Volume 29 Number 4

Fun

Jobe

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Dominick

by Patsi Montineri

Ah, what a wonderful and joyous time it was when my husband Paul and I learned we were pregnant. I was in my mid-30's so the anticipation of becoming a mother was overwhelming. Of course, being a little older when I got pregnant, I had to undergo more tests than usual. At 28 weeks, I was scheduled for a stress test at Northside Hospital on a sunny Saturday afternoon. Paul was at work, oblivious of any emergencies that were about to confront our family...

Once I got to the hospital the doctor discovered the baby had stopped moving. After reviewing the ultrasound, the obstetrician said the baby had to be delivered immediately through an emergency C-section if he stood any chance of survival! My initial response was "What?!? I'm not prepared for this." After collecting myself, I called Paul to give him an update, to which he responded: "Do I need to come down there?" My immediate response was: "What, are you kidding me? You're about to have a baby! Of course you need to come to the hospital."

After getting prepped and taken into surgery, our precious Dominick was born at 6:30 that evening, weighing just 2 pounds. Due to the trauma he suffered prior to his birth, his little body was entirely blue. He was not breathing. His left forearm, from elbow down, was black, almost gangrenous.

Immediately after his birth, the nurses whisked him away to ICU. We were not allowed to see him for 24 hours while the doctors and nurses struggled to keep him alive. We only had a small photo of him the nurses had placed beside my bed.

Dominick spent 10 weeks in the ICU at Northside Hospital. He was born with a hole

in his heart, bleeding in the brain, retinopathy of prematurity, respiratory issues, and a gangrenous forearm. Day by day, his fingers started to dry up and fall off. Paul and I cried at each crisis. There was nothing the doctors could do to save his hand. However, with all of the daily medical crisis Dominick was experiencing,



he was alive and making slow, arduous progress each day!! Paul and I were advised that Dominick might also be blind. None of this mattered. We just wanted our son to survive and come home. As the days and weeks went on, miraculously the bleeding in his brain resolved itself and the hole in his heart repaired. Eventually, our darling Dominick was able to come home (with a ventilator, of course!!) and our life as a family began, with hope and prayers that our child would grow into a strong, happy, self-reliant adult.

Fast forward to 2012. Dominick is an amazing 14 year old who will be attending high school this fall. He plays on a lacrosse team and has just received a scholarship to attend a lacrosse camp. We are truly amazed at the progress he has made and how capable he is. None of us have ever considered Dominick "handicapped" in any way. For example, he mastered riding a bike. He mastered playing baseball. He plays lacrosse with the best of them. He has mastered all that he has undertaken in his short 14 years.

Dominick is a wonderful young man with a great sense of humor. Whatever life has in store for him, he will meet it head-on and conquer it. After all, he is the DOMinator!!!

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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.

Service Learning & Partnerships

FOCUS is fortunate to partner with Mercer University Department of Physical Therapy and Chattahoochee

Technical College Physical Therapy Assistant program. Both groups volunteered at FOCUS outdoor day camp, Camp TEAM, and Mercer students also volunteered at Camp Hollywood. Students and campers benefit from this partnership - the students gain experience by playing one-on-one with our campers ... and campers have fun!! Thanks for the extra hands, the added energy, and the wonderful friendship!!

FOCUS



From the Editor by Lucy Cusick

Albert Einstein is credited for saying, "Insanity is doing the same thing over and over again but expecting different results." Whoa – he was a really smart man, that Mr. Einstein!!

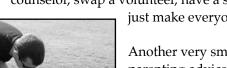
As a mom, I quickly learned that while children love consistency, they also need incentives and to know the punishment. Going to bed wasn't a popular activity in our house and no amount of timeouts or promises of gummy bears for breakfast made it popular. But, reading an extra book or sleeping on the floor sometimes made bedtime more appealing. Our kids also loved to know the expectations ahead of time: if you get dressed tomorrow morning without being told, we'll have time to have hot chocolate with breakfast. Our child with cerebral palsy also responded well to "if you do this," then "we can do this." "If you hit the cat with your wheelchair, we will go the vet instead of the park." The carrot had to be worth it, though. He upped the ante from gummy bears to M&Ms pretty quickly.

Back to Albert Einstein. During the preschool years, we called dinnertime "the bewitching hour." I know some parents have a four-letter word for those hours between 5 and 7 pm. "No snacks, dinner is almost ready ... I do want you to practice with your walker, but *I'm trying to finish dinner. Watch the cat!"* Tired and cranky children + tired and cranky parents + doing the same thing every night =Insanity. How can you get different results? Hey, I'm not Dr. Spock, but I do know that trying something else might work. We gave baths BEFORE supper – baths kept the kids from having a late afternoon nap (which then caused them to not want to go to bed on time), kept them entertained, and made after dinner a little easier. It didn't always work, but when it did, some semblance of peace prevailed.

