September/ October 2014

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Expecting"

by Rand Glenn Hagen

Fun omfort.

In approximately five weeks, we are expecting the arrival of our third child. After having two girls, we are now having a boy. Whenever people hear this, they make such comments like, "I bet your husband is excited!" or "Watch out - boys are a handful," or "Oh, you are going to love having a boy; they sure love their mamas." I understand that gender holds a lot of meaning in our society, and so does expecting a child. However, my first two girls have taught me a thing or two about expectation.

As soon as you find out you are going to have a baby, a mental roadmap immediately begins to unfurl. What and who will this child look like? What will she be like? What will he like to do? I'll never forget overhearing someone ask my father a question when I was pregnant with our first, who was also the first grandchild. Knowing my father had parented two girls, a friend of his remarked, "Hey Tom, betcha hoping for a boy this time so you can get out there and teach him to fish, go sailing, all that great stuff!" My dad replied, "Oh, I can do all that with a little girl, too." I was grateful and proud, and I could not have agreed more.

When I was expecting my first daughter, Lila, no one was a stranger; everyone had his or her two cents and was more than willing to share. Interestingly, some believe that parenting one child makes one an expert on all children. We've all heard expert theories on feeding, sleeping, bonding, etc. I had a cab driver in Manhattan assure me there was only one way to make it through labor (not how I did it). An elderly man on the street pointed to my belly and yelled, "You're havin' a boy - that's for sure!" (I wasn't). And when I was past my due date, I received countless theories for ways



to get the baby to come (nothing worked – she came when she was good and ready). Another piece of advice people shared was that going from one child to two was way more difficult than having just one. I personally disagree. I found the process of becoming a mother for the first time a much steeper learning curve than assimilating a second child into our family. Lesson number one: we are all different and can experience a similar situation in diverse ways.

From the very beginning, with my firstborn Lila, my expectations of how it was all going to be were challenged... From the delivery (I was told three weeks before my due date that she'd come any day, but she came 8 days late) to what she looked like (I figured my dark brown hair and eyes were clearly dominant, but she's fair skinned with blonde hair and blue eyes). I also expected to dress her in sweet little-girl clothes, but this child's own sense of style emerged at around 1 ½, and she has been dancing to the beat

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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.

Check the Calendar!

Remember to check the calendar on our website for upcoming events! We have "Fridays at FOCUS," a party just for parents, and several great fund raisers.

Now's a good time to get involved. Come to FOCUS for Comfort, Hope, Fun!

www.focus-ga.org/calendar/

Have You Moved or Changed Your Email Address?

If you do not receive weekly emails from FOCUS through Constant Contact, we either do not have your current email OR your email provider thinks we are spam. Call 770-234-9111 or email inquiry@focus-ga.org and we'll try to fix the problem!



From the Editor by Lucy Cusick

As I write this, the news is filled with the sudden death of Robin Williams. I'm not a real celebrity watcher, so I'm embarrassed to admit I didn't know that Robin Williams struggled with alcoholism and depression. I only read *People* magazine in the dentist waiting room – and if they are running on schedule, then I don't make it past the cover story. In watching re-runs of past interviews, he was very open about his battle with alcohol; he often slipped humor in, always an entertainer, even when discussing his demons.

I vaguely remember *Mork & Mindy; Good Morning Vietnam* was the next real role that I recall, followed by *Aladdin, The Birdcage*, and *Patch Adams*. I didn't love the dramas, maybe because these movies came out during the years I was in the trenches of motherhood. I guess I needed the laughs!

Depression and anxiety are often two by-products of having a child with special needs. The responsibility is overwhelming – and fear is always knocking at our door. We put on happy faces and people comment about how special we are. We rarely let down our guards – maybe because we're afraid our hearts will shatter and we won't be able to glue the pieces back.

The experts preach taking care of the caregiver: find time for relaxation, exercise, good nutrition, and sleep. While I agree with all of these 'necessities,' I also know that many of us do not know how to do that ... how to turn off the mommy-button and take time for what feels like luxuries. I do know, however, that parents who take care of themselves and take breaks probably have more fun, sleep better, and are better parents, in the long run.

No easy answers here – but we are all in the same boat. Figure out what works for you and your family: find a friend and challenge each other to eat less and move more; make a doctor's appointment (for yourself!) if you think you are depressed; get involved in a support group – any group – and learn and lean on others in similar situations. Paddle hard ... and don't forget to breathe.



