



FOCUS

**Extraordinary Families
★ & Kool Kidz ★**

FOCUS

Volume 27, Number 3

May/June 2010

How's Kai?

By Cassandra Jeyaram

What seem like simple and unassuming questions, "How are you doing?" and "How's Kai?" are often the most difficult ones for me to answer.

For those who don't know that seven-month-old Kai has William Syndrome, my typical response is, "We're hanging in there; Kai's doing great! He's growing so fast!" For those who do know, and for those who I think actually want a "real" answer, it's a little more complicated. But there's always that momentary conflict of, "How should I really answer these questions?"

For the past seven months we've struggled with Kai's eating and sleeping. Basically, he does neither!! Every two hours – all day and night – he eats very little and the feedings

at night are often followed by hours of screaming due to extremely painful gas (despite Herculean efforts to burp him, keep him upright for 30 minutes after each feeding and a myriad of medicines). Needless to say, after seven months of having what really equates to a newborn's sleep schedule, my husband DJ and I are sleep-deprived and at wits end. This, of course (to which many of you will be able to relate), is on top of all

the therapies we take him to every week.

After agonizing for months of whether I should continue working a demanding job or stay at home, the answer became very clear at 4 a.m. It was the third night in a row of Kai's nonstop screaming and no sleep. Juggling Kai's schedule and work was too much. As a result, I left a job I loved to take care of our little one. We couldn't continue to live like zombies, and I worried that my professional reputation would suffer. We're blessed in that staying home was an option, and since leaving my job a few weeks ago, I've never looked back. On the first day of my new job as a stay at home mom, there was such an amazing calm and happiness in our home. And although my new boss is demanding, makes me work 24/7, and doesn't offer any vacation time, I wouldn't trade anything for staying home with Kai and the serenity that has ensued (even despite the ongoing feeding and sleeping issues!)



Since Kai's arrival, we've learned that answering simple questions like, "How are you?" and, "How's Kai?" can be a little more complicated, and we've come to accept that sometimes life with a special needs child dictates what you need to do versus what you want to do. But somehow, in the end, it all seems to work out – sometimes even better – than we could have imagined!

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MISSION STATEMENT

FOCUS offers emotional, informational, and physical support to families of children with disabilities or with ongoing medical conditions through a variety of programs such as support groups, respite care, and summer day camps. FOCUS networks parents who share common experiences and information with each other, providing a sense of community to families with children with disabilities.

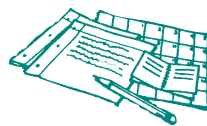
SUBSCRIPTION INFORMATION

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.

Family & Friends Give Back

Despina Vastakis and the Atlanta Chapter of the Maids of Athena had an Easter bake sale at the Greek Orthodox Cathedral and raised \$1,000 for FOCUS!

Metro Market Atlanta gave a portion of the proceeds from their December sale to FOCUS! Go to www.metromarketatlanta.com for information on future events!

**From the Editor**

by Lucy Cusick

Life is all about attitude ... the half empty vs. half full. Half full: Springtime in Atlanta is a thing of beauty and a wonder to behold, especially after this cold and dreary winter!! As I write this, the forsythia is glorious, the dogwoods are opening, and the azaleas are promising that next week will be filled with color! Half empty: Springtime in Atlanta is full of pollen and traffic! Weeds of all kinds are taking over!! Get the point?

As parents of children with special needs, we are entitled to our half-empty days ... but living in a half-empty world can be pretty depressing!! That's not to say we should go around, putting on a happy-face just to make others feel better ... but sometimes putting on a happy face for just a few hours will actually make you feel better. If you don't believe me, well, then Google "if you act happy, then you are happy" like I did! You'll find this website: <http://www.wikihow.com/Look-and-Act-Happy-when-You-Don%27t-Feel-It> with six *easy* steps to happiness, with my interpretation in parentheses.

1. **Do the right thing.** (Don't ignore problems that are big – see a therapist, talk to a friend. Ignoring doesn't make it go away – the only way is through.)
2. **Be positive.** (Try and stop the flow of negative thoughts, don't bask in self-pity, find something to look forward to each day.)
3. **Smile.** (Stop frowning and force yourself to smile every day.)
4. **Find people to make you feel better.** (Strengthen positive friendships, don't isolate yourself, talk to people each day, call FOCUS!!!)
5. **Distract yourself.** ("Do" something other than your child, even if just for 5 minutes. Make a to-do list and check items off. Get a hobby that can be done while your child is in therapy. Read a light book, get a part-time job, take up yoga.)
6. **Be your own best friend.** (Be kind to yourself with small treats or rewards. Tell yourself that you're doing a good job; look at what you HAVE done, not what NEEDS to be done!!)

