



Connections

Information & Support
for Families of Children with Special Needs
Alleghany, Ashe, Avery, Mitchell, Watauga, Wilkes, & Yancey counties

Winter Issue 2007

FAMILY SUPPORT NETWORK OF THE HIGH COUNTRY

2359 Hwy 105
Boone, NC 28607
(828) 262-6089

Toll-Free Family Line:
(866) 812-3122

Fax:
(828) 265-5394

Email: hayeskl@appstate.edu

www.parent2parent
highcountry.org

Our Staff:

Kaaren Hayes
Director

Julie Getty
Outreach Coordinator for
Avery County

Norma Bouchard
Outreach Coordinator for
Alleghany, Ashe, Wilkes Counties

Teresa Emory
Outreach Coordinator for
Mitchell and Yancey Counties

An Affiliate of
Family Support Network-
North Carolina

With Support From

Appalachian State University

Children's Developmental Services
Agency—Blue Ridge

High County United Way

Friends of Family Support
Network—High County

Avery Partnership for Children

Mitchell-Yancey Partnership for
Children



Happy Holidays from Parent to Parent FSN-HC



I Wish I Could Give You A Gift

By Dr. Anne Margaret Wright

If you have ever been discouraged or sad or just tired, I wish I could give you a gift. It doesn't come wrapped in bows but it will warm your heart nonetheless. My gift would be a day at our house. Why is that a gift? Because here you would see God's love in action, His grace revealed, and His peace lived out. This gift does not come from my wonderful husband and myself, because we are so inadequate to give a gift of this magnitude. No, the gift comes from our beautiful children. They give of their love so freely and so completely that your heart would be warmed and your cares would melt away.



The first thing you might notice when you walk in is the toys on the floor and the medical equipment all around. There might be a bag of diapers waiting to go out. The dishes have probably been done, but might be waiting on the counter. If you called first, the house will probably be pretty clean, but no guarantees! You would see the books and teaching materials as we homeschool our little brood so that everyone can move at their own pace and in their own style of learning. Oh, and you will quickly notice all the happy little faces running around. Someone might

be having a meltdown, but don't worry, it won't last long. Then the smiles will return and you will see why this gift is so special.

We might introduce you first to our oldest son, Josiah, who is 13 years old. He is the self-designated #1 Safety Officer and best helper in the world. He chases after his brothers and sister with a twinkle in his eyes and a witty saying on his tongue. God blessed us with Josiah through birth after infertility treatments. Next, you might meet our Benjamin, who is 8 years old and has Down syndrome and a smile that doesn't end. God blessed us with Benji through adoption and he is now part of our hearts. Benji is friendly and would tell you all about his favorite Veggie Tales movie which he probably just earned by going on the potty. Gabriel is 5 years old and also has Down syndrome. He is a little shy and might be sitting in the kitchen reading a book because he gets overwhelmed with lots of new people. God blessed us with Gabriel through adoption. He is kind and loving, with a giggle that is contagious. You would likely notice Abigail next, who is 4 years old. She is the only girl and if it's a good day, she will be playing on the floor, trying hard to crawl to get to the next toy. If it's not a good day, she will be stuck in her chair again, because that is often the only position that allows her to breathe well. Abby also has Down syndrome and God also blessed us with her through adoption. She has courage and a joy that comes straight from God. Last, but not least, is the little fireball, Zechariah, who is two years old. God



We Have Moved!

Find us at 2359 Hwy 105
(next to The Super 8 Motel)

Thanks to the CDSA who has graciously provided us two office spaces!

I Wish I Could Give You A Gift, Continued...



blessed us with Zachy through birth after 10 years of infertility and three miracle adoptions. We thought we were done, but God thankfully had another plan. Zechariah has a sweet heart and a passion for his siblings.