We even try to apply Albert's wisdom to FOCUS programs. We've been in day camp for over a month now. Every week, we have two new groups of campers. While we can't change the whole plan for one camper who has difficulty, we might be able to make some simple adjustments that will make everyone happier. To move a counselor, swap a volunteer, have a snack, or take a break might

just make everyone's day better!

Another very smart person gives great parenting advice. Here's a favorite, from Erma Bombeck: "All of us have moments in our lives that test our courage. Taking children into a house with a white carpet is one of them."



Technology allows us to be more connected than ever! Finding other parents in similar situations has never been easier – from Facebook to Caring Bridge to individual blogs, those of us with desktops, laptops, smart phones, and iPads have made friends all over the world. Here's a blog we follow that makes our heads nod like that little dog you see in the back of a car window!! (Send us your favorite blogs!!)

Living Life with My Special Needs Mom Blinders On

by Ellen Seidman of www.lovethatmax.com

Like a race horse, I power through life with blinders on. Special needs mom blinders, actually. They help me keep my focus on Max, avoid comparing him to other kids, and not obsess about problems that may lie down the road. This, I've learned after putting my heart through the paces again and again when Max was younger. It only bred anxiety.

Will he talk? Will he read? Will he write? Will he go to college? Will he have a good job? Will he fall in love? Will he get married? Will he be a dad?

STOP IT STOP IT STOP IT, I'd tell myself. Eventually, I listened.

I can do my best to help Max reach his potential, but no good comes of chasing answers to what he will be "like" and what he will/won't be able to do.

And so, I don't let myself think too much about challenges the cerebral palsy and brain damage may someday present. Oh, yes, I know that Max is going to be at much higher risk for seizures when he reaches teenage-dom and his hormones go wild. I know, from last summer's serial casting, that as he spurts up his leg muscles are going to keep on tightening and perhaps other ones as well. But with my trusty blinders on, I keep my sights on Max in the here and now.

The major problem with wearing blinders is that when they get knocked off, you might just freak out.

That right foot Max got serial casted has started to turn inward again. His physical therapist at school noticed it first. One day as Max was walking around the house, I saw his right foot going crooked and my heart lurched. Max was due for a new set of orthotics, though, and his therapist and I hoped they'd do the trick.

He's been in the new orthotics for a couple of weeks and I thought I saw improvement, but not consistently. Then I got an email from his PT. She's been watching his leg closely, she told me, and she thinks the problem with his foot turning inward is starting at his hip. The therapist said it was nothing to be alarmed about, and that she just wanted to keep an eye on it and prevent it from getting to be more of an issue as Max grows.

I was totally unnerved, and scared. It was a new body part to worry about, another way the cerebral palsy may cause trouble.

I handled it in my usual way of dealing: take action. I'm trying to get an a.s.a.p. appointment with the physiatrist. I've Googled hip problems and cerebral palsy. (Says Children's Hospital of Boston, "Weak muscles do not support the bone and joints as well as they should, which can lead to scoliosis, hip dislocation and foot and ankle deformities.") Also, I ate too many Oreos.

I'm trying to not let worry get the best of me. Only my blinders are completely trained on Max's right hip. Is it moving well? Is it off? What's a hip supposed to look like, anyway, when it moves? And is that foot straight or crooked?

Oh, sweet boy, please be OK. ■

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Upcoming Events at FOCUS!

August 10-12: Under the Stars Family Camp 1 at Camp Twin Lakes Rutledge. Camp is full, but the waiting list is short. If you are interested, email joy@focus-ga.org for an application.

September 22: FOCUS Day at the Georgia Aquarium. Applications will be mailed (bulk rate) to all families in late July. Follow application directions carefully – first preference is given to families who have not been to FOCUS Aquarium Day in the past 3 years.

October 6-7: Under the Stars Family Camp 2 at Camp Twin Lakes Will-A-Way. Camp is full, but the waiting list is short. If you are interested, email joy@focus-ga.org for an application.

November 10: FOCUS Day at Zoo Atlanta. Information will be in the next newsletter.

Currently being scheduled: FAST Fins Swim Team Practice Schedule, FOCUS Moms Day Off on the Houseboat and FOCUS on Fashion. Information will be sent by email – if you do not receive emails from FOCUS, please give us a call or email inquiry@focus-ga.org!!



