



Comfort. Hope. Fun.

When 'Less Than' Becomes 'More Than'

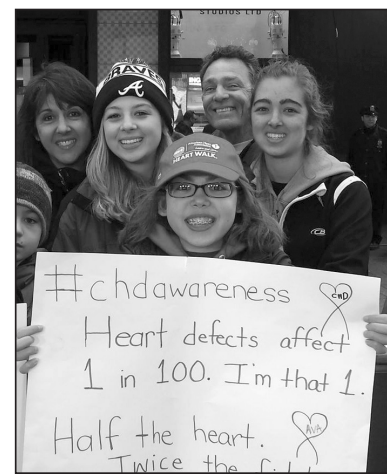
by Melissa Bernardino

"I'm sorry, but there's something wrong with your baby's heart. We can only see three chambers. You have several options but I'm afraid the outcome for this type of defect is not very good." It's been 15 years since we first heard those awful words, beginning a life of uncertain outcomes, extended hospital stays, surgeries, round-the-clock feedings and care, doctors' appointments, daily medications, and multiple therapies per week. We were told numerous times that our daughter, Ava, would not survive, and if she did, that her quality of life would be 'less than.' Despite our sunny resolve to make each and every year a good one, we have continually been met with new and unique challenges, each reminding us of the alleged 'less than' quality of her life.

But less than what? By what standards are we being measured? Did her initial inability to engage in a meaningful way mean she brought less joy to our lives? No. Did her unwillingness to eat make togetherness at family mealtime less important? No. Did her lack of motor control and speech mean that she couldn't interact in positive ways with her sisters? No. Did her delays in meeting developmental milestones lessen our resolve to make the most of the hand we were dealt? No. Does heart disease, Tourette's, chorea, liver damage, lung disease, narcolepsy, reflux, and poor weight gain make her 'less than'? No, no, no, and repeatedly no.

'Less than' just means she has to work harder to meet goals. It means we have to change our expectations slightly and then spread these expectations out over a longer period of time. It means working with the school system in new and creative ways to meet her needs rather than forcing her into a standard that doesn't work for her. It means that we have to shorten our planning cycles, learning to enjoy where

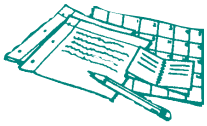
we are rather than focusing on where we are going. It means staying in the moment of 'what is' and not venturing into the land of 'what if.' It means altering our plan for her life as God's plan unfolds.



As hard as it was to hear those words, and as difficult as it has been to navigate the complex medical terrain since, I do not believe her life has been 'less than.' On the contrary, I believe her life has given us 'more than' we ever could have hoped for! It has given us an appreciation for every day. There is joy in the smallest victories and renewed hope for bigger ones. There is recognition for meeting milestones with anticipation of more to come. We don't take nearly as much for granted and we are more focused on the present with less concern over what may be coming next.

This child who was late walking completed a one-mile heart walk, as patiently and deliberately as a marathon runner, and painstakingly climbed to the top of St. Paul's Cathedral. The same child I was told would always be irritable was on Good Morning America, holding her sign proclaiming "1 in 100" with a CHD awareness ribbon and lighting up Times Square with her smile. The child that was supposed to struggle in school recently completed her first semester of high school and is on track to graduate with her peers. She takes each

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From the Editor

by Lucy Cusick

FOCUS started in 1983 by two couples, whose children shared a hospital room. These parents did not know each other before this visit, but they became lifelong friends, supporting each other during the life and after the death of each child. FOCUS began as a handful of parents with children who were very medically fragile; they comforted each other when a diagnosis was added or after the first seizure. Since Dr. Google wasn't in every home then, they helped each other find specialists, therapists, and information. They gathered in living rooms for Share Groups and, in between groups, they talked to each other ... on phones with cords.

So, now 33 years later, with better medical care, we have more children who are medically fragile surviving. We've grown from that first handful of parents to reaching almost 4,000 families in and around metro Atlanta. We offer programs to parents, to children/teens/young adults, and to the entire family. We've had growing pains – FOCUS has had to grow up, too. We operated with volunteers for many years, but as the number of locations of programs increased, we needed insurance, computers and software, a place to plan programs and store supplies, and staff to plan and supervise quality programs. The budget grew, the need for funds increased, to keep up, FOCUS had to grow up!