If you are very discouraged, you will likely focus on Abigail's oxygen and saturation monitor which helps us keep her alive another day. She and Gabriel both have heart conditions and have both had open-heart surgery – Abby's had three. You would see her g-tube for feedings and how very delayed she is because she has been fighting for her life since her first day. You might notice how much effort it takes for Gabriel to make his wants understood. You would see the joys of having four children in diapers because it is such a hard skill to master when your body does not cooperate. You might see meltdowns when three kids fight against their sensory systems that do not process incoming experiences properly, so sounds and lights and tastes are just too much sometimes. You might hear meltdowns when they just cannot find any other way to express how overwhelmed they feel. And if you see us out and about, you might laugh at us pushing two double-strollers to get everyone safely to our destination. Please just ignore the trail of cereal and the glasses gleefully thrown over the side when we are not looking (but feel free to retrieve the glasses)!

But my prayer is that you would see what we see and what we believe God sees when He looks at our family. He does not see perfect parents who have it all together and can always meet the many needs of our children. Far from it! He alone knows just how far and how often we fall short. He sees only willing hearts and then reaches in to provide the skills and resources that we need daily, using our inability to display His ability. He sees the smiles – oh, the beautiful smiles. What fun we have in the midst of our chaos. Blowing bubbles can bring such wonderful shrieks of laughter. Gabriel's smile is so big it barely fits on his face, and he readily, easily, quickly shares his smile with anyone willing to look. God sees Josiah sacrificing his own wishes so often because someone needs something, again. What reward must be waiting in Heaven someday

for this fine oldest brother! God sees Benji sharing his toys and his treats – sometimes pre-tasted, just to make sure they are good before passing them on. He sees Abby's patience and perseverance in the midst of terrible medical trials. He sees Gabriel, who can barely talk, teaching his little brother how to count to ten and say the alphabet, and Zechariah repeating the numbers and letters carefully after his mentor. He sees a father who loves his children so deeply and fully we all can rest in the safety of his love and devotion. God sees what the world so often overlooks because He looks to the heart, while we look to the outside.

If you are the parent of a very special child, you have probably also had many long, and often difficult, days. Many times you have probably felt lonely, as we have, because so few understand the challenges in front of you. Sometimes the tasks are daunting and the hurdles seem too high to reach. Parent to Parent Family Support Network-High Country can help you reach out to other families who understand and have walked the same path you are on. You are not alone.

Sometimes in the midst of a difficult day when the needs are many and the accomplishments few, I feel God tugging at my heart. First, He gives me a gentle word of hope, and then He tells me to hug my kids – not a gentle little hug, but a scoop'em up and dance around the room with them kind of hug. As they giggle and relax, I tell them how much I love them, and how very happy it makes me to be their mama. Then I watch as my own frustration and worry melt away a little bit, and I remember what amazing gifts we have been given. "Let us not become weary in doing good, for at the proper time we will reap a harvest if we do not give up." Galatians 6:9 (New International Version)



Parent to Parent FSN-HC honors and respects personal expressions of faith but does not endorse any specific religion or creed.

Holiday Stress and Children

By John Riddle



The holiday season is upon us, and for many people that means decorating the house, baking cookies and shopping at the mall. The sound of Christmas music can be heard everywhere you turn. But if you listen carefully, you'll hear more than just Bing Crosby dreaming of a white Christmas. Those other sounds you hear are children who are suffering from **stress** associated with the holiday season.

Families want their holidays to be special and happy for everyone, especially the children. But what many parents fail to remember is that the holiday season can be a time of hustle and bustle... and a never-ending whirlwind of stress for their children.

Think about it. Because children are especially vulnerable at this time of the year, it's important to remember that they need to find some time to relax and enjoy the most wonderful time of the year. But how can parents expect children to relax when they are running around like crazy, shopping, baking, decorating, and becoming stressed at the thought of blowing the holiday budget after just one trip to the mall.

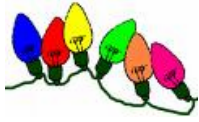
You can help your children beat the holiday stress beast by following these tips:

- **Limit TV and video games** — It's very easy at this time of the year to allow the TV and video games to become the baby sitter. But children who are stressed need some type of physical activity or exercise.
- **Remember routines** — For parents of small children, this is especially good advice. During the holidays children will find their routines disrupted. They are often dragged along on shopping expeditions or taken to events over which they have no control. And when a routine is broken, stress can result.
- **Nutrition** — Ever notice the lines at the fast food restaurants as it gets closer to the holidays? They are getting longer because parents typically are

too busy to go home and cook a nutritious meal. And factor in all of those sugary holiday treats, and you end up with a stressed out, hungry family. Plan at least one healthy meal as a family everyday. And don't forget to toss in a healthy snack while you're visiting the mall.