This is not the advice from a therapist, only from a lowly mom who has parented a child/young adult for 24 years. Happiness is not an easy state of mind.

So ... aren't the flowers pretty in Atlanta? And summer is nice because we don't have to meet the school bus at 6 am. Yup. I feel happier already ... ■

McKenna's Story

By Debbie Genn

I had never heard of Rett Syndrome until five years ago ... now I want to bring awareness to others. Rett Syndrome is often undiagnosed or misdiagnosed as cerebral palsy, nonspecific developmental delay, or autism.

My daughter McKenna was born on June 21, 2002 and appeared to be a typical baby. At her 3 month check-up, I mentioned to her pediatrician that she was very "floppy" and couldn't hold her head up. She was referred to the Babies Can't Wait program and a search for a diagnosis began. She was slow on all milestones: she sat at 12 months and walked at 24 months. She was diagnosed with cerebral palsy, even though she had no birth trauma. By age 3, she could say and sign about 40 words, point to pictures in a book, knew her ABCs, numbers, colors and shapes.

But soon after her third birthday, McKenna started regressing; she lost all the skills she had learned. She stopped signing and talking. I frantically searched the Internet for answers; Rett Syndrome seemed to be the culprit. In April 2006, a neurologist gave a clinical diagnosis of atypical Rett Syndrome because she tested negative for the Rett syndrome blood test but had a fulfillment of the diagnostic criteria. Just recently she has been retested with a newer, more updated test for Rett Syndrome, and we are still waiting on the results. Our McKenna enjoys music, being outside, playing in water, taking showers and watching game shows! She is in second grade at Atha Road Elementary, in the severe and profound class. She is a happy and loving little girl and brings sunshine to our lives daily!

About Rett Syndrome

A girl is born every 5 hours with Rett Syndrome. Rett Syndrome is a unique developmental disorder that is almost always seen in girls and rarely seen in boys. It strikes all racial and ethnic groups and occurs worldwide in 1 of every 10,000 to 23,000 female births. Rett Syndrome causes problems in brain functions that are responsible for cognitive, sensory, emotional, motor and autonomic function. These can include learning, speech, sensory sensations, mood, movement, breathing, cardiac function, and even chewing, swallowing and digestion.

Rett Syndrome symptoms appear after an early period of apparently normal or near normal development until six to eighteen months of life, when there is a slowing down or stagnation of skills. A period of regression then follows with lost communication skills and purposeful use of hands. Soon, stereotyped hand movements, such as "handwashing," gait disturbances, and slowing of normal rate of head growth become apparent. Other

problems may include seizures and disorganized breathing patterns while awake. In the early years, there may be a period of isolation or withdrawal with irritability and inconsolable crying. Over time, motor problems may increase, but, in general, irritability lessens and eye contact and communication improve.



A simple blood test to identify the MECP2 mutation can determine the possibility of Rett Syndrome. To confirm the diagnosis, a molecular diagnosis of the mutation or a clinical diagnosis based on signs and symptoms (or both) must be done.

Rett Syndrome can present with a wide range of disabilities, ranging from mild to severe. The course and severity of Rett Syndrome is determined by the location, type and severity of mutation and X-inactivation. Therefore, two girls of the same age with the same mutation can appear quite different.

Rett Syndrome presents many challenges, but with love, therapy and assistance, children can benefit from school and community activities well into middle age and beyond. They experience a full range of emotions and show their engaging personalities when they are included in social, educational and recreational activities at home and in the community. ■

If this information helps just one family, then I have done what I set out to do ... bring awareness to Rett Syndrome! For even more information, please visit www.rettsyndrome.org and www.rethelp.info.

Support FOCUS!

Join the FOCUS Birthday Club! Not a new concept, just a new way of listing our wonderful FOCUS families and friends who honor FOCUS with donations. Does your child have enough toys? Do you have enough coffee mugs, picture frames, or candles? Does your grandmother really need another wallet? Ask for gifts for FOCUS instead!! We'll acknowledge the donor and the honoree – and list the birthday person in the newsletter!

Thank You

Thank you! Many thanks for all contributions to FOCUS. We work diligently to use all contributions to help families of children with disabilities or ongoing medical needs.

