that by 2014, we will be cyber-gurus!! Day camp registration was emailed to families on March 1 – if you did not receive yours, please contact Karen at karen@focus-ga.org or at 770-234-9111 if you need a paper application.

But wait! There's more!! FOCUS Day at Six Flags Over Georgia is a hugely popular event!! We're going to be even greener this year, by emailing the registration to families. This will be emailed to families on March 15. Again, please follow the instructions carefully, or call if you need a paper application.

We do request that you not post our day camp or family activities on list serves. While we want to support children and families, we want to be more than just ticket brokers or caregivers! We love getting to know our families BEFORE we take on the responsibility of caring for their children. So, feel free to post information about contacting FOCUS – we will then offer them Comfort, Hope, and FUN!

(Continued on page 6)

Summary of E-Dates at FOCUS

March 1 -

Email will be sent about registration for Camp Hollywood & Camp TEAM

March 15 -

Email will be sent about registration for FOCUS Six Flags Day

April 19 -

Email will be sent about registration for FOCUS Under the Stars Family Camps

Fun omfort.



Comfort & Hope for the FOCUS Parent!

he FOCUS Facebook page is a source of comfort, hope, and fun for our parents! It's the fastest and easiest way to communicate with parents – send your questions to inquiry@focus-ga.org for the Facebook page! Here are several snippets we received from parents, when asked about "Random Acts of Kindness" that you have received from others.

"The week of Thanksgiving I took Hannah to eat lunch in the cafeteria at CHOA in between appointments at the Emory Children's Center. Hannah was her normal happy self, just smiling and "singing." I noticed a couple at the next table just staring at her. I just tried to ignore the stares and continued to eat and feed her. The couple got up and walked out, but came back a few minutes later. They just sort of awkwardly stood at my table. Then the father spoke and said, "Our baby girl is in the NICU here and watching your daughter just really made us smile today." Then the mother pulled out a gift bag and said, "I hope you don't mind but we bought her a gift." The gift was the softest, cutest stuffed unicorn I've ever seen. Hannah fell in love with it instantly and now sleeps with it every night. I wish I had gotten the couple's name, but every time I put that unicorn in Hannah's arms I think about and pray for their baby girl."

— Jennifer Harris

"We travel to Oklahoma City nearly every year to spend Christmas with my in-laws. This past Christmas, there was a new addition to their home: a very boisterous miniature schnauzer puppy with a very piercing bark. With several rambunctious toddlers running around the house, including my sensory-seeking 4 year old with autism, the dog's barking was constant! This resulted in massive screaming meltdowns from my son, who is also extra sensitive to high pitched noise. He began self-injurious behavior, something we have never seen him do.

At our hotel, I began calling every dog boarding place, vet clinic, and pet store that I could find. We either had to board the dog or we could not spend Christmas with the family. It was Sunday, Dec 23^{rd} and most places were closed until Wednesday. I left multiple messages, but finally found an emergency vet clinic that was open. I described the situation to the receptionist (who had already told me that their boarding was full). Before she hung up, however, she told me she was part time at the vet clinic with another part time job in child psychiatry. Not only did she know exactly what we were dealing with, but she was also a schnauzer owner!! She offered to personally take the dog into her own home over Christmas if we could not find another option.

I sat in the hotel lobby with tears in my eyes, tears of happiness and relief. Someone understood my desperate plight and was willing to help a stranger. Thankfully, I found an actual pet boarding facility with an opening, so we did not have to take her up on her generous offer. I called her back to let her know how much I appreciated her understanding and kindness. It was so much more than most would even consider. I will never forget it." — Shelley West

"We went on Julia's Make A Wish trip to Disney World last November. There is a new character area in New Fantasyland. It was very difficult to navigate two children in wheelchairs through the crowds, but the Disney staff was doing a great job of getting us through to meet all the characters. While we

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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.

were in line, a gentleman we did not know who had an adult son in a wheelchair approached me & asked if he could give light-up Tinkerbell buttons to Julia & Maya! It was such a lovely thing to do, especially from another parent to a disabled child. What a moment of solidarity!"