We had lots of comments on our last compilation of FOCUS Facebook postings! "Be our Fan" at http://tinyrul. com/focusgeorgia. Here are a few of the latest popular Facebook statuses:

FOCUS is compiling a list of churches in metro Atlanta that offer programs for children with special needs – either inclusive or self-contained. We did this a few years ago, but we need to update the list! Share your church's name and location if your child is loved!

- Alpharetta Presbyterian Church
- Browns Bridge Community Church Cumming Georgia; North Point Community Church – Alpharetta
- Johnson Ferry Baptist Church, Marietta, (East Cobb) Greenlight Program
- Burnt Hickory Baptist Church, Powder Springs (NOAH ministry)
- Faith Baptist Church, Monroe (Stone Soup respite and they even love my baby and many others during Sunday school and church on Sundays!)
- St Peter Chanel Catholic Church, Roswell. Jeanne Lyons rocks!
- Blackshear Place Baptist Church in Oakwood. Don't know all the details.
- Tabernacle Baptist Church in Hiram ;-)
- St Brigid Catholic Church in Johns Creek they have both inclusive and self-contained classes for kids.
- Tucker First Baptist has a wonderful program!
- Smyrna Presbyterian Church, Conyers. Whatever it takes!
- Faith Baptist Church in Monroe, 1789 Hwy 11. Inclusive Sunday School, children's church, youth and adult ministry. Inclusive Awanas, Stone Soup Friends of All Abilities Respite once a month, Stone Soup camp
- Faith Baptist Church Monroe (www. faithbaptistmonroe.org) Faith Baptist Church in located in Monroe. We are a nontraditional Church associated to the Southern Baptist Association.
- North Point Community Church. The volunteers in my son's classroom are wonderful! So caring, patient, and loving.
- Mountain Lake Church in Cumming
- We've recently had success at Passion City Church in Buckhead – inclusion. One of the teachers in the 3 y/o class is a SN teacher for her day job and others are OT in training. They're all pretty young, but it's the most comfortable we've been in awhile.
- Cornerstone UMC in Newnan. There are A LOT of special needs kids who are loved there.
- Shadowbrook Baptist in Suwanee. We have RESPITE once a month and there is a new worship for our

children every Sunday (so that parents may worship together)! WONDERFUL group (PURE Ministry)!

- St. Aidan's Episcopal in Milton/Alpharetta. We don't have a formal program, but the parish has always been very accepting of all of our children.
- Forgot to mention, that Burnt Hickory is a selfcontained classroom(s), and they have VBS in a separate class as well
- North Metro First Baptist has Sunday school, VBS, and a monthly respite called AGAPE.
- Hebron in Dacula also has had monthly respite. North Metro is on GA 20 and Old Peachtree. We
- have over 30 for special needs VBS class this week. And Sunday School is offered at SS hour and during worship
- The Church of the Apostles on Northside Parkway at West Paces Ferry has a wonderful special needs classroom!
- Sadly I cannot add to the list but this is an awesome idea. Keep them coming!
- First Baptist Church, Newnan
- Passion City Church, Atlanta. I can add to this wonderful list ... great idea!
- Crossroads Baptist Church in Newnan
- Loganville First Baptist. Special Needs Sunday School Also Snellville First Baptist. Special needs Sunday School, VBS, and once per month Tuesday respite.
- Roswell Presbyterian Church Roswell. They have a great shadow program for children with special needs.
- For any Jewish families, contact Amit Atlanta, the Jewish agency that serves local families who have children with special needs. They have 2 self-contained Sunday School classes, in addition to connections with local synagogues who provide assistance in the regular classes.
- This is a great service you provide the community. How do I get a copy?
- Johnson Ferry Baptist is offering a special needs class for VBS, and they have one on Sunday mornings as well!! East Cobb Presbyterian is finding a teen buddy to escort my autistic son around during VBS!!!
- All Saints Episcopal, Rhythms of Grace, second Sunday of every month at 3 pm in the Chapel. This service incorporates biblical storytelling, sensory experience, music and Eucharist into a worship experience where all forms of physical and vocal responses are accepted and encouraged. While Rhythms of Grace is created intentionally for families with kids with special needs, all families with extra-wiggly, extra-creative children are welcome to worship together.
- Alpharetta First UMC free camp this summer for children with special needs and siblings, monthly

parents night out, and "shadows" during Sunday School and Church. The church is also building an all-inclusive playground to be completed this fall. All the information is on their website. You do not have to be a member to take advantage of these services.