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Fulton County Human Services Dept.
IBM Employee Services Center
Maids of Athena, Atlanta Chapter
Metro Market Atlanta
Patterson Barclay Memorial Foundation
John & Mary Franklin Foundation for
Camp Infinity

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Memorials

In memory of James Ralph Marchman
by Celia, Frank, Kirk & Scott Lawton

Honorarium

In honor of Kelly & Matthew Bryan
by Lisa & Wally Bryan
In honor of Greg Pappas
by Margaret & Butch Hansen
In honor of Jane Wells Birthday
by Nancy & Tom Chewing
In honor of Dr. & Mrs. Philip Beegle
by "A Grateful Patient"

For the Love of Children Donations:

The Argo Family Fund
Ann & Michael Bagley
Frances & Mike Galifianakis
Debbie & Bill Grom
Barbara & Larry Perlis

Look for a complete list of "FORE FOCUS"
Golf Classic Sponsors in the next newsletter!

This list from Melanie Durity, who says that her humor turns a little sarcastic when things are hard:

You know you are the parent of a medically fragile child when ...

- Your most prized possession is your child's new wheelchair
- Half of your kitchen is dedicated to medical supplies
- You have enough therapy equipment to open your own clinic
- Your living room's focal point is the wall of therapy equipment and toys
- After many years, you are still using many of the items you were given at your child's baby shower
- Going out, your first thought is, "How will I get my child in and out of the building?"
- Going out, your second thought is, "Will my child disrupt anyone there?"
- Going out, your third thought is, "Is it a place where I can lay a mat down on the floor for her?"
- Going out, your fourth thought is, "Never mind, it is easier to stay home."
- Christmas and birthday gift ideas come from therapy sessions
- Any changes you dream of making to your home are for handicap accessibility
- While out, a toddler who can barely talk, points at your child and says "baby"
- When it makes your day (or week, or month) when your child does something new, that he/she should have done 6 years ago
- You know enough medical procedures to become an RN
- You wished you had bought stock in a store that sells vitamins

The Most Precious Gift

By Ashley Lyn Moon

My oldest son, Jaxson, has been truly a gift from day one. He was born on my birthday almost nine years ago, and we have been going ever since! On his first birthday he began having violent seizures, which was so scary. Jaxson is severely delayed, nonverbal, wears diapers, and takes 13 pills a day. He first walked without assistance when he was seven years old. But, let me tell you something, his smile is like no other!! Even though he cannot tell me he loves me, I can see it in his eyes.



The day I was told that Jaxson will never be "normal" was life changing. I have been through denial, anger, and jealousy; it hurts so much to see mothers with babies who are walking and talking. But I know how blessed I am to have Jaxson. I am a different person because of him and all of the tests, specialists, medications, life flights, ambulances, hospital stays, seizures, and dirty diapers. It's hard to always be happy because of how tough life is, but, in the end, happiness is all I have.

When Jaxson smiles at me, my heart smiles. I know God has given me the most precious gift of all. ■

Coming Up at FOCUS ...

Always check out the FOCUS website at www.focus-ga.org for details!

May 1 • 2 pm

Adapted Swim Team Intramural Meet at Mountain View Aquatics Center

Come cheer on our swimmers and
check out our 'kool kidz!'

May 2

FOCUS Family Day at Six Flags Over Georgia!

Tickets were presold. No more tickets available.

Kool Kidz Closet

Gently Used Toys & Clothes
for Children

2500 Old Alabama Road
Village Terrace Shopping Center

*Open for shopping or donations
from 10 am to 2 pm every Tuesday,
Wednesday, Friday and Saturday!!*

SummerFest at Sweetwater Brewery

Saturday, June 5

Kick off summer with FOCUS!

Contact annie@focus-ga.org
for more details.



Summer Share Groups

FOCUS appreciates the
parent volunteers who
help with the support
groups around Atlanta
during the school year.

We take a break from Share

Groups in the summer since families
are on vacation and children are out of school. However,
the FOCUS staff is around to share – give us a call if you
want to talk!

Extra Special Saturday

Extra Special Saturday takes a break in June, July &
August while kids are having fun at Camp Team and
Camp Hollywood. Please take a moment to thank our
wonderful caregivers and volunteers at each respite in
May. Because of them, FOCUS continues to offer fun for

FOCUS and Summer Time!

the children (and a break from their parents!) in eight
locations – up to 140 kiddos each month!!

