



NEWSLETTER - EDUCATION ISSUE

August, 2004

TSA-RMR Board of Directors

Governing Board

- Loree Vanderhye, President
Co-Chair - Education/Advocacy
Maggie Byrnes, Co-Vice President.
Chair - Member Services
R. Barkley Clark, MD, Co-Vice Pres.
Chair - Professional Outreach
Jeff Barker, Treasurer
Chair - Finance
Judy Harrigan, Co-Secretary
Co-Chair - Education/Advocacy
Donna Davies, Co-Secretary
Chair - Fund Raising
Snow White-Wardell
Chair - Education & Legislative Committees

Advisory Board

- Tracy Fischer, Director
Ronald Rabin, MD, Director
Lauren Seeberger, MD, Director
Carol Tierney, PhD, Director
Steve Duhon-Thornton, Director

Honorary Board

- Diana Blair
Jeanette Cornier
Nancy Crone
Christopher O'Brien, MD
Paula Pattschull
Tom Summers, MD
Steve Umbro
Paige Vickery
Douglass Wieder

Staff

- Suzanne Partain, Administration
Jerry Alley, Webmaster

WISH LIST

(approx. cost)

Underwrite Library Materials for Support Groups \$500 each

Underwrite Training Specialists Expenses to Travel/Train \$2,500

Sponsor Wine Tasting Fund Raising Event \$3,000

Sponsor TS Training in Schools (CDs & material) \$50 each

A SPECIAL TRAINING OPPORTUNITY

Tourette Syndrome Association, Inc. - Rocky Mountain Region is VERY pleased to announce that Denver has been selected to host a TSA Regional Training Program, August 28th & 29th, 2004 (Saturday & Sunday). The presenters are two incredibly talented TSA National leaders, Susan Connors and Kathy Giordano. You may recognize their names from TSA National video's, newsletters, brochures, or their regularly published information on the TSA National website www.tsa-usa.org. Susan and Kathy are both highly experienced educators and TS specialists who live with TS everyday. Susan and her family have TS and Kathy's son has TS. This opportunity won't happen again for some time, so please don't miss the chance to learn from the experts! This Newsletter includes a few of the many papers written by these talented ladies.

Registration deadline is 8/23/04 - register today!!!

LEADERSHIP EDUCATION & ADVOCACY TRAINING

When: August 28 & 29, 2004 - 8:00 AM - 5:00 PM (each day)

Where: Swedish Medical Center - 2nd Floor Meeting Room
501 E. Hampden, Englewood, CO

You will learn how to;

- Present the complete TSA Education Curriculum to Educators
Attributes of a successful TS advocate
How to prepare for an IEP and/or 504 Meeting
Successful meeting techniques
How to accomplish your meeting goals
Understanding and writing a Functional Behavior Assessment & Positive Behavior Intervention Plan
How to Advocate for an Effective Functional Behavior Assessment
Help children with TS be successful today and in the future!

Register: Phone or e-mail your registration information today. Send check in the amount of \$30.00 payable to TSA-RMR to: TSA-RMR, 2020 S. Oneida St. # 19, Denver, CO 80224

Cost: \$30.00 (charge to cover expenses)

CE Credits: Colorado Continuing Education Certificates will be issued to each attendee.

Who should attend: Adults who want to learn how to advocate for children with TS. This includes parents of children with TS, teachers, therapists, other professionals.

Hotels nearby: Marriott Southeast (I-25 & Hampden) 303-758-7000, Hampton Inn (I-225 & I-25) 303-804-9900, Super 8 South (I-25 & Orchard) 303-771-8000

Dear Members:

This Newsletter is the annual TSA-RMR Education Issue. We provide as much education related material as possible in these pages to help members learn and share information and knowledge with people who can positively affect children with TS. This Newsletter (and past), are also available on our website at <http://www.sensiblenet.com/tsa/>

The TSA Regional Training Program described on the Page 1 is a wonderful opportunity to learn how to make a difference for children with TS. Attendees will learn how the education system should work for children with TS and how to advocate for the accommodations that are needed for each child's individual needs. TSA National is underwriting the cost of sending these two exceptional teachers and trainers to Denver and it is a first for our region. I hope you are able to attend – it is very important and rewarding!

Have you sent us your favorite recipes for the TSA-RMR Cookbook? Time is running out – do it today! We would also love to have recipes from your favorite restaurant – ask the restaurant owner or chef to share their favorite recipe. We will include their name with their recipe(s) in our Cookbook! We are also accepting advertisements to be included in the Cookbook. Once published, sales outlets such as restaurants, bookstores, specialty shops will be prime locations for distribution –any recommendations? See last Newsletters for forms and information or call TSA-RMR 303-832-4166, we can also e-mail it to you if desired.