Find us on Facebook at http://tinyurl.com/focusgeorgia

Non-Negotiable Rules

By Marjan Holbrook

wrote down these rules down in February 2014. I was tired of living with chronic back pain, acute anxiety, severe seasonal allergies, insomnia ... you know the rest. By following these rules for 90 days, I am off all my meds and my fat percentage is 14%. I went from running for no more than a minute at a time to running a 5K in February and a 10K on July 4th. I have met great people and made lifelong friends. Zero pain! My 90 days rules have become my forever rules.

Four Parts: Eating, Exercise, Environment, and Everyone around you.

- Eat simple and clean. Nothing fancy, you don't need to know how to make organic veggie burgers from scratch or spend a lot. Google clean eating.
- 2) Say goodbye to sugar. The first week of the sugar detox is tough. My first week was during the snow in February. Stuck at home with my kids and unable to eat sugar. All I could think about were sweets dreams of being alone with a jar of Nutella. It was like a bad breakup with a boyfriend I knew was not good for me, but I wanted anyway. Awful.
- Don't have the time? Get off Facebook, stop watching Bravo, and no more pinning on Pinterest. Here's my routine: 2 days a week walk/jog/swim; 2 days yoga/balance/Pilates; 3 days a week strength training. By strength training I don't mean sitting at a machine and looking at the picture trying to figure out how to do it. What I mean is walking over to the section with the free weights. I lift weights to the point where I make ugly faces and weird noises. (Always consult your doctor first!)
- 4) If you don't know how to work out, hire a personal trainer and have them teach you proper form. Yes, it can be expensive. Where do you want to spend your money ... on a personal trainer or co-pays? Sorry, Kaiser.
- 5) At least 2 days of your workouts must be with other people. Friends to keep you accountable. Join a social run club. Zumba? You should see the Zumba people at my gym, they are awesome. I go on Sunday afternoons just so I can watch them.
- 6) Don't let your home get cluttered. Read "It's All Too Much" by Peter Walsh. It changed the way I look at my house. I recommend the audio book. Peter's sexy Australian accent will convince you to get rid of the things you don't need.

- 7) Surround yourself with people you love and respect.

 Make the time to see them face to face because they might be transferred next week.
- by Set a timer before phone calls with toxic people. Sure, it would be great if we could avoid them all together, but we will always know toxic people. Prepare yourself ahead of time and set the timer.



Marjan (L) with her daughters and running partner

- 9) Read biographies of people who have overcome great obstacles and hardship. When I don't want to run another minute I tell myself: a double amputee finished the iron man (Scott Rigsby); a nun who is old enough to be my grandmother completes triathlons.
- **10) Belong to a group or a club.** Can't afford the Atlanta Athletic Club? No problem! Most churches, synagogues, and support groups are free country clubs.
- 11) Thank people, especially if they are taking care of your kids. You don't need to make them a homemade treat (no-sugar) or some other fancy Pinterest thank you gift. How about sending an email to their boss to let them know you are thankful?
- **12) Volunteer to do the things you love.** I don't like meetings so I don't volunteer for the PTA or HOA. I love helping in the classroom and throwing neighborhood parties.
- 13) Never say anything negative about yourself.
- 14) If you break rule #13 you must write down at least 15 positive facts about yourself. Set the timer and tell yourself about all the things that make you fabulous.

The last rule is the most important one for me: *you cannot do this alone.* You need to ask for help and work on building a network of people who want you to succeed.

"Expecting"

(Continued from page 1)

of her own fashion drum ever since. Finally, and most significantly, it is my eldest daughter's strong will that surprised me the most. Whatever misconceptions I had about my level of control as a parent were quickly... adjusted.

When we found out we were having a second baby, we chose not to find out the sex before delivery. Our firstborn had taught us that the individual is way more significant than gender. Boy or girl, this child would show us his/her individuality and personality. Interestingly, Lila had no doubts, as throughout my pregnancy she declared, "It is a girl. And her name is Alice." While this was endearing, my mommy intuition told me that it was a boy. Once again, I was wrong. It was a girl. And we named her Alice.

I was thrilled at the idea of Lila having a little sister. As one of two girls, it was a family system with which I was familiar; I thought I knew how sisters worked, both the challenges and the blessings. And the hand-me-downs! Once again, however, life challenged my assumptions. Early on, it was obvious that my two girls had very different temperaments. Alice was much more laid back than her big sister. Additionally, while Lila was one to reach her milestones quite early, Alice seemed to be in no hurry. I was encouraged to relax and just let Alice be Alice. However, when she was 8 months, and still not sitting up on her own, I decided to check in with her pediatrician. That is where my remaining expectations of parenthood just sort of ceased to be relevant. The next morning, my baby was in the hospital getting an MRI, and soon after getting blood drawn for myriad genetic abnormalities.