– Gina Gareaux-Clark



http://tinyurl.com/focusgeorgia

Chores, Money, and the Epiphany!

by Karyn Campagnone

lacksquare'll admit it. Sometimes, I have really good intentions, but lack the follow through. There, I've said it. I'm guilty. This is especially true when it comes to chores and allowances for my children. I know they need chores. They need to contribute to the family, which helps them learn many things. I know all this, BUT (and moms back me up on this), I have a lot to do in a very limited time. Sometimes, it is easier to send them out to play and do it myself! I have tried many systems of assigning chores, even tying in an allowance so they complete them. Then I forget to check off their chore list – and don't even get me started on calculating the amount of allowance they have earned. This never works for our family. Then, I had an epiphany! I realized ... wait for it ... I am working too hard ... and the kiddos were blowing through the family budget every time the ice-cream truck came through our neighborhood!

It all started when we bought the pool. The boys would beg me to swim with them, but I always had something to do, some chore to finish. Enter the epiphany. I stumbled across a blog by a mom who used a system for chores that she got from watching the Duggar Family. I quickly went to work and tweaked the system to fit our family. Then, I called a family meeting.

Every so often, our family has what we call a "Come to Jesus" meeting. I think "Come to Jesus" is supposed to mean you come to the meeting with a loving heart and open mind, ready to share a moment as a family to try and solve a dilemma. However with our family, they usually mean "you better get to the table and figure out what is wrong with you right now or you're gonna SEE Jesus!" As the boys gathered around the table, I spelled out the situation for them. We had two issues:

- 1. Mommy was working too hard to clean up messes she didn't make. I explained I wanted to have time to play with them, but I spent the days picking up after them and cleaning.
- 2. Mommy and Daddy work jobs and when they get paid, they must pay bills, tithe, put some in to savings, and then decide how to spend the rest. The boys need to learn the importance of budgeting their own money. It was our job to teach them that.

Then, I implemented the Campagnone grand plan. Here are the details: I purchased some index cards (white and multi-colored) and plastic index card holders from



the store. I typed up the chores that needed to be done on the computer. Since Joey cannot read yet, I put pictures beside each of the chores. I printed them, cut them up, and glued each of them to individual index cards. I also saved the template to replace any destroyed cards. Each day, each boy gets his card holder with his daily chores in it. Before they are allowed to go outside, turn on the TV, or play a video game, they must do their chores. Every now and then, I slip a colored index card into the mix. They are always excited about the colored cards, but those are bonus chores for extra fifty cents! They realized how quickly that adds up!

Speaking of money ... I explained that they would get an allowance every week. A friend once told me she gave her children .50 x the age of the child. I thought this was a great idea! I also told them the allowance would have nothing to do with their chores. (Logan was especially excited about that.) Why? Chores should be what you do to contribute as a member of a family. You don't get paid for doing it. You also don't get a choice in whether or not you complete your chores.

That's it. The system was all laid out for them. So we began in June ... and it worked!!! Three months later, it is still working! The children come home from school, eat a snack, do their homework, quickly get their chore boxes and get to work. I even overheard one say to the other one evening, "Don't leave your toy there! I might have to clean the living room tomorrow!" Why does this work when MANY others have failed?

- I don't give them the same chores every day. It is always a surprise to see what is in their chore box.
- Slipping a color card in their every now and then adds to the excitement.
- Because there is no chart to put a smiley face on or earned allowance to add up at the end of the week, it is relatively simple for me. I simply pick out three of four cards to put in the holders after they go to bed.

(Continued on page 8)

Looking Back ...

FOCUS Education Conference. FOCUS families enjoyed a day of information and networking at the 26th annual FOCUS Education Conference. Thanks to Dunwoody United Methodist Church for hosting, Chick-fil-A for donating lunch, and the speakers and exhibitors giving for their time!