Camp TEAM & Camp Hollywood

Camp TEAM is full at the time of printing. Camp
Hollywood has some openings in some locations. Send
applications by May 10!!

Under the Stars Family Camps At Camp Twin Lakes

We hear there will be PIRATES at both FOCUS family
camps this year! We're going "Under the Staaaars,
Matey!" Weekend 1 at Camp Twin Lakes Rutledge
(August 13 – 15) is full with a long waiting list; we are no
longer accepting applications. Weekend 2 (October 2 -3)
is full with a short waiting list; you may apply, but send
NO deposit. We'll take care of the finances if your family
gets in!

Sad Goodbyes and Happy Hellos

By Joy Trotti

Even as a former Scottish Rite “regular,” I dreaded scheduled surgeries for our daughter and lived in fear of emergency admittances. While FOCUS can’t erase those feelings for our families, we can bring a lot of caring and a few treats to ease the stay.

For the past 10 years, Rosemary Underwood, a former FOCUS Board member, haunted the halls and was the face of FOCUS at Children’s Healthcare of Atlanta at Scottish Rite Hospital. After work and on weekends, she visited once, and sometimes twice, a week bringing chocolate, stuffed animals, and other treats for children and their parents. Because she saw them so often, she developed special relationships with quite a few medically fragile children and their families. Rosemary came to FOCUS MVP parties whenever possible to see her favorite kids. Unfortunately, work demands at her law firm have increased, and she has reluctantly given up her visitor role. Thank you, Rosemary, for your great love for our families, all of the selfless visits, and the many parking passes and special treats that you funded out of your own pocket!

Taking on her mantle is Sarah Provow, already a valuable FOCUS friend and volunteer. Sarah volunteers at FOCUS’ Extra Special Saturday respite child care and Camp Hollywood in Alpharetta Presbyterian Church and at the Kool Kidz Closet. She has already stocked up her pantry with chocolate and treats and waits for her weekly marching orders!! Welcome, Sarah, to your added FOCUS role of Scottish Rite Hospital visitor!

Spearheading the visitor duties at Children’s Healthcare of Atlanta at Egleston for the last seven years are Ann and John Schramm. Ann is an attorney; John is an airline pilot; together they raise two children, Laura and Will. In their “spare” time, they visit FOCUS families at Egleston, bringing smiles and treats.

So ... if your child is hospitalized, or has a planned surgery or visit, be sure to email joy@focus-ga.org or call 770-234-9111. We’ll do our best to send one of these fabulous volunteers to visit, with goodies and hope ... from FOCUS! ■

The Navigator Team Project of Parent to Parent of Georgia

The first 10 Navigator Teams were formed in 2006 by Georgia’s Parent Leadership Coalition (PLC). In 2008, the project was turned over to Parent to Parent of Georgia. By 2010, the Navigator Team Project has expanded to 47 teams serving 62 counties! The goal is to have a team serving every county by 2011.

The mission is to strengthen Georgia families, especially those with children with disabilities, through a parent-led leadership network. The purpose is to ensure that every county builds comprehensive resources so Georgia families have increased access to positive education, advocacy and strategies; and families have more control over essential resources to meet their needs.

So what exactly does a Navigator Team do? Anything and everything! Team leaders hold town hall meetings to assess what members of the local community need and want. Then the team starts to work. These are just a few examples of recent projects:

Butts County Navigator Team has sponsored Sweetheart/Prom Dances for the past four years. Formal attire is requested but not required. They have found that students who have suits or formal dresses will gladly

wear them and those who do not will wear their Sunday best and look great!

Floyd County Navigator Team holds Quarterly Group Outings providing socialization and recreational outlets for children with activities including movies, inflatable playgrounds, bowling, and swimming. They have offered events that include family participation as well as parents’ night out for respite.

Bulloch Candler County Navigator Team sponsors “Buddy Ball.” Children with special needs and the Georgia Southern baseball teams have the greatest day ever! The kids buddy up with a baseball player for the day and play ball.

Henry County Navigator Team just presented a workshop for parents, guardians, caregivers and special education professionals on “Summer Activities for your Special Needs Child.”

Interested in joining a Navigator Team or starting one in your community? Just check out the Parent to Parent website at www.p2pga.org, and click on Navigator Teams! ■

TRAVEL CORNER

DC: To See or Not To See

By Lynn Taylor

Yes, we have a child with cerebral palsy. Yes, he is legally blind. No, we didn't stop our plans in raising our sons to experience some of the history of our beautiful country!