The next mental step was the expectation of a diagnosis with some sort of course of action. Surprisingly – and mercifully – the tests showed no results that explained her significant global delays. And now, two years later, we still have no diagnosis, no prognosis. For a Type A planner and organizer like me, this has not been an easy process. And because my expectations as a parent were turned upside down, I struggle when people (friends, therapists or physicians) ask me for my goals for Alice. Sure, I'd love for her to walk on her own someday. I'd love for her to communicate – to wave, nod, or maybe even speak. However, she is healthy and just

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Coming Up at FOCUS!

September 6, 2014

FOCUS and Dare To Hope Foundation present Parent "Time Out" Party at Holy Cross Catholic Church

(3773 Chamblee Tucker Road, Atlanta 30341) from 7 to 10 pm. Cost is \$15 per person and includes dinner, drinks, dancing, and raffle tickets. RSVP to elizabeth@focus-ga.org

September 21, 2014 FOCUS Day at the Georgia Aquarium is full!

Registration was on-line – please keep FOCUS current of your email address!

Fall SibShops

Having a sibling with special needs can be difficult and wonderful! FOCUS' fun, activity-based sibling support group will continue this fall for siblings ages 8-18. Led by Dr. Jennifer Tumlin Garrett, SibShops include games, mixers, snacks, and interesting conversations. The group will again meet at Mt Bethel Community Center, 4608 Lower Roswell Road, Marietta, GA 30060. Sibs should make every effort to be at each session; the fee for three sessions is \$30 total. Contact joy@focus-ga.org for an application.

Meeting times are:

- Sunday, September 28 from 3-6pm
- Sunday, October 19 from 3-6pm
- Sunday, November 16 from 3-6pm

October 3 - 5, 2014

Under the Stars 2 at Camp Twin Lakes Will-A-Way

We'll have more "Under the Stars Wars" at our second family camp for 2014! We have a few openings for families – contact <u>joy@focus-ga.org</u> for the application! Join the fun!

October 19, 2014 FOCUS Moms Day Off on Lake Lanier!

Yep, it's a Sunday – join us from 11 am to 3 pm. For those who don't want to miss church, we'll have quiet time on the top deck from 11 to 11:30!! You must RSVP to elizabeth@focus-ga.org

October 25, 2014 MVP Boo-B-Que

Medically fragile children and their families are invited to the 6th annual Boo-B-Que at Holy Cross Catholic Church, sponsored by the Knights of Columbus. Contact <u>elizabeth@focus-ga.org</u> for details!

November 1, 2014 FAST Fins Intrasquad Swim Meet

The Fall season is underway – eight teams this season! Come cheer our swimmers on at the Mountain View Aquatic Center in Marietta – call FOCUS for more info!

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Coming Up at FOCUS!

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November 2, 2014 FOCUS on Fashion at Oglethorpe University

Join FOCUS for a magical afternoon, celebrating FOCUS children and the professionals who care for them. If you are interested in more details about your child modeling in the show, please contact elizabeth@focus-ga.org

November 8, 2014 FOCUS Day at Zoo Atlanta!

Registration will go out by email in mid-September. Call Joy at 770-234-9111 if you need a paper application.

Fridays at FOCUS!

Join FOCUS on Fridays for workshops about this and that! For a complete schedule of dates and topics, go to the calendar at www.focus-ga.org

Fund Raising at FOCUS!

Contact <u>lucy@focus-ga.org</u> with questions about FOCUS fund raisers – or if YOU would like to help raise funds for FOCUS!



September 28, 2014 "FOCUS Climbs for Kids!"

FOCUS Friends and FOCUS Kids climb together to raise money for FOCUS! At Stone Summit Climbing & Fitness Center, 3701 Presidential Parkway, Atlanta. Email elizabeth@focus-ga.org for more info.

October 19, 2014 Spin for Kids

Ride your bike for TEAM FOCUS and the money you raise supports FOCUS programs at Camp Twin Lakes. Email lucy@focus-ga.org for more informtaion.



The Best Fund Raisers are those that are done FOR us!!
Come to the Madison Avenue
Soapbox Derby on September 27, 2014!!
Email lucy@focus-ga.org
for more information.

Ongoing at FOCUS

MVP Events for Medically Fragile Families

For more information, email elizabeth@focus-ga.org.

Teen/Young Adult Activities for ages 13 to 29

Please email Mackenzie@focus-ga.org for information on monthly social outings and other events for teens/young adults.

Extra Special Saturday Respite – Fall 2014

Extra Special Saturday respite is unstructured play time for children ages 1 to 13. Staff includes a nurse, trained caregivers, and volunteers. Children can come to different locations, but not in the same month – no double dipping! To register, email Karen@focus-ga.org with the names and ages of the children and which location and dates you wish to register for. If this is their first ESS, please note that so we can send an application for you to complete and return.