Don't glaze over yet ... I'm getting to the point here! This past year, the James M. Cox Foundation gave FOCUS a grant for a 5-year strategic plan (that's big stuff!). We contracted with the Georgia Center for Nonprofits to lead the effort. They researched how Atlanta would grow over the next 5 years (it's scary). They conducted extensive interviews with parents, funders, directors and advisors, and staff. They asked us to dream and to create a vision (not so scary ... kinda fun!). The process was long (and often painful), but we persevered. The end result was a 13-page document and a 2-page 'road map,' giving our board of directors and staff what we need to do to better serve more children and families. Because, to serve more families with more programs, we need more of everything: technology, volunteers, funds, staff. If you haven't looked at our calendar lately, take a quick gander – we have programs almost every weekend as it is. We can't work much faster – we need a plan, if we want to grow.

And now we have one. We're working on improving our technology, especially how we communicate with families. This leads to improving our marketing, so parents will be able to find us. This leads to finding more volunteers and keeping them, ditto with staff. All of this costs money, so we have to increase that, too.

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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 \$25 for families (waived if necessary) and \$50 for professionals.

So, we sound like big business now, huh? Well, maybe more like medium business! But we love the grassroots part, the heart of what we do and how we do it. How we still hurt for new parents as they begin this journey, how we wish we could wave our magic wands to improve services and get parents what they need without fighting, how we grieve when we lose a sweet kiddo. This medium business supports the heart of FOCUS so we can surround our families with what we do best: Comfort, Hope, Fun.

We look forward to the next five years and hope you will grow with us. ■

Life Changing ... Changing Lives

By Kitra Johnson

My husband and I will never forget March 17th, 2004. We went for (what we thought would be) a routine ultrasound – we were so excited to have another peek at our first baby, Hayley Michelle. During the ultrasound, the tech become very upset after trying several times to get the baby to open her hands. I asked the technician what it meant if she didn't open her hands. The tech became very emotional and stated that the doctor would be in to tell me. I could see her heart beating so I knew she was alive. I couldn't image what the problem could be. Hayley was such a hearty kicker, and I hadn't had any complications at all!

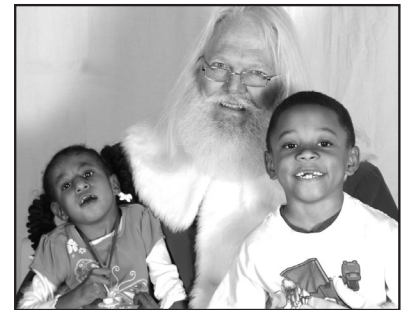
The doctor (whom I had never met) came in and silently began to probe my almost 6-month pregnant belly. After a series of grunts and long stares at the ultrasound machine, the doctor told me this baby has a very severe abnormality which is "not compatible with life." I asked what the baby had, and the doctor told me I needed an invasive test to confirm her suspicions. The test was scheduled for the very next day.

After anxiously awaiting the results, we received (what we thought then as) the worst news ever. Hayley has Trisomy 18, also known as Edward's syndrome, a fatal genetic chromosomal error. Trisomy 18 has many anomalies that accompany its diagnosis, and studies have shown that only 50% of babies with Trisomy 18 are born alive. A tiny bit of good news was that baby girls have a slightly higher rate of being born alive. Trisomy 18 has no known cure and only 10% survive to their first birthday, according to the latest stats from www.trisomy18.org. In 2004, the outlook was even bleaker

My husband and I were told the only alternative was to terminate the pregnancy immediately. We were terrified and dismayed. The specialist and doctor assured us that the baby would probably not be born alive. But, every time the word "termination" was used, the baby kicked me extremely hard, as if to say "I'm still here!" After careful consideration we decided termination was not an option for us. On June 25, 2004 at 8 pm, we welcomed Hayley Michelle into our world.

After four days in the NICU, we took Hayley home. We were warned that her life would be very short. We left the hospital with lots of monitors and special instructions. The first year of her life, we took turns sleeping in a rocking chair and holding our girl. Then, we began to realize that we could plan for life WITH Hayley, instead of without her!