So ... following yesterday's theme, we'll call today Wild Wednesday! What 'one thing' in this world of parenting a child with special needs really gets your goat and makes you mad ... and how do you handle it??

- Parking in a handicapped space with no tag (or, almost worse, the ramped out section of the space) ... just makes steam come out of my ears!! Sometimes I leave a note, sometimes I decide to just keep moving & not ruin my day
- Hearing the "R" word! I try to educate those who are misusing it! Also, when people act like we need pity because my son has Down syndrome ... we aren't cursed, we're blessed! :)
- Pity or sympathy. That may sound harsh and I sure don't mean for it to but when I talk about my kids and if I mention each of their disabilities, people often say, "I'm sorry." Why???? I'm NOT sorry and neither are my children. We're all quite happy, actually, and feel very blessed.
- The Judgment you get when your Autistic son has a meltdown. They just assume you're a bad parent and don't discipline your child when in reality it isn't a behavior issue that caused the melt down but a sensory issue such a LOUD piercing noise or the flicker of lights. Got to love when they tell you a good Spanking would nip that in the bud.
- I hate when people say, if you had only known you carried this before. What does that matter now? He is here and I can't live without him so I can't imagine missing out on being his mom. I just nicely respond, it would not have made any difference.
- Parking in a handicap spot WITH the proper plates and people arguing with me because they do not "see" a handicapped person. Just because we don't always drag out the wheelchair doesn't mean someone isn't in need of a closer spot for other reasons ... like a very poorly functioning heart! One time my daughter had a backpack carrying her g tube feeds and another one that I carried with TPN bags all hooked up to her port. She had just had open heart #2 and I was carrying her. Some lady with a cane came over screaming that I wasn't handicapped and I "took her spot." I was so angry (built up hospital tension, lol) I simply lifted Madison's shirt to reveal her new 10 inch scar, 4 chest tube scars, her accessed port and accessed g-tube. She went reeling back apologizing as she scurried back to her car. Never judge a book by its cover lady, anyone can buy a drug store cane ;-)
- Ditto to all of the above!!!
- Also hearing the 'R' word. It brings my mind back to finding out my daughter's diagnosis and all the hurt I felt back then.

- The stares and the comments that people don't think we hear but we do. My son is not an 'alien.' Yes his head, hands and feet look different, but if you get to know him, he's one of the happiest, brightest little boys you'll ever meet. He runs, plays, jumps, and does just about everything any other kid his age would do. He just has to go to the doctor a lot. He's still oblivious to the whole thing which helps, and his outgoing nature is usually what calms the situation.
- This will sound crazy, but I have felt so much relief reading these ... We are not alone, we are NOT alone!!!!!!
- The constant flow of paperwork and follow-up phone calls. I need a secretary!
- All the above, especially the meltdowns. There is nothing I can do about it, just wait and pray for it to be short.
- Everything is so much harder: going somewhere, taking care of myself, having time with the other children, keeping up with the needs of our special needs girlie, keeping up with all the things the therapists want us to do with her in our "spare time." It makes life all together overwhelming.
- Constantly being told that my child "looks" fine so she must be fine (like all her diagnoses are in my head ... a big conspiracy between me and her 5 + Specialist doctors and 5 therapists) and being told by people they don't know why I am jumping through all these hurdles to keep her that way....
- The looks I receive or George receives when he jumps and squeaks delightfully. He's just happy! And yes just about everything above, too. But good to know we think alike!
- People with small cars and no wheel chair lift parking in the spaces plainly marked for VANS ... We often have to pull part way in, get the children out, and then pull the rest of the way in. Yikes!~!!! Also hate the R word.
- When people assume because of my son's speech that he is not smart. He is very smart but because they won't take the time to try and understand his speech (affected by his CP), in their rush to move on, they'll never know what a great conversationalist he is.
- I'm with Judy ... those little cars in VAN ACCESSIBLE handicapped spaces and/or those folks parking illegally in handicapped spaces cause they're just 'running in for a minute' ... makes me angry!
- We were parked in a handicapped spot to go see a movie in Athens, when we came out, someone had parked in the striped area right next to my Wheelchair Accessible van. I started to lower the ramp before getting to the van, but I saw the car just before the ramp lowered. I had to go in the "TJMAX" store and tell the manager. She found the owner of the car. The woman's excuse was that she could not find any other spot to park, then she said she didn't see the stripes ... I was so mad!

(Continued on page 6)

FOCUS and Facebook

(Continued from page 5)

Don't leave home without it – what do you ALWAYS take to the hospital when your child is hospitalized??