MVP Valentines With Character.

The 7th annual MVP Valentine's Party was a fabulous afternoon! Children enjoyed dress-up, arts and crafts, photos and autographs with princesses from Fleetwood Dance Theater and superheroes from Hero

Alliance, and entertainment by Atlanta's own Queen Glitter. A special thanks to the Greek Orthodox Cathedral

for the use of the beautiful church, to the Philoptochos Ladies Auxiliary for providing the delicious desserts, to Marie Reynolds for her face-painting ability, and to Nina Shields and Tobias Roybal for their photography talent!



On February 23, FOCUS celebrated 30 Years of Support by recognizing 30 individuals who helped FOCUS begin, survive, and thrive. The ballroom was beautiful – and over 400 guests celebrated with us! FOCUS parents Brad & Amy Gibbs shared their story about their daughter Claire, how they found FOCUS, and

their hopes for the future of FOCUS. We are thankful for each sponsor, donor, and guest – what a fabulous evening celebrating the past, present, and future!





Coming Up at FOCUS!

May 5, 2013 FOCUS Day at Six Flags Over Georgia

Registration information will be sent by email on March 15. If you need a paper registration form, you must call FOCUS or email joy@focus-ga.org

May 28 – 31*
Camp TEAM at Mercer University
in Chamblee

June & July* Camp Hollywood

*Brochures and applications for day camps were emailed to FOCUS families on March 1. If you need a paper application, please call FOCUS or email karen@focus-ga.org right away!

August 9 – 11**
Under the Stars Family Camp 1
At Camp Twin Lakes Rutledge

October 5 – 6**
Under the Stars Family Camp 2
At Camp Twin Lakes Will-A-Way

**Brochures and applications for family camps will be emailed to FOCUS families on April 19. If you need a paper application, please call FOCUS or email joy@focus-ga.org right away!

Special Events

13th Annual
E*TRADE Financial
FORE FOCUS Golf Classic
May 8, 2013 • Bear's Best Atlanta

SummerFest at SweetWater Brewery August 17, 2013

Raise a glass and celebrate FOCUS camps with SweetWater brews, brewery tours, cornhole tournaments, and food!

Workshops at FOCUS

Friday, April 26 at 10 am at the FOCUS office.

Heidi Moore will present the basic information on applying for the NOW/Comp Waiver.

Please RSVP to elizabeth@focus-ga.org

Friday, May 3 at 10 am at the FOCUS office.

Debbie Dobbs will present the basic information on applying for the Katie Beckett / Deeming Waiver.
Please RSVP to elizabeth@focus-ga.org.



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It's Not Easy Being Green (Continued from page 1)

Frequently Asked Questions at FOCUS!

Does FOCUS charge fees for programs? Several FOCUS programs do have fees, and we require a small deposit for these programs. The deposit is the commitment of the parent to the program, that parents check the calendar and are fairly certain they can attend (assuming no last minute illness, of course!). We spend a lot of time preparing for programs, making sure we have enough counselors, and/or making sure we have enough space for everyone; we also pay deposits and minimums, so we want to make sure that as many people as possible enjoy the event.

The fees charged for FOCUS programs, however, do not support the program! For instance, FOCUS pays \$35 per ticket to Six Flags Day; parents pay \$15 per ticket. FOCUS pays \$50 per ticket for Aquarium tickets; parents will pay \$20 per ticket this year. The fees for both of these activities include admission, parking AND a meal!! The cost of Camp Hollywood to FOCUS is \$350 (including insurance and staff costs); parents pay \$145 per camper. FOCUS fund raisers and contributions help make up this difference.

Does FOCUS offer scholarships to programs?

FOCUS does offer scholarships to summer camps, but parents must include a tax return, showing their income for the past year. We know expenses for our families are high, but we must have some way of awarding scholarships objectively.