- **Family traditions** — Many people fail to underestimate how important traditions are to themselves and their children. Family traditions offer great comfort and security for children when everything in their lives is being disrupted by the holiday season. Perhaps your family would enjoy creating an Advent calendar together, or baking cookies and delivering them to a local nursing home or soup kitchen.
- **Attitude check** — Both children *and* their parents need to have an attitude check before the holiday season begins. Take a deep breath, and have everyone in the family pledge to make the holiday season a time of joy and peace. Remind everyone that with the right attitude, that goal can be met.
- **Rest and relaxation** — Everyone, especially children, needs to take a "time out" over the holiday season to rest and relax. For parents of younger children this is especially good advice, because a well-rested child will be much happier on a trip to the mall than one who is in desperate need of a nap. Schedule some R & R time for everyone in the family.
- **Laugh** — Laughter is still the best way to beat stress and change everyone's mood from bad to good. Take time to read the comics to your children, or find a holiday joke book with family humor at your bookstore or library.

The holiday season doesn't have to be a time of stress and exhaustion. Make sure you do your part to make the most wonderful time of the year live up to its reputation. You and your children will be glad you did.



Check this out!

Washington Learning Systems has FREE parent education handouts on their website. Please visit www.wlearning.com for more information. These materials include activities for adults and young children that encourage early language and literacy development from Birth to Preschool. These material are also appropriate for children with disabilities.

Preschool focus on:

- Language development
- Phonological awareness
- General print awareness

Infant-Toddler focuses on with over 20 activities

- Language development
- Sounds and Rhythms
- General book and print awareness



Lending Library



The NC Family to Family Health Information Center is adding health and disability specific books to the lending library at The Exceptional Children's Assistance Center. Our library has over 2,000 books which are available to NC parents at no charge. To borrow a book or other library item, please call Shandra Umazar, ECAC's librarian at (800) 962-6817 ext. 13.

Health Related Books Added This Month:

- Understanding Sensory Dysfunction by Polly Godwin Emmons and Liz McKendry Anderson
- Healthcare for Children on the Autism Spectrum by Fred R. Volkmar, MD and Lisa A. Wiesner, MD

GENERATION REWIND ASU DANCE MARATHON 2007



This year's dance marathon sponsored by A.C.T at ASU was a huge success! 90 ASU dancers raised over \$18,000 for Western youth Network (WYN) and Parent to Parent FSN-HC.

You are ALL AWESOME!

Special Thanks to Mast General Store for a general sponsorship and to over 20 dinning faculties for feeding the dancers during the 24 hours. This could not have happened without YOU!



Family Support Meetings Held Around the Counties!

Please call your county below for more information, location and times:

Ashe, Alleghany, and Wilkes– Norma at (336) 246-3222

Watauga– Kaaren at (828) 262-6089 or toll-free 1-866-812-3122

Living with Tourette Syndrome: Yes, it's difficult. Don't let anybody tell you otherwise.

By Andrew Jensen

Tourette Syndrome has gained some amount of media attention in recent years, usually as the brunt of a joke in a movie or television show. But it is no laughing matter, regardless of how many punch-lines the media throws out about Tourette sufferers.

I always looked up to my older brother - wanted to do the things he did, like the things he liked, act the way he acted. I wanted to be him. And for good reason. My older brother excelled at everything. He taught himself to play the guitar. He played the saxophone and the piano. He set Texas state records in track and field events. He was a talented artist and a straight-A student. He was everybody's best friend.

He also didn't tic.

Understandably, I always felt a little inferior to my brother, but the thing that really set us apart was the fact that, unlike him, I could never keep myself still. He'd sit across from me at dinner and say, "Do you have to keep doing that with your mouth? For heaven's sake, stop blinking like that. Can't you just keep your shoulders still for two seconds? What's wrong with you?"

