



The July / August issue of the FOCUS newsletter is always challenging. FOCUS day camps began on May 28 and run until July 12 which leaves little time for compiling a newsletter! We hope you enjoy these articles from some of our favorite blogs – we are grateful for their permission to reprint!!

To the Me of Ten Years Ago

by Phoebe Holmes
www.phoebeholmes.com

You ... yes you, holding that sweet baby girl in the plaid dress. Let's chat.

You don't know it yet, but that sweet baby girl has a secret. One that will slowly and not completely reveal itself over the next few years. It's going to break your heart. Repeatedly.

But I promise you, it will be okay.

No. Really.

Sure, you'll need therapy. And you'll get a bottle of Prozac with that therapy. It'll help. It will help you crawl out of the big cloud of overwhelmedness you will feel for a year or so. But you won't need them forever.

That baby girl's going to keep you up at night – literally and figuratively. You will worry over her like no other child has made you worry. I'll be honest, you'll never get over that worry, but it won't haunt you constantly.

One by one, you're going to give up on the dreams you had for this baby girl. The ones of her going to school, going to college, what she could be as an adult. The furthest ones will fade first. For a while, you live in the moment. Eventually, you allow yourself to think a couple of years ahead tops. Oh, you will plan for her long-term, but in the most generic of days. Inheritances. Guardians. You even ponder the idea of a group home. But mostly, you don't

think of those things. You just take it a few days at a time. It's just easier that way.

You will meet all sorts of people because of this child, and their true selves will be revealed. You'll learn that some people just suck, some people mean well but should keep their mouths shut, some people are kind but sometimes clueless to what you're going through. But you'll learn that most people, at heart, are good. This child will help restore your faith in mankind again, and again, and again, just in how they treat her.

You will spend the next nine years wondering how you ended up the parent of a special needs child. You kind of get used to it, but at the same time, you will never get used to it. It will be this feeling of constant surprise when you sit back and think about it. How did I get here? How did this happen?

No, you will never quite get used to it, no matter how much you do accept it.

You will learn to be a fighter. You will find strength you never realized you had and overcome your fear of confrontation. You do this because not doing this is not an option. That baby girl needs you to be this way. And you're not about to let that girl down.

Those three amazing kids you had before her? Are even more amazing than you could imagine. They

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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.

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From the Editor

by Lucy Cusick

The July/August newsletter is always a minor miracle – we are busy at Camp Hollywood and compiling a newsletter is not at the top of the list!! This is an article that I wrote 10 years ago – yikes!! I didn't remember it, so I doubt you do either!! Enjoy!

I've read several articles lately about the Lost Boys of Sudan and their experiences as newcomers to the United States and our world of technology. Stories about their introduction to microwaves, telephones, and grocery stores are heartwarming and even amusing. All the 'things' that we take for granted, they marvel at.

Josh and I always try to make summer at least somewhat productive. Josh, at 16, needs the summers to re-energize. He has cerebral palsy, but is in a regular education program. School is hard for him – not necessarily the academics, but the rest of it – figuring out where to go when and with whom takes a lot of his energy, not to mention the homework. So during school, we don't work on too many self-help skills; we save those for summer!

Josh learns through doing. But doing from a wheelchair takes planning and experimentation. This summer, his goal is to get out of bed and dress – without help or advice from you-know-who – the 'mom police.' Today is June 14; today he cut his time from 45 minutes to 21 minutes! Not bad!

His second goal is to learn enough about the kitchen so he won't starve if I get caught in traffic. Here's where the Lost Boy story comes in. The toaster and microwave were foreign objects to him. I mean, he knows what they do, but no clue how to do them. As he pushed the toast down, he wanted to watch the coils heat up. I was amazed at his amazement. Don't forget, this is a child of technology – he learned e-mail before I did! Today, we plan to pop popcorn in the microwave. That'll send him through the roof!

So happy summer. Remember that summer is for cloud watching and re-energizing. If you set any goals, set at least one that you can accomplish. Like 'eat chocolate once a day.' Now that's a goal!

Pampering with a Purpose

The Mary Kay love grows as Pampering With A Purpose, spearheaded by bereaved FOCUS mom and independent Mary Kay consultant for Mary Kay Jennifer Dicello, continues to collect amazing roll-up bags for FOCUS! FOCUS hospital volunteers report that they love delivering the Mary Kay bags to moms when their child is hospitalized!