Having a child with a disability sometimes means deciding which parent will be the primary caregiver and which will work to maintain financial stability. Before Hayley, we were a two-income household, but returning to my lucrative, but demanding, job likely would not be possible. One income left a daunting financial gap, plus insurance did not cover all of her medications and supplies. I tried a few jobs: working from home, babysitting, and working at the mall. Unfortunately, none lasted long because Hayley was in and out of the hospital; she survived a near-fatal virus and had extensive back surgery. We manage our budget very closely. All families have to make changes. We had to learn to ask for help from family and friends. We have sacrificed a lot, but we are willing to do anything for Hayley.



Communication was key, as was building a network of support. We called FOCUS the week after Hayley was born. We love their annual conference and workshops, and sometimes just talking to other parents who have similar issues is helpful.

The bottom line is having a child with a profound disability is life changing. We have learned patience and what is really important in life. It is well-documented how much we love our special children, but we often fail to talk about the financial circumstances. Because we are very careful to never complain, this means others are usually not aware of our financial challenges. I know we are not the only family with this struggle – let's find a solution together! ■

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day in stride and reminds us that the joy is in the effort, not in the outcome. Her smile never fades, nor does her courage. Structurally, her heart may be less than perfect but it is more than enough in ways that matter.

Thanks to Ava we laugh more, love more, cry more, appreciate more, and hope more. I'll admit I sometimes feel guilty because she has far surpassed what we were told in those early years. And while I am thankful that the doctors were wrong, I am still grateful for their harsh opinions, for it was through the preparing for less that we were actually given more than we ever could have imagined. ■

Information You Can USE!

Georgia Medicaid Covers Diapers!

Georgia Medicaid is now purchasing diapers OR Pull-Ups (one or the other), diaper liners OR chux pads (one or the other), for children ages 4 – 21 with eligible diagnoses of documented disabilities and a diagnosis of incontinence of bowel and/or bladder. Diaper wipes are NOT covered. Here's the drill:

1. Call one of the suppliers (listed below).
2. Supplier will set up a profile and discuss your child's age, weight, and diaper needs. Supplier will also need your child's Medicaid number and name/contact info for children's primary care physician (PCP).
3. Supplier will confirm child's Medicaid status and contact PCP for a copy of physician's license. Supplier will then mail samples to parents for a 'best fit' and 'most effective' product.
4. Parent tells supplier the products they wish to order. Supplier will contact PCP for prescription and letter of medical necessity. This must be documented in your child's records.
5. IMPORTANT NOTE: Child MUST have seen PCP within SIX months of request for Medicaid to approve supplies.
6. Supplier submits a request for the specific products to Medicaid for authorization. This might take 30 to 60 days.
7. Diapers eventually are delivered to your home!
8. Parent must order by phone or online every month from the supplier.
9. Supplier MUST speak to the parent every month, BEFORE the supplies are shipped.
10. Authorizations are now for 12 months. Supplier will re-authorize.

A few exceptions: If the child is receiving in-home nursing services, the child is not eligible. Parents should contact their Nursing Agency. The Nursing Agency can contact Medicaid to see if they can be reimbursed if they provide incontinent care products to the child. Again, this is the responsibility of the Nursing Agency who is providing services. If the child receives services from CMS, the parent must order the diapers from the supplier. CMS does not order diapers.

Also note that when a child is in the hospital, the hospital should supply diapers. Diapers are not the responsibility of the parent when a child is hospitalized. That said, if a particular diaper works best for your child, you might need to take them!

Suppliers: Uromed 1-800-841-1233
 S2 Medical 1-888-799-3767
 Advanced Medical Group 1-877-645-5170 ■

Are You HIPP?

Some resources feel like a best-kept secret! Georgia has a program for Medicaid members called HIPP (Health Insurance Premium Payment). If your child has Medicaid, then he/she is a "Medicaid member" and can apply for HIPP. From a parent on the FOCUS Facebook page: Once an individual has been approved for Medicaid, you may then apply for HIPP. A calculation is made to determine if it is more cost effective for the state to give the child a separate insurance policy or just reimburse the family for the premiums it pays through its employer. For us, it is cheaper to reimburse us each month for the ENTIRE FAMILY'S premiums through my husband's employer than it would be to pay for a separate policy for just my one child. I submit paystubs each month. They are processed in about a week and a check is mailed to me. Easy and a super perk! Here is the website: <http://dch.georgia.gov/health-insurance-premium-payment-program-hipp>

Upcoming Fund Raisers at FOCUS!