I developed my first tics when I was seven years old, but they were not debilitating, just inconvenient, sometimes annoying to others, and always embarrassing to me. I was not diagnosed with Tourette Syndrome at that time. Diagnosis would not happen until twelve years later, at age nineteen. What overshadowed the problems I was experiencing due to my somewhat mild symptoms was the development of far more severe symptoms in my younger brother when I was eight. He was just two.

Tourette Syndrome typically does not manifest itself in children until around the age of eight. At seven, I may have been slightly early, but in the ballpark. Two is an impossible age at which to experience such things. My younger brother, Peter, would throw himself into the sides of his crib as a toddler, screaming incoherently as he did so.

Thinking he wanted to get out, we'd put him on the floor. He'd scream louder and try to get back in the crib. We'd put him back, he'd throw himself into the sides, and the ritual would continue. He would stay awake, thrashing, for hours on end. Then, his body completely exhausted, he'd sleep for sixteen hours straight. This pattern of torment in his body would continue for thirty years.

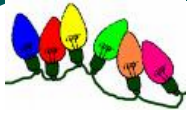
Our parents knew nothing of Tourette Syndrome. In 1977 it was not exactly a hot conversation topic. Doctors weren't much better off. My parents took Peter to doctor after doctor, had innumerable tests performed, and not one doctor could offer the slightest explanation of my brother's bizarre behavior. Then, when he was ten years old, he saw a child psychiatrist in Provo, Utah. After five minutes with my brother the man told my parents, "I believe your son has Tourette Syndrome. Let me call a colleague of mine in Salt Lake City. He'll want to see your son." That was the first time any of us had heard of Tourette Syndrome, but it was not the end of Peter's problems. Rather, it was the beginning of a long and tortuous experience, not just for Peter, but for all of us.

The reason Peter developed symptoms so early was because his case would eventually be documented as one of the most severe Tourette cases doctors had ever encountered in this country. In fact, by the time Peter was 29, his tics had become so severe, and medications so ineffective, that he could no longer feed himself, could not even chew and swallow food. Peter's tics were literally killing him.

By that time he had already dislocated his shoulder several times while doing his tics. He had ruptured his abdominal walls and caused internal bleeding. He had



torn muscles and ligaments in his arms, legs, and hips, and still he could not stop his increasingly



Living with Tourette Syndrome, continued...

violent tics. The medications he had been taking since the age of ten offered no relief. He had been cycling through a list of medications for years, because his body continued to build up tolerance to the drugs, rendering them ineffective after a few months' use. By 2004, there was nothing left to take for any sort of relief.

I don't believe any of us, Peter's siblings and parents, ever really understood what he was going through. I had my own frustrations to contend with, and I didn't want to be bothered with his problems. Clothes were a constant bother for me. I hated to tuck my shirts in. I still do. My socks have to be pulled tight all the time. If they start to slip I can think of nothing but my slipping socks until I fix them. And don't even try to talk me into wearing a turtleneck! On a really good day I can handle one for a few hours, but then I've got to find the baggiest t-shirt with the biggest neck I can find and change shirts. There's nothing more tic-stimulating to me than something tight around my neck. I frequently have to adjust my steps while walking because they feel uneven. My mouth and lips often feel stretched – that's the closest word to describing the sensation – and I have to pinch or crinkle them to get them to feel better. I frequently have to blink my eyes really hard, pinch them down, so they feel right.

My son, when he was two, began mimicking me when I'd tuck him into bed. He thought my blinking was a sign of affection, like a kiss goodnight. As far as he was concerned, it was part of the nightly ritual, because I did it every time I put him in bed, right before and after I'd kiss him. So he started doing it back to me. He'd take my face in both of his tiny hands, look me straight in the eyes, and do my eye-tic. It was one of the sweetest moments I've had as a father. Here was my two-year old son, mimicking my tics out of love, rather than as a joke.