I tell all my friends that FOCUS offers cheap tickets to different activities in Atlanta! Ok, this isn't a question, but it is true! We do offer great deals on tickets to various venues in Atlanta! But, we are more than a ticket broker. We offer these activities for FOCUS families to enjoy together! It's nice to feel part of a group, to be a part of something bigger! So, yes, the tickets are cheap, but the purpose is to see old friends, make new ones, and be there together, not just to save a few bucks!

Who is eligible for tickets to Family Activities?

Tickets to family activities (Six Flags, Aquarium & Zoo Days) are for the parents (up to two adult tickets), the child with special needs, and siblings in the family under age 18. We can't offer tickets to visiting relatives, fiancés and their children, or people who live-in-your-house-who-feel-like-family! If every family got just ONE extra ticket for a cousin-in-law, then 62 FOCUS families would not be able to go! So, please don't ask for an extra ticket ... we do not like being the bad guys!

The Future of FOCUS

by Brad & Amy Gibbs

We were so flattered when FOCUS asked us to speak at the annual "For the Love of Children" dinner, dance, & silent auction. This organization has done so much for our entire family (grandparents, aunts and uncles included!) that we were eager to share our story and help others see what a



worthwhile organization FOCUS is.

Brad and I tag-teamed to deliver our remarks. He introduced us and talked a little about Claire's early days. He was so sweet and said a tender thank you to me. It was so special! I then spoke about finding FOCUS and our hopes for the future with FOCUS. Here are some of my remarks from the dinner-dance. I hope you enjoy them!

Our story began on August 3, 2010, when I was 15 weeks pregnant with Claire. Just days before, Brad and I had a lovely dinner at a nice restaurant, celebrating our 8th wedding anniversary. We had just returned from a week-long beach vacation and were tanned, relaxed, and content. In the car ride to the restaurant, I remember thinking that our life together was perfect:

- I had a wonderful, handsome husband.
- We had a strong, loving marriage.
- We both had the careers that we wanted and promising futures ahead of us.
- We had a house that we loved in a quaint, family-oriented neighborhood with a pool, a park, and a soccer field nearby.
- And, most importantly, I was expecting the first combination Masters' Champion / U.S. President / Supermodel the world had ever seen.

Just a few days later, everything we thought we knew about our lives and our future changed. There are some days in your life that you never forget, and you're never quite the same afterwards. This was one of them.

But on that August day, we sat in a darkened ultrasound room and listened in disbelief as a doctor told us our baby had too much fluid on its brain and was bound to have significant brain damage. We heard words like "severely disabled" and "limited cognitive functioning." I remember very clearly hearing the doctor tell us that our child would have a "limited opportunity for a typical life."

After that day, life didn't feel perfect anymore. It felt scary and uncertain, and we both wondered whether we would ever be happy again.

While we didn't know what the future held, we were certain of one thing: We loved our little girl and were excited to meet her. We decided we would help Claire face her challenges with all the courage and strength we could provide, and we would do whatever we could to give her the best life possible, even in spite of her limitations.

Claire was born on January 5, 2011, and, as predicted, she had a rocky start. She stayed 30 days in the NICU. She had seizures almost immediately after birth and was on heavy sedation medication. As a result of the medication, she had trouble eating.

When we finally made it home, we adjusted to a whole routine. Most new parents go through a period of adjustment when they bring a new baby home. But for us, on top of the regular issues like late-night feedings and diaper changes, we had to worry about things like medication schedules, doctor's appointments, and therapies. Life felt chaotic and uncertain. This was not what we had planned or expected. But then we found FOCUS.

I remember the first time I called FOCUS. I've often heard Lucy [Cusick, the Executive Director of FOCUS, and a special needs parent herself], say she came to FOCUS "kicking and screaming," and I can't say my experience was much different. One of Claire's social workers kept encouraging me to call, but I kept putting it off.