Last May, a trial "Mom's Club" meeting was held at Reivers Restaurant in Denver. It was a great success, so a second is planned for September 22nd at 6:30pm. "Mom's Club" is for mothers and grandmothers of children with TS. We get together for dinner and drinks ... laughs and tears! RSVP's required – call 303-832-4166.

Also in May, was the first annual TSA-RMR Charity Golf Event. It was a huge success in spite of inclement weather – and – TSA-RMR made a nice profit! Because Newsletter space is limited to Education Issues, we will have pictures and more information in an upcoming issue. If you were a player – we thank you for the support! Plans are to do it again in 2005!

I look forward to seeing some of you at a TSA-RMR event soon!

Loree Vanderhye, President

### **Silver Sponsor:**

Special thank you to **Estelle Wolf of The Flowe Foundation** for the "Wish List" donation to fund a new printer for TSA-RMR. The gift is greatly appreciated!!

### **Volunteer of the Quarter:**

**Snow White-Wardell:** Snow and husband Jim planned, organized, recruited players, gathered prizes, and found sponsors, and made the TSA-RMR Charity Golf Event happen. Snow, you are remarkable!!

## **Rocky Mountain Region Departments of Education**

### **Colorado**

State Office Building  
201 East Colfax Avenue  
Denver, Colorado 80203-1799  
CDE Main Phone: 303.866.6600  
CDE Main Fax: 303.830.0793  
<http://www.cde.state.co.us/>

### **Idaho**

General Mailing Address 650 W. State St.  
PO Box 83720  
Boise, Idaho 83720-0027  
Ph: (208) 332-6800  
State Department of Education  
Switchboard: (208) 332-6800  
<http://www.sde.state.id.us/Dept/>

### **Nevada**

Nevada Department of Education  
Carson City Main Location  
700 E. Fifth Street  
Carson City, NV 89701  
Phone: (775) 687-9200  
Fax: (775) 687-9101  
<http://www.doe.nv.gov/>

### **Wyoming**

Wyoming Department of Education  
2300 Capitol Avenue  
Hathaway Building, 2nd Floor  
Cheyenne, WY 82002-0050  
(307) 777-7673 <http://www.k12.wy.usa>

**TSA – RMR website:**  
**<http://www.sensiblenet.com/tsa/>**

**TSA – National website:**  
**[www.tsa-usa.org](http://www.tsa-usa.org)**

**Legislative Information:**  
**[www.ourchildrenleftbehind.com](http://www.ourchildrenleftbehind.com)**

## **Tourette Syndrome Education Advocacy**

### **WHAT IS EDUCATION ADVOCACY AND WHEN IS IT NECESSARY?**

*By Kathleen J. Giordano, TSA Education Advocacy Specialist*

It is my experience that advocacy should begin as soon as there is a suspicion that a child is experiencing difficulties in school. However, advocacy does not always require special education services. Advocacy is sometimes no more involved than having a discussion with a teacher, and/or providing information regarding specific symptoms that are interfering with the child's daily functioning in school.

Sometimes advocacy is very time-consuming and can involve research and meetings with a variety of individuals. This becomes necessary for many reasons which could include:

- ♦ A decline in grades
- ♦ Increased frustration
- ♦ Decrease in the child's self esteem
- ♦ Social difficulties
- ♦ A negative change in attitude regarding school
- ♦ Behavioral Issues at school
- ♦ Increase in TS symptoms due to stress or anxiety
- ♦ Difficulties at home that are a direct result of school issues.

Sometimes parents are afraid that their child will get "labeled" if they let the school know that he has TS. It has been my experience that if the symptoms are significant enough that a diagnosis has been made, then most likely the symptoms are serious enough to interfere with school in some fashion. For instance, a simple eye tic may not be seen by the teacher as being a problem; however, there is one person for whom the tic is causing difficulties - the student with TS.

You have waited too long to begin advocating for your child if he/she is:

- ♦ Failing
- ♦ Refusing to go to school
- ♦ Causing considerable difficulties at home due to the stress of school

Attending school can be challenging in many ways for children with TS. Parents advocating in a positive manner demonstrates their intention of being a member of the team that supports their child in attaining an education.