These tics of mine are not particularly difficult to live with. They can be trying at times, probably more for my wife than for me, but they are manageable. That was not the case for my brother, Peter. Because of the life-threatening nature of his Tourette symptoms, Peter was accepted as a candidate for an experimental brain surgery at the University

Hospitals of Cleveland. He now has electrodes implanted in his brain and attached to two pacemaker-like devices that regulate electrical impulses to certain nerve centers.



You can read more about Peter and his successful surgery and subsequent recovery at the links to the news stories at the end of this article.

Most Tourette cases are not nearly as severe as Peter's. Tourette Syndrome is very seldom a life-threatening disorder. Most cases are similar to my own. But make no mistake; it is not a trivial disorder. Living with Tourette Syndrome is difficult for everyone involved, not just the person with the disorder. Children can be cruel, and for the Tourette sufferer who cannot control his tics, the taunting of classmates, not to mention family members, can be especially devastating. In addition to physical tics, Tourette sufferers often have verbal or vocal tics as well, combined with obsessive-compulsive behaviors, attention problems, learning disabilities, phobias, and severe anxiety. Each symptom presents its own unique challenges. Tourette sufferers with multiple symptoms may need multiple treatment programs. But what they need more than anything else is patience and understanding. That's what I wish my older brother had offered me; it's what I wish I had offered to Peter; and it's what my son gave me, unconditionally, that first time he blinked back at me as I put him to bed.

For more information about Peter Jensen, please see the following news stories:

Living with Tourette Syndrome, continued...

NBC Dateline:

- www.msnbc.msn.com/id/14304455

KSL Television (Utah):

- www.ksl.com/?nid=148&sid=418640



For more information on Tourette Syndrome in general, please visit the following websites:

- www.ninds.nih.gov/disorders/tourette/detail_tourette.html
- www.kidshealth.org/parent/medical/brain/tourette.html

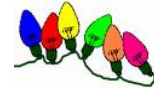
Or contact the Tourette Syndrome Association:

- Tourette Syndrome Association
42-40 Bell Boulevard
Suite 205
Bayside, NY 11361-2820
Tel: 718-224-2999 888-4-TOURET (486-8738)
Fax: 718-279-9596
e-mail: ts@tsa-usa.org
www.tsa-usa.org

You can also contact the TSA's Mid-South regional office (serving Alabama, Arkansas, Kentucky, Louisiana, Mississippi, North Carolina, Tennessee and West Virginia):

- Tel: 334-502-0055
e-mail: tsamidsouth@bellsouth.net
www.tsa-usa.org/TSANatLocal/Chapters/Midsouth.htm

System of Care Collaborative



- Concerned about children with emotional, behavioral and/or substance abuse challenges?
- Looking for a way to make a difference?

Join the System of Care Collaborative in your community and work along side other concerned and committed programs, agencies and families to identify challenges, gaps in services and problem solve ways to make things better for children and families.

Everyone is welcome!

For more information, contact:

Carolyn Greene, local System of Care
Coordinator
Tel: (828)263-5653
e-mail: greencar@smokymountaincenter.com.

Schedule of meetings:

Alleghany: Monthly 3rd Wednesdays 10 am Alleghany BREMCO conference room.

Ashe: Monthly 4th Tuesdays 10 am Ashe County Agriculture Building conference room.

Avery: Monthly 1st Wednesdays 11:30 am Avery County Dept. of Social Services County Board Room.

Watauga: Bi-Monthly 1st Thursday 9:00 am Watauga County Human Services conference room.

Wilkes: Monthly 2nd Tuesday 9:30 am Wilkes County Courthouse Juvenile Justice conference room.

Family Support Network-HC
2359 Highway 105
Boone, NC 28607



Family Support Network-HC
2359 Highway 105
Boone, NC 28607



Please support our program so that we can continue to serve families and the community. Any help you can give will be very appreciated. Please detach this form and send any donations to the address below. Donations are tax deductible.

Name _____

Address _____

City _____ State _____

Zip Code _____

Amount \$ _____

Name of Honoree _____

Thank you for your contribution!



Family Support Network-HC
2359 Highway 105
Boone, NC 28607