The "Mary Kay Ladies" also attend FOCUS events to pamper moms. You never know where you might see these

'pink' ladies – on the houseboat for Moms Day Off, at FOCUS on Fashion, or maybe at the FOCUS office!

Many thanks to Jennifer and her band of merry Mary Kay friends. We are grateful for your recognition of how hard our moms (and dads) work every day, and we are thankful for your gifts of fabulous beauty products!

Six Secrets of Strong Special Needs Dads

By Suzanne Perryman, blogger at www.SpecialNeedsMom.com

I recently wrote about the secrets special needs moms won't tell you, but heard from many special needs fathers that they felt left out. My husband, Zoe's Dad, was my inspiration to write about what I know about special needs dads.

We are in the kitchen, my husband and I, cleaning up after dinner and talking about our day. I am telling him a sweet story about Zoe, a challenge she encountered. The story ends with success and as I happily share the outcome, I look to his face for the approval and excitement that I know he will offer, his endless encouragement something I rely on. Instead, I see he is still working through my words, that his face is still, caught in the moment when Zoe was vulnerable and unsure of her abilities, and in that few seconds, his face fills with pain and I see the heartache I know he lives with.

1. Special Needs Dads suffer silently with broken hearts. These dads are productive and they find their daily dose of happy, but that doesn't mean they don't carry heartbreak around. They had a dream that turned out differently too. I watch my husband wipe away single stray tears at unexpected moments. I can feel the grief in his quiet breathing at night, when he is awake when he should be sleeping. I feel the heaviness in his heart when we talk about the future and his fear that he won't be here for this child of ours. When other men hear him speak in detail about our amazing child, often, there is awkward silence, or even apology. Most men we know can't talk about disappointments, differences or delayed development as well as the moms do.

There are stories I have had to tell my husband, after-the-fact stories that detail the way our daughter cried, or when her eyes just filled with tears and her lip started to quiver. Stories about the way a needle hurt during a hospital stay, or how someone's words made her sad, or simply the way another child stared – or even how an adult unknowingly made something difficult for her. In moments like these, my husband goes silent and tense, he controls his outrage, he holds back his anger. His simple response is deeply meaningful: "I wish I could have been there."

2. Special Needs Dads struggle with being the protector. This is something dads cannot successfully do – protect their families from harm. There are too many physical forces beyond their control. Special Needs Dads also have fate getting in their face, 24/7. Fate that comes to call in the middle of the night, in the form of a physically sick child. Fate on the phone with a new diagnosis. No matter how many precautions they take, how physically present they

are, how hard they work to support their family, even how hard they try, Special Needs Dads will see their child and their family experience pain, over and over and over again.

I am in the kitchen, laying out the medicine tray for after dinner, when my husband starts telling me a story about work, something I am interested in and excited about. Zoe interrupts him mid-sentence. At the end of the day her words slur with fatigue, but she wants to tell her Daddy something, so we stop and wait while she tells her story. In the middle of the night Zoe calls for me, sometimes hours after, and I will feel my husband's hand on my shoulder. I have fallen asleep in our daughter's bed, and he has awakened, and is unable to fall back to sleep. He needs me too, and waits without resentment, while I take care of our daughters first, before coming back to him.

3. Special Needs Dads are strong. Our family life can be lonely and although we steal our moments together, much of our marriage is about what is best for the health of our children first. When we consider stealing away on a weekend vacation, our hearts hurt when we think of leaving our kids behind, and what could happen in our absence or if tragedy struck, to them or us, taking us both away from our kids. Special Needs Dads choose to put their family first, and are strong about doing what needs to be done. This is the strength that fuels their dedication. Maybe not all Special Needs Dads started out this way, but there is little room for selfishness with such strength.

There are times when I overflow with worry, trying to plan and prepare for every challenge our daughter might encounter. I see roadblocks where my husband sees opportunities, and at the end of the day, when I am weary and out of words, my husband opens his arms to my daughter, she crawls into his lap and while he holds her, he talks about his own life, how he always tries his best and why she should too.

4. Special Needs Dads learn how to be life-long leaders. Leaders empower. They spearhead change, advocating and working hard to make a difference. They empower their children, encouraging them to do more and believing they can do anything. These leaders continue to learn -- about their child's disability, about their child's needs, about the world around them. Leaders are responsible; they do what is best for their families, they choose the harder path.

