



# Connections

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

Fall Issue 2007

## FAMILY SUPPORT NETWORK OF THE HIGH COUNTRY

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An Affiliate of  
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North Carolina

With Support From  
Appalachian State University  
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Services Agency—Blue Ridge  
High County United Way  
Friends of Family Support  
Network—High County  
Avery Partnership for Children  
Mitchell-Yancey Partnership for  
Children

## Family Information Center

### BACK TO SCHOOL KIT 2007

Schwab learning aspires to help kids with learning and attention problems lead satisfying and productive lives in an environment that recognizes values and supports the unique attributes of every child. To help you get ready for the new school year, the Schwab Learning back-to-school kit offers a handy selection of articles on learning struggles, basic skills, homework, and more. Get practical strategies now to prepare yourself and your child for a great year at [Schwablearning.org](http://Schwablearning.org)



For additional fun for kids 8-12 with learning disabilities check out Spark Top at [sparktop.org](http://sparktop.org). By providing kids with age-appropriate information about their brain, helping them recognize their unique strengths, and showcasing their creativity, Spark top can help kids gain confidence and insight about themselves and how they learn.

**Check them out!**

### The NC Family to Family Health Information Center

*A Project of the Exceptional Children's Assistance Center*

#### Information Packets Available!

The NC Family to Family Health Information Center provides packets of information **FREE to NC parents**. To order a packet or schedule a training workshop for your group, please contact Wendy Ward at (800) 962-6817 Ext 35 or [wward@ecacmail.org](mailto:wward@ecacmail.org). The available packets/fact sheets include:

**Health Consumer Laws and Rights**  
(HIPAA, ERISA, COBRA, EMTALA, FMLA, MHPA)

**Private Health Insurance**  
(Private Health Insurance, Denials, Appeals, Complaints)

**Public Programs 1**  
(Medicaid, CAP, EPSDT, SSI, Medicare)

**Public programs 2**  
(Title V, NC Health Choice, Public Health, CSHS, Low Cost/Free Clinics)

**Prescription Assistance Programs**  
(Help with prescriptions)



### 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

## Information Overload



### *How to sort through information about treatment options for your child with special needs*

By Adrian D. Sandler MD

This morning, I “googled” the term “*new treatments in autism.*” In less than half a second, I had 1,400,000 “hits.” I checked out the first 20 and gave up in despair. They included outdated and hopelessly inaccurate reports of treatment that have since been discredited, glossy advertisements for exotic and expensive supplements, or brief summaries about a range of autism treatments that were too general to be of much use to anyone. None of the websites I read described emerging treatments that really are the cutting edge of the rapidly changing field. Important nuggets of information are in there somewhere, but I was disappointed to see how they are to be found.

In our clinics at the Huff center, parents often ask me about various new treatments for their children with autism or other developmental disorders, such as ADHD, learning disabilities, cerebral palsy or developmental delays. They may have learned about these treatments from other parents, from Internet searches, from alternative medicine (CAM) practitioners, or from conferences they have attended. Their feelings about a particular new treatment may be anywhere on the spectrum from enthusiastic to healthy skepticism, but they are seeking information and gathering advice from trusted sources.

If I were a parent of a child with a disability, I would do the same. In responding to their questions, I examine the new treatment option from my biomedical perspective with an open mind. I have come to understand a little about how powerful hope is in healing, and I try to be encouraging and supportive to parents and at the same time, I have to consider what is best for the child and do no harm. I think back a few years to the excitement about secretin injections, a new treatment for autism that was heralded with great excitement around the word. 1999 headlines-such as “*Matthew Shocks His Parents by Holding His First Normal Conversation*”-proclaimed the curative power of secretin. Our research and the subsequent work of other teams from 1999-2004- and effort that included several clinical trials and more 700 children with autism and their families- found that secretin was in fact quite useless as a treatment in autism. But we could not have

known that without careful research.

Some new and unproven treatments developed or discovered by responsible people, may hold great promise and need to be considered very carefully. Some CAM treatments may be especially appealing because they seem more natural or because they appear to have low risk of harm. But how do parents sort through the mountains of information? How do you make informed choices? How can you gauge the risk or potential harmful effects? How can you be a critical consumer in this age of information overload? **Parents, beware of the profit motive: “RED FLAGS”**

Parents of children with special needs may be uniquely vulnerable to exploitation by profiteers because they want to do whatever it takes to improve the quality of life for their child. Charlatans make a lot of money peddling treatment that they know or suspect are bogus-but hey, business is business. Treatments are sold using sophisticated marketing techniques and tactics. Children with conditions like autism may show a lot of day-to-day changes in their behavior. When parents feel hopeful about beginning a new treatment, they may notice positive changes in their child’s behavior that they attribute to the new treatment-placebo effects are very powerful. Charlatans will exploit this for profit. The table shows some important “red flags” that should raise your suspicion.