Sometimes, it was because I was in denial. I felt that we didn't need FOCUS, we were just fine. Other times, it was because I honestly believed that Claire's challenges were too significant for FOCUS to handle. (Boy, was I wrong on that account! If there is one thing I have learned over the past two years, it's that FOCUS is for everyone.)

So, one afternoon, in order to placate that pesky social worker, I picked up the phone and called. And an amazing thing happened. Joy [Trotti, Associate Director] answered. And she listened with compassion, empathy, and understanding as I told her about Claire and the challenges she had already faced in her young life.

After that, an even more amazing thing happened: Joy shared her own story with me. She told me about her daughter Rachel. She shared her own family's triumphs and challenges, and, as I listened, I realized that I was talking to someone who truly understood what our life was like. Later, I talked to Elizabeth Hewell and had a similar experience as she shared her story.

I knew then that we had found a group of parents that we could really learn from. And learn, we did. We learned:

- That we didn't have to do therapies with Claire 24-7.
- That it was "okay" to do "normal" things like read stories or go for walks.
- That missing a dose of medication wasn't the end of the world.

Most importantly, we learned that life could feel perfect again.

Over the past two years, we have enjoyed family activities with FOCUS.

- We went to the Zoo with other FOCUS families.
- We have enjoyed MVP events, like the BooBQue and the Valentine's Party.
- Claire had a private audience with Santa.
- She even had her moment in the spotlight strutting her stuff at the FOCUS Fashion show. (Maybe this supermodel business will work out after all!)

At all of those activities, we have met many families with children of all different ages. We've had an opportunity to find support and comfort and share information such as:

- Which wheelchair headrest works best
- Which therapies we should consider
- Which seizure medications we should ask about at our next neurologist visit
- The pros and cons of a g-tube
- And, most importantly, how to get the Special Needs Access Pass at Disney World!!

We are really looking forward to growing with FOCUS over the coming years, and I know we have a lot to look forward to. Thanks to FOCUS, Claire can attend summer camp when she gets older. She might be able to participate in a swim team. She can dance with her daddy at the father-daughter dance.

FOCUS makes these kinds of typical experiences possible for Claire and for children like her.

FOCUS also helps us prepare for the future by offering programs like the Parent Education Conference, where we can learn how to set up a Special Needs Trust, and the Extreme Home Modification Tour, where we can visit the homes of other FOCUS families and learn about adaptations they made to make their homes more accessible for their children.

To keep programs like these going takes a lot of time and effort from people who care about children like Claire. It takes a lot of generosity and a lot of funding.

We are so glad that 30 years ago, two parents had the foresight and wherewithal to create a parent network and lay the foundation for FOCUS. We are grateful for your past support that kept FOCUS going through those years. As fairly new FOCUS parents we are looking forward to growing with the organization over the next 30 years, and we appreciate your continued support and generosity in making that possible.

FOCUS has enabled us to give her the most typical life we can, despite her disabilities. Thanks to FOCUS, Claire no longer has a "limited opportunity for a typical life;" in fact, the sky is the limit for our Claire!

Contributions

(Continued from page 5)

Leslie & Gary Null, in honor of Helene Prokesch Betsy & Todd Oglesby, in honor of Saxon Dasher Costa & Vicky Panos Vicky & John Patronis Asiemoula Papadopoulos Barbara & Larry Perlis, in honor of Lenore Maslia Christina & Victor Polizos, in honor of Anna Kostopoulos

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Chores, Money & the Epiphany!

(Continued from page 3)

 The boys have stopped asking me for money. They have their own money and make their own decisions on what to spend it on. For the record, I've noticed the boys are much more discriminating on what they buy when spending their own money!

A few weeks ago, a neighbor got the boys off the bus for me. When I got home, she commented on how quickly the kids did their chores without fighting. I printed the template for her, and she now uses them with her own children. When you find something that works, you want to share it. If you would like a copy of the template, message me at my blog and I will send it to you! If you decide to use this system, please let me know how it works for you!