(Continued on page 5)

Coming Up at FOCUS!

Always check www.focus-ga.org for details!

August 9 – 11: 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 the on-line application.

August 17: SummerFest at SweetWater Brewery. Help raise fund for FOCUS camps! See page 8.

September 7: FOCUS Family Night!! More details to follow – watch your email!

September 15: FOCUS Day at the Georgia Aquarium. If you've never been to the Georgia Aquarium with FOCUS, we hope you'll join us on Sunday, September 15! We will send out an email with a link to the application on July 9. Please let us know if you need a paper application mailed to you. Tickets are \$20 each and include admission to the special private opening, a gourmet brunch in the Oceans Ballroom with viewing windows, and accessible parking for one vehicle per family.

We will again select 700 FOCUS family members who may purchase tickets for the event. Applications should be sent to FOCUS by August 9. We will give first preference to families who have never come to the Aquarium with FOCUS. If we still have room, we will add families who last came in 2007, 2008, or 2009, respectively. (Based on past experience, it is very unlikely that we will have room to accommodate families who came in 2010, 2011, or 2012. You can apply, but don't be mad if we don't have enough tickets!!)

September 28: FOCUS on MOMS!!! More details to follow – watch your email!

October 5 – 6: Under the Stars Family Camp 2 at Camp Twin Lakes Will-A-Way. Camp is almost full – apply quickly! Email joy@focus-ga.org for the on-line application.

October 10: FallFest at SweetWater Brewery! Help raise funds for FOCUS activities! More details to follow – watch your email!

October 19 – 20: Spin for Kids Bike Ride. Ride for or donate to TEAM FOCUS and support FOCUS programs at Camp Twin Lakes.

October 26: MVP Boo-B-Que. More details to follow – watch your email!

FOCUS Fund Raisers

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!

August 17, 2013
4th 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 more details.

September 21, 2013
"Take On the Night," a glowing 5K experience

FOCUS receives 10% of the registration proceeds – run OR volunteer for this unique event!! Go to www.takeonthenight.com or contact lucy@focus-ga.org for more details.

October 19 & 20, 2013
TEAM FOCUS in Spin for Kids



Dr. Robert Bruce is team captain of TEAM FOCUS in Spin for Kids! Dr. Bruce rides every year to support FOCUS programs Camp Infinity, OctoberFest, and Family Camps "Under the Stars," all offered at Camp Twin Lakes. He also volunteers his time as a counselor! All

funds raised by TEAM FOCUS go directly to FOCUS programs at Camp Twin Lakes – ride or support TEAM FOCUS and help kids go to camp!

Contact lucy@focus-ga.org for more information about any of these events.

Please visit
www.focus-ga.org for the
Calendar of Events for
July and August.

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Six Secrets of Strong Special Needs Dads

(Continued from page 3)

"Daddddddddy," Zoe calls from her bedroom. My husband walks down the hallway, answering her demand. "How was your day?" she asks eagerly. She wants details then, so my husband provides them. She asks silly questions, and he patiently answers each one. "I missed you today, Daddy, and I love you" she vows. He easily, sweetly returns her I love you, something he says to her each day. Bending down, he touches his lips to hers as she reaches up for him.

5. Special Needs Dads are vulnerable. They love actively and affectionately. Often, their touch is the sole communication, a love language they share with their children. Loving this way comes from an open heart, a trusting heart that is left open to hurt and pain.

"I miss Daddy" Zoe tells me. It is bedtime and her dad is out of town, something that seldom happens. "It's not the same, when he is gone," she sighs, laying her head on my chest. She is missing his laughter, the way he gathers her in and holds the gift of her close.

6. Special Needs Dads live life with purpose and perspective. My husband has found his work /life balance, choosing to be present for his family yet still feeling the constant pressure to provide. Daily, he embraces the simple gifts in our life: emotions, our family love, even the food we prepare together. He has learned the value of each gift in life and how important a moment in time can be, how moments shouldn't be wasted or life lived with regret.

I hug her tight and try to soothe her to sleep, knowing there is nothing I can do to fill the space her Daddy holds in her heart. ■

To the Me of Ten Years Ago

(Continued from page 1)

will show compassion and understanding beyond their years which will make you proud.