### **Red Flags that may indicate profiteering**

- Claims that new treatment cures many different conditions
- Dramatic claims of effectiveness
- Reliance on personal anecdotes and testimonies
- Not describing specific treatment objectives
- Claims there are not harmful effects
- Claims that clinical trials unnecessary
- Indicates available from only one source
- Unethical manipulation of patients and clients
- Language of advertisers: “doctor recommended,” “patented design,” “secret formula,” “clinically shown,” “astonishing....miraculous....amazing breakthrough.”

## Information Overload—continued



### Not all science is good science

Evidence-based treatments rest upon a solid foundation of science. A hunch about a new treatment must proceed through a hierarchy of testing in order to be proven safe and effective. If a treatment appears to be safe and helpful in uncontrolled studies of single cases and small series of patients, researchers proceed to controlled clinical trials. These generally involve comparing the new treatment to placebo treatments. Through scientific research, and publication of research studies in reputable peer-reviewed journals, a literature is established that allows one to make informed decisions about using a new treatment for an individual with a particular condition. Some studies are convincing, while others are flawed. For some treatments, there may be strong evidence, and for some there may be weak evidence: the level of evidence supporting a new treatment can be determined objectively by reviewing the literature. However, to do so takes time and experience. It is easy to be manipulated by a claim on the Internet that takes shreds of circumstantial evidence and weaves them together into a complex, persuasive pseudo-scientific argument. I have often waded through such pieces, finding that the claims do not hold up to the scrutiny: Complex biochemical speculation frequently masquerades as scientific evidence—especially in the field of autism.

### Strategies for searching on the Internet

In general, reliable sources include government agencies, professional associations, recognized disease/disorder-specific organizations and accredited medical schools. The last three letters in a website address indicates what type of organization set up the sites that are designed to sell you something. The Family Support Network of Western North Carolina has a great publication *freely* available on their website at [www.missionhospitals.org/childrens-handouts.htm](http://www.missionhospitals.org/childrens-handouts.htm) entitled “A Parents Guide: Evaluating Health Information for Your Child on the Internet.” This includes examples of useful websites. The list on the next page is a list of excellent websites containing treatment information that I commonly recommend to parents of child with developmental differences.

### Is it safe? Evaluating potential harm

Any substance that is described as “harmless” or “natural” is not necessarily either of these things. The differences between pharmaceuticals, nutritional supplements, or herbal treatments are mainly in how

these products are regulated. Pharmaceuticals are approved and regulated by the FDA. Although recent experiences with Vioxx and other drugs raise serious questions about the process of drug regulation, I have more confidence in the purity, consistency and safety of regulated products than unregulated ones. Reading about a drug in the Physicians Desk Reference (PDR) is enough to make you break out in a rash, but it is better than not knowing about potential risks. Many nutritional supplements that are commonly used in the treatment of children with special needs, such as omega fatty acids, dimethylglycine, Vitamin B6, magnesium, and melatonin really do appear to be safe if used at the usual low dose, but there are many examples of other “natural” products preciously thought harmless that have caused severe illnesses. New treatments may also cause emotional harm when families invest their hope and limited resources into something that proves to be futile.

### Talk to you child’s doctor: the value of a primary care medical home

A trusted physician who knows your child well can be a great resource in your efforts to cope with information overload. A primary care medical home refers to an approach to providing comprehensive primary care that is accessible, coordinated, family-centered, culturally coordinated, and compassionate. For children with special needs, it is especially helpful to have pediatricians working in partnership with the child and his/her parents to assure the very best care for the child. The pediatrician’s responsibilities –as stated in official policy from the American Academy of Pediatrics–include evaluating the scientific merits of new treatments and discussing these fully with parents. Physicians are well trained in reading scientific literature and can be very helpful in identifying potential risks. One useful strategy is to send relevant information about the new treatment to your child’s doctor and make an appointment for a conference to discuss it further. If a new treatment is started—whether a CAM treatment or a conventional medical treatment—the pediatrician can help monitor you child’s progress and evaluate his/her response to the treatment.