Karyn writes regularly about her life as a busy mom of three boys, one of whom has Down Syndrome and autism, on her blog Campagnone Capers at www.campagnonecapers.blogspot.com.

PLEASE DELIVER PROMPTLY DATED MATERIAL

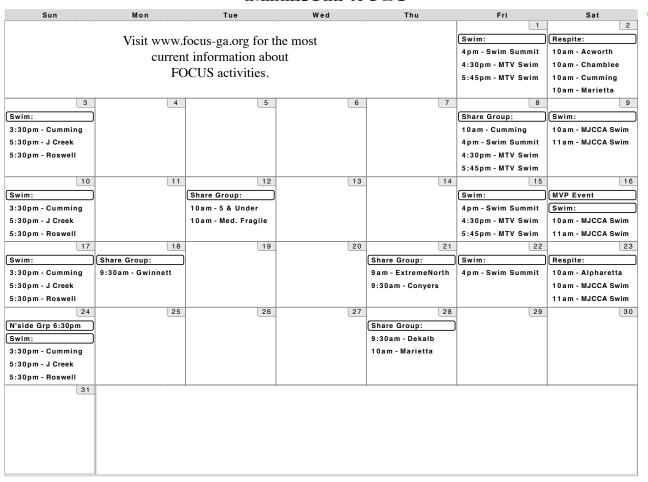
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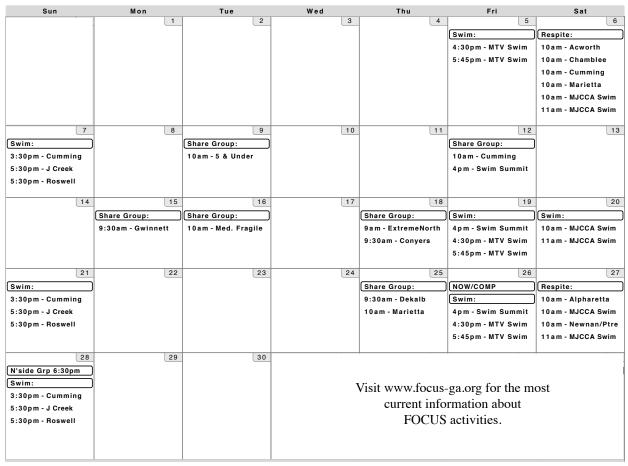
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MARCH 2013



APRIL 2013





Share Group Calendar by Location!

Please call (770) 234-9111 or e-mail (elizabeth@focus-ga.org) to RSVP and for reminders, directions, or further information.

5 & Under - 10:00 am

This group is especially for parents of children with special needs who are 5 years old and younger. FOCUS Office – 3825 Presidential Parkway, Suite 103, Atlanta 30340

March 12

April 9

Conyers - 9:30am

Chick-fil-A 1610 Hwy 138 SE Conyers 30013 March 21 April 18

Cumming – 10am

Chick-fil-A
Lanier Crossing
653 Atlanta Rd, Cumming
March 8
April 12

Dekalb - 9:30am

Old Hickory House 2202 Northlake Parkway in Tucker March 28 April 25

Extreme North - 9am

Starbucks 4646 Woodstock Rd. Roswell Mabry Rd. and Highway 92 **March 21 April 18**

Gwinnett - 9:30am

Chick-fil-A, Hwy 124 (Scenic Hwy)

March 18

April 15

Marietta/Kennesaw - 10am

Chick-fil-A
1201 Johnson Ferry Rd., Marietta
Woodlawn Shopping Center
March 28
April 25

Medically Fragile - 10am

Kimberly Forester's home in Alpharetta RSVP to Elizabeth@focus-ga.org for directions and reservations.

March 12 April 16

Northside - 6:30pm

Northside United Methodist Church 2799 Northside Drive, Atlanta March 24 April 28