But those three will have to put up with so much because of their sister. Hours in waiting rooms, stuff broken by her, my inability to multi-task and spread my attention to everyone evenly. Your heart will break for them, that at a young age, they will realize that they will someday inherit this sister. But once again, these three kids will amaze you, for they will never resent that little sister. Be annoyed by her? Oh sure. But in normal ways. Those three little children who would hover around Maura's bassinet and announce every time she cried will continue to look out after her over the coming years. They will let you know that you've done at least one or two things right.

That little baby girl? Is going to work so very hard the next ten years to learn things. Slowly, but surely, she will learn things. I promise you, she will walk, she will get there. She will talk too – not great, but enough. Can't promise you on the toilet training, but don't give up, she should get there.

You can't tell right now, but that baby girl's brain? Is going to freak out on her. She will be diagnosed with epilepsy. It will freak you out at first. I promise, promise that it will be okay. It will not stop her from anything. In fact, you'll find out that things will improve for her after the diagnosis and starting medication. It will quickly go from something scary to something to be oddly grateful for. And then it will just become something that you all will be able to live with. Yes, that thing that will be on top of your "Big Scary Things I Don't Want My Child to Have" list will suddenly be not that scary.

I promise that.

Speaking of medical things, your days of never seeing the pediatrician because your kids are so dang healthy? Those are over. You will get frequent flyer miles at the doctor's office. You will collect cards of all sorts of medical professionals. You will learn which blood lab does the best blood draws on children. You will be able to write things like "epicanthal folds" and "oxcarbazepine" without thinking. You will also know that as much as you're dealing with, you're grateful that is all you are dealing with. Because there could be more, it could be worse.

Your back is going to spasm out from carrying that child around so much. You'll end up with tennis elbow from lifting her as a seven year old into her car seat. You will put on weight from stress eating. You will lose your mind a little.

It'll be okay.

Your world will revolve around poop. Your friends may think you talk about it too much. They will have no idea just how much you could speak of it. Don't worry though, you will discover a small group of other moms obsessed over bowel movements. And you will be able to over-share with them.

Your life is not going to go as you had vaguely planned it. It's going to veer off in a new direction. People will link you to the heartwarming tale "Welcome to Holland". You will hate it. That's okay. You're allowed to hate it.

You will find out that there are cliques even in the special needs community. So you'll start your own damn support group. It'll be called "Who wants to get coffee with me?" It will be great.

You will learn to view adults with special needs in a whole new light. You will see a man in his 50's happily buying a coloring book and it will make you think of your daughter. You will not cry in the store, but later on, there will be some tears.

You will feel so very alone with this child at times. Sometimes, at home, at night, other times, in the middle of a crowd. You will feel a cold wave of loneliness that you're certain no one else will ever really understand.

You will feel jealousy, of other people and their children who are developing normally. Of their seemingly placid lives that don't involved fighting schools and doctor visits and poop.

Just remember, you were raised to not whine about things and deal. And you do. You will suck it up and deal with it as best you can. And you will do so with a smile on your face. Because crying is never an option.

Well, most of the time.

You will write and blog about this child, and her life. And in doing so, find a whole slew of people out there who say "Wow! I live this too!" and "Thank you for writing exactly how I feel!" Somehow, you will become a voice for others and you'll realize that you're completely inadequate when it comes to saying "thank you" and still are lousy at accepting compliments. Work on that, okay?

You will discover that while you never expected to be a special needs parent, you will end up a bit of an advocate for special needs children. You will wonder more than once how you ended up on top of a soapbox. Don't worry, you'll be okay up there.

(Continued on page 7)

Secrets Special Needs Moms Know But Won't Tell You

By Suzanne Perryman, blogger at www.SpecialNeedsMom.com

I am a special needs mom. And I have secrets. Things I don't talk about and other moms don't know -- or maybe they just forgot about along the way. Here are six of them.