So the next time you are faced with a million Internet sites, or compelling treatment recommendations that you don’t fully trust or other troubling questions regarding treatment options...consider the sources,

## Information Overload...



research the treatment on appropriate, reliable websites, look for “red flags,” try to assess potential harmful effects, and use trusted resources-including your child’s primary care medical home.

### Useful websites related to children with disabilities

- American Academy of Pediatrics  
[www.aap.org](http://www.aap.org)
- Exceptional Parent  
[www.eparent.com](http://www.eparent.com)
- National Information Center  
[www.nichy.org](http://www.nichy.org)
- United Cerebral Palsy  
[www.ucpa.org](http://www.ucpa.org)
- CanChild  
[www.fhs.mcmaster.ca/canchild](http://www.fhs.mcmaster.ca/canchild)
- Autism Society of America  
[www.autism-society.org](http://www.autism-society.org)
- TEACCH program  
[www.unc.edu/depts/teacch](http://www.unc.edu/depts/teacch)
- First Signs  
[www.firstsigns.org](http://www.firstsigns.org)

### Alternative Therapies

- National Center for Complementary and Alternative Medicine Clearinghouse  
[www.nccam.nih.gov](http://www.nccam.nih.gov)
- NC Health Information/Health Sciences Library  
[www.nchealthinfo.org/ask\\_a\\_librarian.cfm](http://www.nchealthinfo.org/ask_a_librarian.cfm)
- The Feingold Association  
[www.feingold.org](http://www.feingold.org)

In addition to the above recommended sites, you may want to check out [www.quackwatch.org](http://www.quackwatch.org) for any misleading alternative therapies, supplements, etc.

*This list is just the “tip of the iceberg.” Parents and providers can also contact the CDR (Central Directory of Resources) at 1-800-852-0042 or email them at [cdr@med.unc.edu](mailto:cdr@med.unc.edu) to speak with a resource specialist for help with information and referrals. We would also like to thank the FSN of Western NC for allowing us to reprint an article they have previously published in their Winter/Spring 2006 newsletter.*

## The Bully Problem

### Bullying facts and Statistics

Some statistics show that almost 30% of youth in the United States (or over 5.7 million) are estimated to be involved in bullying as either a bully, a target of bullying, or both. In a recent national survey of students in grades 6-10, 13% reported bullying others, 11% reported being the target of bullies, and another 6% said that they bullied others and were bullied themselves. Other reports show up to 75% of children are being victims of bullying.

### Male vs. Female

Bullying takes on different forms in male and female youth. While both male and female youth say that others bully them by making fun of the way they look or talk, males are more likely to report being hit, slapped, or pushed. Female youth are more likely than males to report being the targets of rumors and sexual comments. While male youth target both boys and girls, female youth most often bully other girls, using more subtle and indirect forms of aggression than boys. For example, instead of physically harming others, they are more likely to spread gossip or encourage others to reject or exclude another girl.

### Types of Bullies

In her article entitled “Protecting Against Bullies Throughout the Life Cycle” ([www.ncpamd.com/Bullying\\_Thru\\_Life\\_Cycle.htm](http://www.ncpamd.com/Bullying_Thru_Life_Cycle.htm)), Carol E. Watkins describes four different types of bullies:

- **Sadistic, Narcissistic Bully.** Lacks empathy for others. Has low degree of anxiety about consequences. Narcissistic need to feel omnipotent. May appear to have a high self-esteem but it is actually a brittle narcissism.
- **Imitative Bully.** May have low self esteem or be depressed. Influenced by the surrounding social climate. May use whining or tattling or be manipulative. Often responds well to a change in the culture of the classroom or social setting. If depressed may need other intervention.
- **Impulsive Bully.** He is less likely to be a part of a gang. His bullying is more spontaneous and may appear more random. He has difficulty restraining himself from the behavior even when authorities are likely to impose consequences. He may respond to medication and behavioral treatment and social skills training. He is also likely to be bullied.

## The Bully Problem...

**Accidental Bully.** If bullying is a deliberate act, this individual might not be included. The behavior may be offensive because the individual does not realize that his actions are upsetting the victim. If someone patiently and compassionately explains the situation, the individual will change the behavior. Sometimes social skills need to be taught.

### Risk Factors for Bullying Behavior

Bullies generally appear physically aggressive with pro-violence attitudes, typically hot-tempered, easily angered, and impulsive with a low tolerance for frustration. Bullies have a strong need to dominate others and usually have little empathy for their targets. Male bullies are often physically bigger and stronger than their peers. Bullies tend to get in trouble often, and dislike and do more poorly in school, than those who do not bully others. They are also more likely to fight, drink, and/or smoke than their peers.