There are many ways in which a teacher can be supportive of a student who is having even minor tics without requiring special education services. However, all of them will require that the teacher be aware of what tics are and understand that tics are symptoms of a complex disability. Awareness is always the first step in advocacy.

Advocacy is also the development of a collaborative relationship between the home and the school which, in my opinion, should begin immediately. When everything is going well, it is wise to write notes of thanks and appreciation remembering to send a copy to the principal and the superintendent. It is similar to putting money in the bank. Establishing a respectful relationship by thanking people for doing a good job provides you with credibility when, and if, something occurs later on that needs to be changed.

I have found it to be important to request that evaluations be completed during early years. Completing the evaluation process can take months. Evaluations provide the basis for services and having them completed early prevents the waste of valuable time if, and when, serious difficulties arise for the student.

When I first began advocating for my son, I decided that we had to choose our battles with the school carefully and that two truths had to be kept in mind. The first was that no one was going to be able to cure him of the TS and the second was that school is the setting where learning to prepare to be an adult takes place. He required supports in dealing with difficult situations. However, if every difficult situation was eliminated, he would lose the opportunity of learning how to deal with similar situations as an adult.

**WHEN IS EDUCATION ADVOCACY AND WHEN IS IT NECESSARY – continued**

I believed that it was important that he be allowed to experience many hurdles so that the school could provide him with good strategies to help him overcome these hurdles and be successful later in life. This was not always an easy decision to make or to follow through with, but I believe that it better prepared him to live in an adult world.

Students with TS can experience many difficulties that cause them to be less than successful in a variety of areas. Advocacy must include requesting evaluations for any suspected difficulty in order to determine if supports need to be provided by the school. Learning difficulties that are left undiagnosed frequently lead to excessive stress for the student. Remember that stress generally makes symptoms worse and that failure can snowball into situations that are not easily turned around. Studies indicate that early recognition and intervention works best. That is why advocacy should begin early and stay as positive as possible.

Early and Positive advocacy demonstrates to the child:

- ♦ That self-advocacy skills are extremely important

It is never too soon for the student to learn to advocate for themselves. By advocating at school for their child, parent's are teaching their children positive methods of self-advocacy which will serve them well throughout their life.

- ♦ That the parents are not ashamed of their child having TS.

Being honest about symptoms demonstrates that the parents are proud of their child and that they understand that difficulties are not the fault of the child.

- ♦ That the parents and the school are on the same team.

I have experienced situations when the child knows that the parents and the school are in constant battles. Imagine the stress this creates for the student who is spending his day in an environment that the parents described as being destructive. This increases the stress level of the child as well as setting up a situation where the child can easily play the school and parents against each other. Disagreeing and advocating in a positive fashion is a healthy solution while prolonged anger and negative discussions with the child present can be dangerous to the child's well being.

Advocacy is an ongoing process throughout school. Choosing battles carefully is important, but so is keeping abreast of changing circumstances. In my experience, it is helpful to begin advocacy early and to encourage this positive relationship whenever possible.

There are times when impartial hearings and publicly disagreeing with the school is necessary and is not the fault of the parent. However, any and all attempts at avoiding this are well worth the effort.

**SOME ADDITIONAL EDUCATION ADVOCACY CONSIDERATIONS**

- *Typically, school personnel, even special education teachers, are not taught strategies in college that assist students with TS symptoms.*
- *Parents know their child best and therefore are their child's best advocate.*
- *Students with TS frequently receive high grades but may still be eligible for special education support.*
- *Receiving special education services does not require that a child be removed from the general education environment.*



Call today ...for your Albertson's Community Partners Card **303-832-4166** *It's Free and TSA-RMR Benefits!!* All you have to do is shop at Albertson's and have the card swiped. Total sales throughout the chapter are compiled and TSA-RMR receives a quarterly contribution from Albertson's. Please remember to shop at Albertson's or Osco Drug and use your card. **If you do not have a card, call TSA-RMR today and ask to have cards sent to you today!**

## SAMPLE - IEP SUMMARY PAGE

By Snow White-Wardell

Create a one-page summary of your child's IEP or 504 Needs & Accommodations. Personally deliver a copy to each teacher and specialists involved in teaching or supporting your child. Review it regularly with these professionals and deliver any updates or changes during the year. You will be supporting your child, become known to the professionals, and insure better delivery of services.

**Classification:** Other Health Impaired

**Diagnosis:** Tourette syndrome, ADHD, Obsessive Compulsive Disorder, Executive Dysfunction

**Services:** Sp. Ed. Teacher to consult w/General Ed. Teacher and provide small group instruction. Para educator to assist in organizational skills, and recess monitoring. Behavior specialist will consult ALL team members on behavior plan.