Like it or not, fund raising is a part of every nonprofit. While FOCUS does have fees for some programs, here are some basic facts about fund raising at FOCUS:

- Fees charged at FOCUS do NOT cover the cost of the event
- Tickets for FOCUS Six Flags Day cost FOCUS \$36 each. Parents pay \$20 each. FOCUS fund raisers cover the additional \$16. Multiply that by 900 and you have the amount we pay Six Flags each year!
- Camp Hollywood day camp requires paid counselors, supply fees, and lots of liability insurance. These costs add up to over \$350 per camper. The fee we charge for one week of Camp Hollywood is \$150 per camper, well below the cost of a day camp for 'typical' kids. We offer even more financial assistance, according to the parents' income. FOCUS Fund Raisers and grants cover the remaining \$200+ (or more, depending on the level of scholarship).
- FOCUS on Moms, Share Groups, MVP Events are all FREE! FOCUS covers the cost so parents can enjoy the FUN!!

So, you get the idea – FOCUS has to write grants and raise money to keep FOCUS programs affordable. Here's where we can use your help! Email lucy@focus-ga.org about all fund raisers – she'll forward to the right person! ■

The Pressure of Life ...

By Anonymous

In 1998, after eight years of infertility treatment and seven in-vitro fertilizations, I had a premature baby. We boarded the NICU roller coaster and away we went, experiencing the highs of new parenthood and the lows of a premie baby. After a diagnosis of cerebral palsy, we collected a myriad of doctors and had numerous treatments, therapies, surgeries and meds over the years. It took a few years, but we finally reached a plateau and knew what we were doing.

Fast forward 17 years, we are learning about even more doctors, treatments, therapies, surgeries, and meds ... all based around wound care. Our daughter is nonambulatory and has driven her own power chair since kindergarten. Last year she began losing motor function and bladder control with no explanation. She's never had any skin problems (skin breakdown in wound care terms) until 2015. In August, we noticed redness on her left ischium (butt cheek). I googled instructions and applied zinc and bandages thinking that would do the trick. By early October, I was out of my area of expertise and called another FOCUS mom for advice. She recommended Piedmont Wound Care because of her prior experience. We boarded a new roller coaster and away we went!

Piedmont Wound Care was great – from the moment we entered their doors, we were taken care of. First, my daughter received treatment to remove the necrotic tissue, followed by a wound vac weeks later to speed up the healing process. She was instructed to eat at least 100 grams of protein daily to help heal the muscle. By mid October, she was put on bed rest at home and on the hospital/home bound program through school. This is her senior year with graduation in May so staying current on her studies was important. A few weeks into treatment, the doctor said that surgery

would likely be required to close the wound. Surgery followed by a 4-week-stay to recuperate ... oh boy!

More new procedures, now in a new hospital! Wound surgery was done at Piedmont in December and she was at Shepherd Center for the 4-week recovery. Even admission was different – we were admitted to Shepherd at midnight the night before the surgery, which was scheduled for 7:30 am. She went to Piedmont just for the surgery – a mere 47 minutes. She was back in her room at Shepherd before 10 am. She was turned from her right side to her back every 3 hours, expected to drink a supplement called Juven to help with tissue repair, and was catheterized. We have learned way more about wound care than I ever wanted to know!

We also added new equipment to our already large equipment collection! We have a new ROHO cushion, which provides pressure relief, allowing the seat cushion to constantly adjust to an individual's body movement; a new mesh sling for the hoier lift; and a sleep number bed, which helps ease the pressure points and allows for position changes. Her mattress is now far nicer than the one I sleep on!

Throughout the process, something even better happened along the way. My daughter learned to advocate for herself, speaking up and asking questions. She talked to the doctors and now knows how to prevent another wound/pressure sore. She's been advised to let her parents/caregivers know how and where to check for blanching of the skin to make sure there is no redness of any bony

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Coming Up at FOCUS!