Children and teens that come from homes where parents provide little emotional support for their children, fail to monitor their activities, or have little involvement in their lives, are at greater risk for engaging in bullying behavior. Parents' discipline styles are also related to bullying behavior: an extremely permissive or excessively harsh approach to discipline can increase the risk of teenage bullying.

Surprisingly, bullies appear to have little difficulty in making friends. Their friends typically share attitudes and problem behaviors and may be involved in bullying as well.

### Long-term Impact on Youth

There appears to be a strong relationship between bullying other students and experiencing later legal and criminal problems as an adult. In one study, 60% of those characterized as bullies in grades 6-9 had at least one criminal conviction by age 24. Chronic bullies seem to maintain their behaviors into adulthood, negatively influencing their ability to develop and maintain positive relationships. Bullying can lead the children and youth that are the target of bullying to feel tense, anxious, and afraid. It can affect their concentration in school, and can lead them to avoid school in some cases. If bullying continues for some time, it can begin to affect children and youth's self-esteem and feelings of self-worth. It also can increase their social isolation, leading them to become

withdrawn and depressed, anxious and insecure. In extreme cases, bullying can be devastating for children and youth, with long-term consequences. Researchers have found that years later, long after the bullying has stopped, adults who were bullied as youth have higher levels of depression and poorer self-esteem than other adults.

### Effective Programs

Effective programs have been developed to reduce bullying in schools. Research has found that bullying is most likely to occur in schools where there is a lack of adult supervision during breaks, where teachers and students are indifferent to or accept bullying behavior, and where rules against bullying are not consistently enforced.

### Risk Factors for Being Targeted by Bullies

Children and youth who are bullied are typically anxious, insecure, and cautious and suffer from low self-esteem. They are often socially isolated and lack social skills. One study found that the most frequent reason cited by youth for persons being bullied is that they "didn't fit in."

### Bullying Victim Warning Signs

The following may be signs that your child is being bullied:

- Avoiding certain situations, people, or places, such as pretending to be sick so that he or she does not have to go to school
- Changes in behavior, such as being withdrawn and passive, being overly active and aggressive, or being self-destructive
- Frequent crying or feeling sad
- Signs of low self-esteem
- Being unwilling to speak or showing signs of fear when asked about certain situations, people, or places
- Signs of injuries
- Suddenly receiving lower grades or showing signs of learning problems
- Recurrent unexplained physical symptoms such as stomach pains and fatigue

## The Bully Problem...

### Treating a Bullying Victim

- **Talk about it.** Encourage your child to talk about school and friends. Keep the lines of communication open so they feel they can talk to you about what's going on. Tell the child or adolescent that you care and that you are concerned and provide an opportunity for the child to talk to you openly. Explain that telling is not tattling and that you need the information in order to help. When the child begins to talk, respond in an accepting and positive way. Make it clear that the bullying is not the child's fault, and that telling you was the right thing to do.
- **Build their Confidence.** Work deliberately to build your child's confidence. Remind them about what they do well and that they are great people who deserve to be treated with respect.
- **Try Something New.** Trying new things such as playing an instrument, team sports or a new board game can help build children's self esteem.
- **Avoid overprotection.** Rather than sheltering your children from difficult situations, give them the skills to deal with them on their own.
- **Teach Assertiveness.** Encourage assertive, but not aggressive, behavior so your children can stand up for themselves. Remind them that a bully only has power if it's given to them.
- **Encourage Socializing.** Encourage your children to try and develop new friendships and to surround themselves with friends.
- **Help the victim.** Make an effort to get to know kids who are picked on. If they seem sad or worried, tell them there is help available – they can tell a parent, teacher, or coach. Be sure they know that they are not alone.
- **Bullies need help too.** Be firm that bullying is wrong, but don't ever be mean to the bully. Remember-they need help and understanding too.

### Put An End To Bullying

**Recognize Bullying.** Bullying comes in many different forms – all equally painful and wrong. Whether it takes the form of hitting, pushing, ridiculing, ignoring or spreading nasty rumors, don't put up with bullying in your school or community. It makes everyone feel bad.

## Legislative Updates

- **Keep Track of Places.** Work with friends to take note of places where bullying occurs. Pass this information on to teachers, playground officers, bus drivers, or any grown-up who want to help.
- **Define Cool.** Spread the word in your school or community that bullying isn't acceptable. Once the word catches on, it won't be long before everyone realizes that bullying isn't cool.
- **Speak up!** State clearly to the bully that you and your friends won't be involved in any bullying. When someone is bullying someone else, speak up and tell them that that bullying is wrong. If it doesn't feel safe, get help.