We have visited several National Parks (Yosemite, Grand Canyon, Canyonlands, Arches), have even been rafting on the Colorado River!. And now we can add Washington, DC to our list of successful vacations in the good ol' USA!!



Grant was born October 31, 1992, full term, no complications. Until delivery. During delivery he was face up, all 8lb, 10 ounces of him! The doctors decided to manually rotate him to ease delivery; we believe that during that time he suffered hypoxia. After we held him, they took him off for his "check up," and we didn't see him again for 3 hours. At that time a neonatologist

came in and said he was suffering seizures and had no pulse in his left arm. This was the start of many years of obstacles. Doctors, therapists, schools, kids. We made the decision early on to expose Grant to as much as we could, discovering that with much planning and preparation, it was possible!

Over spring break this year, we took Grant (wheelchair and all!) and our 13-year-old son Nicholas to Washington, DC. Older places tend to scare us because even though buildings should meet the code for accessibility, it's not always easy! So I started planning; here are my most helpful hints for DC:

Contact museums directly through their education department and request up a docent-led tour specific to your needs for your family. We toured the National Air and Space Museum where the docent brought small models of each of the larger planes he was discussing so Grant could "feel" what he was talking about. He brought astronaut gloves and fabric from the Wright Brother's plane for Grant to try on and feel. At the Natural History Museum, the docent brought GIANT shark teeth for him to touch and took him to lots of

exhibits where he could touch what she was discussing. The docents were very aware of his attention span and moved on as he became restless, I can't compliment them enough.

At the Federal Bureau of Printing and Engraving (where the money is made!), you can show up at designated times for a tour with a wheelchair without having to wait for timed tickets. This is a HUGE time saver. Information is on their website at www.moneyfactory.gov/

The Metro system was doable with a wheelchair, but not necessarily easy. The elevators were not always easy to find, and it was hard to get to the correct side of the track without some work. The doors opened and closed really fast at they busy stops. But since traveling by car around the city was more difficult (i.e., impossible!), we made it work.

Contact your congressional representatives well in advance. They can set up tours; we toured the Capitol and the Senate and House galleries. The earlier you contact them, the higher the success rate for tickets.

In general, everyone was very helpful, and it was a wonderful vacation. So don't be afraid. Get out there, do some research and enjoy our beautiful country – obstacles and all! ■

Send your successful travel stories & tips to lucy@focus-ga.org.

Looking Back ...



FOCUS on Fitness

Families enjoyed gym time at the NorthEast Cobb YMCA in February and Bike Day in March!! Thanks to the YMCA, Freedom Concepts and North Metro Miracle League for their support of these events. FOCUS on Fitness is offered monthly in various locations to encourage families to enjoy being active together.

Let Technology Help You!

We all know that computers should make our lives easier!! And they can ... as long as you limit your Facebook, My Space, and You Tube time! Here are some websites that might save you time by keeping family and friends informed, or you could use them to help someone else!

carecalendar.org CareCalendar is a web-based system to organize meals and other help for families during a time of illness or life changing event, such as the birth of a baby or death of a family member. CareCalendar can also be used for long term situations, including homebound and caregiver respite care needs.

lotsahelpinghands.org Create a free of charge, private, web-based community to organize family, friends, neighbors, and colleagues – a family's 'circles of community' – during times of need. Easily coordinate activities and manage volunteers with an intuitive group calendar. Communicate and share information using announcements, messages boards, and photos.

caringbridge.org CaringBridge helps you stay connected with loved ones during a serious health event. It's quick, easy and free. Caringbridge does not require logging in every time you visit the site, making it very user friendly.

Carepages.com CarePages are free, easy-to-use Web pages, brought to you by Revolution Health, that help family and friends communicate when a loved one is receiving care.

Social Media ... and FOCUS!

Social media is the latest and greatest in public relations!! We've finally figured out how to update the website and now we're learning all about Facebook, Twitter, Linked In and blogs!!

The FOCUS Facebook page is up and running. 'Be our fan' and we'll let you know when we move to the next level ... whatever that is!

PS. If you do not receive an old-fashioned email from us every week or so, please let Facebook or email us and we'll add you to the list. No tweets, please ... yet!

FOCUS is a nonprofit organization that provides emotional, informational and physical support to families of children with disabilities or ongoing medical conditions.

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