Most FOCUS events are now announced in our weekly emails – usually on Monday! If you do not receive an email from FOCUS each week, then we either do not have a current/correct email in our system OR our emails are going to your spam folder. Please email inquiry@focus-ga.org if you do NOT receive our emails. We'll try to figure out why!

FAST Fins Registration has begun! The season begins February 12. Criteria for swimmers and the registration information is online or email brian@focus-ga.org.

Workshops at FOCUS will resume in February. No longer offered only on Fridays, we've dropped the catchy "Fridays at FOCUS!" Workshops are announced in our Monday emails. Email elizabeth@focus-ga.org for more info.

33rd Annual

"For the Love of Children"

Dinner, dance, & silent auction
February 27, 2016

Comfort, Hope, and Fun Honorees
Lauren & John Seidl
Dr. James Fortenberry
Diane Slothouber

FORE FOCUS Golf Classic

May 16, 2016
The Manor Golf & Country Club
in Alpharetta
Tournament Chairperson:
Curt Smith

For more information about either event,
please contact lucy@focus-ga.org

MVP Events for medically fragile children, Share Groups, and Hospital Visits! Email elizabeth@focus-ga.org for info on these FOCUS activities!

Monthly Teen & Young Adult activities! Email brian@focus-ga.org for more info.

Day Camp dates are on the calendar – registration will be sent by email soon! Make sure you read our Monday emails!!

Thank You

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Marion Roletti Foundation
The Kaye B. Smith Foundation
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Tolleson Family Foundation
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Yancey Bros. Co.
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Liam Vilensky Camp
Scholarship Fund
The Nautical Milers Swim Team for
FOCUS FAST Fins
West Georgia Elves
St. Elias Antiochian Orthodox
Church

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Blessed Trinity
Eastminster Presbyterian Church
FAA
The Lovett School
Marist High School
NCL Gardenia
NCL Northeast
NCL Roswell Alpharetta
Doris & Mike Shackley
Bernard Smith
Wheeler High School
Ray Williams
Santa Eddy Rich
Zesto

Individual Contributions & Newsletter Renewals

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Joy & Rex Sims
Tammie Siracusa
Diane & Tristan Slothouber
Lib Smith
Marla Smith
Rob & Gina Steers
Janell Stiles
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Dawn & Eric Swalberg
Diane & Derek Tabor
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Suzanne & Donnie Tew

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Joy & James Trotti
Suzanne & Bo Vaden
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Laura & Mark Weintraub
Karen & Barry White
Chris Willson
Sylvia & Albert Wilson
Lisa & Phil Woody
Lisa & Harold Wyatt
Cheryl & Jerry Ziegler

Memorials

In memory of Nick Vastakis by Elaine &
Anthony Stratis
In memory of Emery Funkhouser by
Keely & Phillip Funkhouser
In memory of Wilbert Schwotzer by
Celia & Frank Lawton
In memory of Benita Mason
by Nancy Pegg
In memory of Dr. C. Maurice Whiddon
by Nancy Pegg
In memory of Michael Gabriel Moir
by Lindy & Bill Moir
In memory of Rosemary Underwood by
Cindy & Joe Camerata
In memory of Vera & Robert Moses by
Belinda & Ted Daywalt
In memory of Emery Funkhouser by
Claude Levinge
In memory of Julie Klee by
Susan & Doug Klee
In memory of Natalie Tumlin by
Beth & Bill Tumlin
In memory of Logan Beasley by
Susan & Doug Beasley
In memory of Philip Benefield by
Doreen & Burt Wittenberg
In memory of Gloria & Melody Wang
by Ivy Li & Li Wang
In memory of Coleman Miller by
Teresa & Butch Miller
In memory of Jennifer Smallman by
Carol & Ralph Smallman for Hospital
Visits
In memory of Walter Monroe Massey by
Rick, Linda & Ricky Raschke
In memory of Robert Dault by:
Aurand
Sheila & Edward Thompson

Honorariums

In honor of Erika Christensen by
Ann & Kelly Christensen
In honor of the marriage of Janet Haury &
Tony Preston by The Sennett Family
In honor of Jordan Smith by
Julie & Steve Smith
In honor of Bret Weiland by
Elise & Gary Meyer
In honor of Jonathan Kanne by
Anne & Robert Shoemaker
In honor of Elliott, Travis & Talia King
by Stellise & Chip Kirk

The Pressure of Life ...