**Strengths:** Very bright, polite, creative and imaginative. Strong verbal, reading and math skills. Eager to learn, and please his teachers. Doing very well w/behavior plan and, has a great sense of humor.

**Concerns:** Mild motor and vocal tics which can interfere with learning. Difficulty with handwriting and other fine motor activities (incl. art). Trouble organizing, attending to details, staying focused, initiating and completing work even with assistance. Some interfering obsessions and compulsions. Impulsive at times, easily frustrated, and reports some teasing from peers.

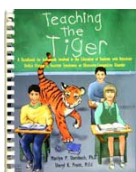
### **Accommodations/Modifications: (partial list)**

- Extra time to complete assignments
- Physical activity to help w/classroom alertness
- Adult redirection as appropriate
- Break down long assignments into smaller parts
- Monitoring/cueing for on-task behavior
- Allow alternative methods to demonstrate knowledge
- Child uses a computer and spell check, a tape recorder, and oral reporting for most of his written work
- Assistance in less structured times, lunch, recess, PE, Art, Music
- Preferential seating
- Positive Behavior Intervention Plan
- Assist in organization and planning Break down long assignments into smaller parts
- Class notes provided

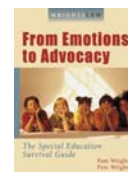
**Communication to parents via email:** parents e-mail address

**Parents:** Names & numbers

**Additional notes:** Mrs. Smith has copy of IEP and behavior plan. Mrs. Smith and Mr. Jones provide a "safe" place for Child to go when he is feeling stressed or upset.



### **Recommended Reading "Teaching The Tiger" & "From Emotions to Advocacy"**



*Handbooks for Individuals Involved In the Education of  
Students with Attention Deficit Disorders, Tourette Syndrome, or Obsessive-Compulsive Disorder  
and more. Order today from TSA-RMR – in stock and ready for delivery – 303-832-4166.*

## Tourette Syndrome Education Advocacy

### RED FLAGS

*by Kathleen J. Giordano, TSA Education Advocacy Specialist*

When advocating for a student with TS, there are red flags to look for that can assist in determining what supports will be most useful. However because symptoms of TS are frequently misunderstood, these 'red flags' are often thought of as being "purposeful **behaviors**" and not related to the disability. The following is a partial list of some of the more common red flags to be aware of:

- **Handwriting problems** Sloppiness, frequent erasing, time consuming effort at perfectionism, reduced output, slowness of handwriting, refusal to write, writing that is difficult to read are In my experience the difficulties that are most often misunderstood and overlooked.
- **Homework difficulties** Lack of understanding of the assignment; inconsistency in copying down assignments; struggles to complete; refusal to begin or complete; failure due to missing assignments; completed homework never turned in; etc.
- **Organization** Disorganization may include problems managing time, tasks, belongings and books. Other difficulties involved with executive deficit are also common.
- **Difficulty with transitions** Problems when changing tasks or classes. Resistant to changes in schedule or difficulties if the routine is changed.
- **Anxiety** Explosive behaviors; school avoidance; shutting down when overwhelmed; excessive trips to nurse, bathroom or counselor; emotional outbursts; etc.;
- **Sensory Issues** Sensitivity to light, sound, touch, smells, tastes; need to harm oneself physically; excessive chewing on objects; etc.
- **Difficulty following directions** Slow to respond; overwhelmed by complex directions; need to always have directions repeated; unable to complete tasks with multiply directions (verbal, written or both); etc.
- **Discrepancy between verbal and performance scores** Significant difference between scores on psycho-educational evaluations (ex: high average range for reading comprehension with low average range for written language skills; high scores in verbal and low on performance, etc.)
- **Symptoms that are seen as deliberate behaviors** If a behavior continues after countless consequences (positive or negative), there very likely may be a symptom that is being overlook or misunderstood.
- **Sudden academic or social failure** Swings in performance and abilities
- **Oppositional behaviors** When there is a refusal to engage in an activity or task, we must ask why, where, and when does the oppositional behavior occur
- **Difficulty with peers** Demonstrating social skills and understanding social cues can sometimes be an area of difficulty requiring Pragmatic Language skills training that is typically provided by a trained speech therapist.
- **Impulsivity** Shouting out answers, making inappropriate statements and exhibiting impulsive behaviors are all areas that can be improved with appropriate support.
- **Behaviors that student knows are wrong** Knowing HOW to act but inconsistently does not perform appropriately while "in the moment"
- **Perfectionism** Erases constantly; is limited in risk taking; must have things just so; is hyper-vigilant regarding rules; is insistent regarding rituals; etc.
- **Difficulty attending** Focusing difficulties that are inconsistent or chronic. Frequently complex tics or obsession can interfere; however, there are times when the student is able to attend even though it appears otherwise. Educators should periodically ask questions to determine the level of attention as many students with TS are capable of paying attention even during complex tics.
- **Immature behavior as compared to peers** Responds to stress in a manner that is not age appropriate. May feel more comfortable with younger children and with toys that are geared to a younger child.
- **Explosive behaviors only at home** May be a result of suppressing symptoms while at school as well as being overwhelmed for various reasons.