1. Special needs moms are lonely. I yearn for more time with friends and family. I have an authentically positive attitude and most often you see me smiling. I may even look like I have this SuperMom thing down, am super busy and have enough help. But I am lonely. Being a special needs mom doesn't leave me the time to nurture and maintain the relationships I really need. I could get super detailed here about the hands-on caring for my child. (Do you remember when your kids were toddlers? That hovering thing you had to do? It's that plus some.) The plus-some includes spreading my mom love around to my other child and my husband, who on a daily basis are put on hold, waiting for my attention. I don't have much time to call or email my friends and even family ... and if they don't call or email me, well then I feel massive guilt about the time that has passed. More negative stuff that I pile on my shoulders. Getting out is tough. I miss the days when I had playgroups with other moms, open-house style, dropping in and drinking coffee at a friend's kitchen table with my child playing nearby.
2. Special needs moms have to work extra hard to preserve their marriages. This work goes along with the high stress of special needs parenting and aims to combat the sky-high divorce rates for special needs families. I put extra pressure on my husband; he is my best friend, and sometimes I expect unrealistic BFF behavior from him at the end of the day (see no. 1). He is my hero: supportive, patient and loving -- and my kids would be totally lost without him. The success of our marriage will affect the health of our children. My husband and I haven't spent a night away from our kids for six years. We "date night" out of the house every few months, for a two-hour sushi date. Our marriage is a priority, so we "steal" our moments when we can.
3. Special needs moms are not easily offended. Despite what our social media status updates say, we are vulnerable, and life messes with us daily. So really, ask what you want to ask and it's OK to start with "I don't really know how to say this, how to ask you ..." I am especially touched when someone cares enough to ask me how my child is feeling, or how to include my child in a social gathering, meal or other event, and am happy to collaborate on what will work for us.
4. Special needs moms worry about dying. We worry

about our kids getting sick and dying; we worry about our husbands dying and leaving us alone; but most of all we worry a lot under the surface, and especially about being around to care for our children. We watch people we know grieve the loss of their children and try not to think about it. On the upside, we live life fully and don't take it for granted.

5. Special needs moms are fluent in the transforming body language of touch. This is the first language we learn, and sometimes the language our kids know best. This therapeutic natural language can relax, redirect and heal. This should be the first language "spoken" in every home.
6. Special needs moms know to savor the gift of a child saying "I love you." For the longest time I wasn't sure if my daughter Zoe would ever speak the words. When she was a newborn, it was her sighs of contentment as I held her against my breast that told me how much she loved me. When she was a baby, it was that peaceful calm that came over her when I carried her in my arms. The first time Zoe found her words, she was already a little girl, and every time she spoke them I cried. She is 10 now, and her words are even more tender and wise. I leaned into her at bedtime the other night, and as her hand reached up, caressing my cheek, she whispered ... "I love you Mom, for taking such good care of me." ■

To the Me of Ten Years Ago

(Continued from page 6)

You will learn that the guy you chose to marry ten years before? Good choice. That man will be the one helping you pick up the pieces when you shatter, will love that baby girl as much as any other child, will take care of life when you can't, and will still find you sexy even after all that stress-eating weight gain.

It's going to be the proverbial emotional roller coaster, these next ten years. You'll have moments where you're feeling so high, only to crash back down. But know this –

You will grow. You will amaze yourself. You will let go of fears. You will embrace the now.

And you will love this amazing, beautiful happy child so much, it will hurt. And you will be okay with that.

Oh, and that straight hair? Is going to start to curl. Go figure. ■

Looking Back at the Fun ...



FOCUS Six Flags Day was quite a wash this year! The monsoons of May were against FOCUS families having fun! The pavilions at Six Flags were flooded on the original date (May 5); some families opted to go to the park and eat on their own – the weather held for most of the afternoon. May 19 was

the rain date – and the weather was worse!! We had good weather for nine years – we'll try again in 2014!!



FOCUS Daddy Daughter Dance & Dessert was amazing! Almost 40 dads, grand-dads, or special man brought their best gal to enjoy dancing and dessert with FOCUS! Each couple had their photo taken before they hit the dance floor!



FAST Fins Spring Swim Meet was a swimming success!! Swimmers from all seven teams competed and enjoyed the cheers, ribbons, and snacks!

FOCUS MVPs enjoyed a wonderful performance of **A Child's Garden of Verses by the Alliance Theater for the Very Young** on March 17. The interactive multi-sensory performance was about a 'cultural' garden in which the children grew their imaginations and became gardeners themselves! Many thanks to Fleur de lis Cupcakery for the delicious cupcakes our gardeners enjoyed after the performance!



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