For more information visit [www.safeyouth.org](http://www.safeyouth.org).

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## Two Victories for North Carolina Children and families

In Raleigh, on July 31, 2007, monumental legislation was signed into law by Governor Mike Easley. The final state budget included **NC Kid's Care** and a 3.5% refundable **earned income tax credit (EITC)**, both of which will improve outcomes for children and families across our state!

NC Kid's Care, which begins on July 1, 2008, will make available affordable health insurance coverage to 38,000 currently uninsured children in families between 200%-300% of the Federal Poverty Line (\$42,000-\$62,000 per year for a family of four). Families would participate in the cost of care in the form of deductibles, co-payments and monthly premiums subsidized on a sliding scale based on income. For more information go to [www.ncchild.org](http://www.ncchild.org).

Additionally, the NC General Assembly adopted a 3.5% NC refundable EITC. The EITC will give a tax credit to more than 825,000 working North Carolinians at the time they file their state tax returns. "By providing a tax refund to moderate- and low-wage workers, the NC EITC will improve tax fairness, supplement wages and help lift families and children out of poverty," stated Barbara Bradley, President and CEO of Action for Children of North Carolina. Again for more information concerning NC refundable EITC, please visit [www.ncchild.org](http://www.ncchild.org)

## Living with Tourette Syndrome

### A Mother's Worries

By Christie Jensen

It's 5:20 PM and I started calling her for dinner ten minutes ago. The bad thing is, she's only eight feet away! But this is almost a typical evening for us. Tonight it's hand-stands – about 50 of them, until she decides she's done enough.



Is this normal, I ask myself? Is this some developmental stage? If it is, I sure don't remember any of my child development textbooks talking about 10 year-old girls doing 50 hand-stands right before dinner at any stage. Finally, in utter exasperation I raise my voice and announce to my upside-down daughter that it is dinner time. NOW!

For most parents, this strange hand-standing behavior might be nothing more than a mere annoyance, but it fills me with budding terror. My husband has Tourette Syndrome, and while his symptoms are relatively mild, he has a sister and brother who's symptoms are off the charts. In fact, his brother recently underwent experimental surgery at the University Hospitals of Cleveland to implant deep brain stimulation devices in an effort to control or minimize his tics. (You can read more about the surgery and Peter Jensen at <http://www.msnbc.msn.com/id/14304455>.) His case is considered to be one of the worst Tourette cases on record.

I know how Tourette works. I've taught Tourette education classes. I know the genetics and the probability my children have of both inheriting the gene and developing symptoms. So I watch them and I wait. And when they start doing strange things like 50 successive hand-stands and can't seem to stop doing them, I start to feel panicky. Will the tics begin to emerge? Will she start making strange and uncontrollable noises? How will this affect her future? But as each year passes I worry a little bit less about my daughters, as each has grown out of some of these strange behaviors (the hand-stands are a thing of the past now). But when I was helping my five year-old son get dressed for school and he announced that his socks felt funny, and that he had to have the right shoe on first, not the left, that surge of panic crept back. And then I walked into my bedroom to find that my husband had gone through four T-shirts and

counting because he couldn't find one that *felt* right. Tourette is not a simple disorder. It has no cure, it is difficult to live with, both for the person who has it and those around him. It is a complex spectrum disorder that manifests itself, not just with tics, but with other life-altering problems as well, such as attention-deficit problems, learning disabilities, obsessive compulsive behavior, severe depression, the list goes on and on. The tics are just the most obvious trait. However, Tourette can be managed and one can live a good life, it may just take them longer to pick out a shirt in the mornings.

**Next issue:** My husband's story about living with Tourette Syndrome.

*For more information on Tourette Syndrome please visit the following websites.*

- [www.tsa-usa.org](http://www.tsa-usa.org)
- [www.ninds.nih.gov/disorders/tourette/detail\\_tourette.html](http://www.ninds.nih.gov/disorders/tourette/detail_tourette.html)
- [www.kidshealth.org/parent/medical/brain/tourette.html](http://www.kidshealth.org/parent/medical/brain/tourette.html)

Boone, NC 28607  
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FSN-HC



**Appalachian State University**

**Parent To Parent**  
150 Den Mac Dr.  
Boone, NC 28607

Phone: (828) 262-6089



Please support our project so that we can continue to serve our parents and the community. Any help you can give would be very appreciated. Please detach this form and send any donations to the address below and help continue this much needed program.

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