- Extra 5ml syringe, slip tip for meds. CHOA stopped stocking them. :)
- Money, change of clothes, bible, hygiene products, toys, music...
- We always took Julie's blanket and her own PJ's
- Phone charger even though they have a box of them at the library (at CHOA) medical record book that I keep in case we get a new doctor, insurance cards and drivers license oh and prescription bottles
- Hair bows, of course!
- Her froggy ... the nurses pretend to give him shots before she gets hers!
- My own pillow and lots of changes of clothes.
- Let's see! All medical information. Bring anything that can be a Comfort Item or Toy.
- My laptop
- My cell phone & CHARGER!!

Random question #429.....when did you learn to trust your mommy/daddy instinct.....was it 'over time' or an 'aha' moment??

- Over time ... but a short time!
- Most definitely a "A-HA Moment"!
- Immediately. Once I confirmed my thoughts/feelings to what was really going on, even when I was in the shower, I knew I had it.
- I usually know, it's just convincing others! But, it was an 'aha' moment!
- Over time when it was proven right over and over again. Convincing others especially "experts" is the hard part. However, some Drs. like Hannah's pediatrician know that if I say something is wrong I'm almost always right.
- I think a little of both I didn't trust my 'gut,' but found I was 'right' most of the time. Then I had the 'aha' moment (shunt malfunction that I figured out before the docs) that proved I really was his mommy & mom really did know best!!
- Over time for one twin. Very complex medical care, got different answers from the doctors. Then in the middle of treatment, no one would continue care when learning he would have a MRI to check his Kari Malformation. Other twin, more instincts took over. However, I had a lot of help.

Looking Back at the Fun ...

May 6 – FOCUS Day at Six Flags Over Georgia

Thanks to the Forrest & Frances Lattner Foundation, over 900 FOCUS peeps enjoyed a day of coasters, chicken, and chatting!!









Swimmers from seven FAST Fins teams participated at Mountain View Aquatic Center







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In memory of Julie Anderson by Kathy & Joseph Lee Edson

In memory of Liam Vilensky by Doreen & Burt Wittenburg for the Liam Vilensky Camp Scholarship Fund

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In honor of Trevor Smith by Pamela & Michael Kipniss In honor of Mr. & Mrs. Lanier Dasher by Bruce Cooper

In honor of Angie Weiland by Rob Storm

In honor of Bret Weiland's Graduation by Deborah Maslia, J. Paul Whitehead, Davis, Elaine, Joshua & Midnight

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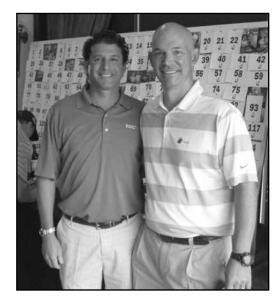
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Thanks to E*TRADE Financial for their support of FORE FOCUS! We had a special guest, progolfer Billy Andrade, who braved the morning rain to give our golfers tips on the driving range. The golf was great, the cause greater – we raised over \$45,000 (after expenses!) for FOCUS programs!

Special Events for Medically Fragile Families ...

... are ongoing. Please call FOCUS or email elizabeth@focus-ga.org_if your child is homebound, hospitalized frequently, or is at significant medical risk.

Teen/Young Adult Activities ...

... are ongoing. Please call FOCUS or email patrick@focus-ga.org for more information on monthly social opportunities and other events for teens and young adults who enjoy socializing but require only a 1:8 ratio.

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DATED MATERIAL

Hosted by Phil & Ann Beegle Run or walk the trails of beautiful Cedargate Farms! Contact lucy@focus-ga.org for more details.

3rd Annual **Run the Farm for FOCUS** 5 & 10K trail run & 1 mile family walk

August 18

3rd Annual

SummerFest at SweetWater Brewery

Cheers to summer and FOCUS camps! Enjoy brewery tours & tastings, Willy's Mexicana Grill, cornhole

tournament and music! Contact lucy@focus-ga.org for

September 29

Camp Twin Lakes plans this awesome event. Ride or support TEAM FOCUS and support the programs FOCUS will offer at Camp Twin Lakes in 2013. For the past three 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!!

October 20 – Mountain Bike Ride October 21 – Traditional Road Bike Ride Camp Twin Lakes – 7th Annual Spin for Kids

Support FOCUS fund raisers AND the programs FOCUS offers by attending FOCUS fund raisers ... and bring friends! Proceeds go to FOCUS programs which are offered at a reduced (or no!) cost to children and families!

FOCUS Fund Raisers

more details.