ACWORTH

Summit Baptist Church
4320 Moon Station Lane, Acworth, 30101
September 13 • October 4
No November • December 13
(You may register for two months,
choose wait list for one month.)

ALPHARETTA

Alpharetta Presbyterian Church
180 Academy Street; Alpharetta, 30004
September 27 • October 18
November 15 • December 20
(You may register for three months,
choose wait list for one month.)

CHAMBLEE

Embry Hills United Methodist Church 3304 Henderson Mill Road; Atlanta 30340 September 13 • October 4 November 1 • No December (You may register for two months, choose wait list for one month.)

CUMMING

North Lanier Baptist 829 Atlanta Hwy; Cumming, 30040 No September • October 4 November 1 • No December (You may register for all dates.)

MARIETTA

Mt. Bethel Daycare
615 Woodlawn Drive; Marietta 30068
September 13 • October 4
No November • December 13
(You may register for two months,
choose wait list for one month.)

NEWNAN

Cornerstone UMC
2956 Sharpsburg-McCullum Road; Newnan 30265
September 27 • October 18
November 15 • December 20
(You may register for all dates.)

Looking Back at the Fun...

FOCUS Family Camp went "Under the Stars Wars" at Camp Twin Lakes in Rutledge in August!

Families enjoyed the art cabin, pool, archery, boating, the climbing wall, and more! Special activities this year included making and launching rockets, led by FOCUS dad Michael Lange, and a Star Wars scavenger hunt, created and led by the Lawton Family. Thanks also to Clark, Stephi, and Grant Howard for again emceeing the annual Talent Show, to Camp Twin Lakes for their excellent program staff, and to the many volunteers who helped make the weekend FUN for families!



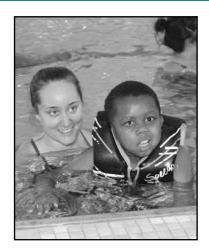








Camp Infinity went NEON this summer. Offered at Camp Twin Lakes in Rutledge, 50 teens and young adults worked on personal goals while enjoying zip line, archery, wacky Olympics, boating, and more. Over 40 counselors volunteered their week to help our campers make lifelong memories – and they had fun, too!





Camp TEAM kicked off the summer with a week of day camp fun at Mercer University in Chamblee. Campers enjoyed sports, nature arts and crafts, swimming, Zumba, and more!







Camp Hollywood was offered for for 1 week in 10 locations around metro Atlanta! Campers enjoyed art, science, music, recreation, and cooking – activities based on the themes of favorite children's movies! Thanks to the churches that continue to welcome FOCUS and our wonderful campers: Alpharetta Presbyterian, the Cathedral of St. Philip, Cornerstone United Methodist, Embry Hills United Methodist, Johns Creek United Methodist, First United Methodist of McDonough, McKendree United Methodist, Mt. Bethel United Methodist, and Summit Baptist.

"Expecting"

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so delightfully happy, it almost feels greedy to hope for anything else.

I also have learned that while I can have my hopes and goals for her, what will be will be. Without more information on a diagnosis or prognosis, my husband and I live in a chronic mode of wait-and-see. Between the doom of some physicians and the high hopes of some friends or therapists, we have had to find our own comfort zone. Without a crystal ball, we have no idea how things will turn out for Alice. We are learning to live with no expectations. We are relieved when things are uneventful, we are getting better at handling the stress when they aren't, and we are elated when we see Alice progress. And I value the perspective this has given us with our other children. We may think we have a roadmap for our "typical" children, but there are potential miracles and adversities around each corner. Letting go of expectation and appreciating the present not only helps us as parents, but also gives our children the space to be who they are, not who we expect them to be.

And now, here I am, expecting another baby, a boy. Will he get my brown eyes? Will he love football? Or ballet?

Or maybe football and ballet? Will he learn to walk or talk? And how about this one: will he even be born? Whatever will be will be, and this little guy, God willing, will show himself to us in time.

Sam was born, in his own time, in February 2013! Rand has been writing this article in her head – we finally convinced her to put pen to paper!

Donations Offer Comfort, Hope, Fun

Georgia Gives Day is Thursday, November 13, 2014. Watch for FOCUS emails about this special opportunity to donate to FOCUS! FOCUS depends on contributions to keep the cost of programs low to families. Of course, donations can be made any day at www.focus-ga.org!!

It's time for federal and state employees to make their annual decisions about contributions to the **Combined Federal Campaign** and the **State Charitable Contributions Program.** Please keep FOCUS in mind: CFC #76177 and SCCP #197007.

Thanks for your consideration and generosity!

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