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prominence of the hip bone, gluteal bone, heels, elbows and shoulder blades. She knows she cannot sit on a cut out seat (like a toilet seat) or to swim for 6 months. She has learned to shift her weight for 1 minute for every 30 minutes sitting (this means tilting all the way back in her wheelchair). She knows that she must be out of her wheelchair after 4 hours, she keeps up with the schedule and follows the rules to the letter! We are so proud that she can understand the care she needs and speak for up for herself. I wish we had not needed wound care, but since we did, I'm so proud of my daughter for growing up and taking charge! ■

Since this young lady is a teen, her mom submitted this article anonymously. She wants other parents to know the importance of checking for pressure sores regularly; our kiddos often do not 'feel' the sore until it is advanced. Healing is difficult and infection is always a concern. This mom found lots of basic information online about pressure sores/wound care – no one article stood out – just ask "Dr. Google!"

Looking Back at the Fun ...

Snacks with Santa – November 30



FOCUS & Lekotek Holiday Party – December 6

- In honor of Paul Wade by Elaine Camacho
- In honor of Benjamin Gilkerson by Barbara Maloney
- In honor of Matthew Ladd by Lizabeth Mahaffey
- In honor of Trey Quinn by Ellen Quinn
- In honor of Dr. Teddy Levitas by Sally Kaplan
- In honor of Hannah Grace Harris by Paula & James Edgar
- In honor of Victoria Brown and the Brown Family by the Miller Family Fund
- In honor of Katie Preuss by Linda Preuss
- In honor of Matt Rivera by Sharon Rivera
- In honor of Julie Lyons Birthday by Elinore Wynne
- In honor of Samantha Leiter by Sue & Bob Leiter
- In honor of Bret Weiland by Lucy Maslia
- In honor of Brian Darden by Jeannette & Edwards Rogers
- In honor of Dr. Howard Schub by Susan & Doug Klee
- In honor of Susan Calhoun by Susan & Doug Klee
- In honor of Lucy Cusick by Lolita Watson
- In honor of Katherine Lucier by Angels 2 You



Extra Special Saturday Respite – Spring 2016

Want your kiddos to enjoy a Saturday morning playing with other FOCUS friends ... so YOU can enjoy a Saturday morning to yourself? Your child enjoys playtime, music therapy, and fun ... so you can have lunch alone, with a spouse, or with a friend? Welcome to Extra Special Saturday respite!!

FOCUS offers Extra Special Saturday (ESS) respite in five locations for children with disabilities and their siblings, ages 1 to 12 years old. Caregivers at each location are experienced in caring for children with special needs; a nurse is on-site to manage G-tube feedings, seizures, and other medical care. Ratio of caregiver to child is 1:4; community volunteers are often there to help and play. ESS is from 10 am to 2 pm and is free to parents, although small donations are accepted.

For registration information and an application, please email sonca@focus-ga.org. In a nutshell, you will need to bring lunch, extra clothes, diapers, and any medication to be given during ESS. All medications must be in the prescription bottle, with correct dosage on label.

Register soon since locations fill up quickly. For most locations, you can register for three months and choose the wait list for two months. This keeps some availability for new families who are just figuring out ESS! If you need help or have questions, call FOCUS!

RESPITE LOCATIONS:

Acworth

Summit Baptist Church
4320 Moon Station Lane • Acworth 30101

Alpharetta

Alpharetta Presbyterian Church
180 Academy Street • Alpharetta 30004

Chamblee

Embry Hills Methodist Church
3304 Henderson Mill Road • Atlanta 30341

Marietta

Mt. Bethel Daycare
615 Woodlawn Drive • Marietta 30068

Peachtree City

Peachtree City UMC
225 Robinson Road • Peachtree City 30265

Go to the calendar at www.focus-ga.org for specific dates of respite.

PLEASE DELIVER PROMPTLY
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Atlanta, Georgia 30340

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