## TS and OT

*by Susan Conners, M. Ed. - Education Specialist, TSA, Inc.*

Are you tempted to skip quickly over this article because you are so tired of educational acronyms that only serve to confuse you more. Before you do, take a moment to answer these simple questions about your child with TS. If you answer yes to any of these questions, I strongly encourage you to read on because you are not alone and there may be some answers.

- ♦ *How many of you have a difficult time buying clothes for your child?*
- ♦ *Are you forever cutting tags out of the back of shirts, are you in a constant search for socks without seams and pants with an elastic waist?*
- ♦ *How many of you have a child who is bothered by bright lights, loud or particular noises, certain smells, the feel of some fabrics?*
- ♦ *How many of you have a child with TS who has very poor handwriting, who continually copies things wrong from a textbook, the chalkboard?*
- ♦ *How many of you have a child who goes quickly into "overload" and becomes very easily out of control?*

These are all behaviors that we see very frequently with children with TS. They are not motor tics or vocal tics, they are not obsessions or compulsions, but they are certainly very common with children with TS.

We don't have all the answers with TS, but we do know that there are certain co-morbid conditions that are seen in very large numbers of children with this disorder. One of these conditions is something called Sensory Defensiveness. I will try to explain it in so that you as a parent can understand what your child is going through. We have 5 senses and any of these can be heightened with children with neurological disorders such as TS. If your auditory sense is affected, you will find it difficult to tolerate certain noises or in particular, loud noises. The auditory system has a difficult time sifting out noises in the environment, so even the quietest of noises which an average person may not even hear, can be very disturbing to you. I once had a young boy with TS tell me that the electric clock on his classroom wall drives him crazy. Electric clocks make a humming sound that most of us don't even hear, but if you are aurally defensive, it could take over your world. It ruins your attention span and if it's a particularly loud noise, it may actually hurt your ears. I had a boy in my class a few years ago with TS and every time the school intercom came on, he would cover his ears. It was just too loud for him to tolerate. Another young boy could not tolerate the sound of his father chewing. He described it as being as offensive as nails scratching across a chalkboard. Dinner time became a time of constant battles and outbursts until the family finally agreed to have the father and the child take turns eating in the living room.

A very large number of these children suffer from tactile defensiveness. They cannot stand to be touched suddenly, They cannot wear certain fabrics, fabrics that are not soft and supple. They hate tags in clothes, anything with obvious seams, long sleeves, turtle neck sweaters and the list could go on and on. If children with this condition are forced to wear something that is tactually defensive to them, their behavior will most certainly be affected. A good comparison that will put you in the place of that child would be imagining the worst sunburn you've ever had and being made to wear a wool sweater. And then once wearing that wool sweater, you must walk through crowded hallways where you are constantly bumped into by other children, you must go to gym class and play basketball and all of the other activities that a child must do in the course of the school day. What kind of a mood would you be in at the end of that day?

Children who experience these types of sensory defensiveness often find it very difficult to maintain control in situations that are over stimulating to the senses; for example, crowded hallways, the cafeteria, the playground and the school bus. Imagine trying to navigate through a crowded middle school hallway during change of classes wearing a wool sweater over a bad sunburn and when every noise is at a volume louder than anyone could tolerate.

And what about this terrible handwriting? A very large number of children with TS also have a co-morbid non verbal learning disability in the area of fine motor and visual motor impairment. Translated this means that their hands cramp very easily when they write and that writing is very slow and laborious for them. It also means that after one or two sentences their handwriting deteriorates to the point of being illegible no matter how hard they try. They especially struggle with cursive writing. It also means that they have a very difficult time copying things accurately from a chalk board or textbook, they tend to reverse letters and they don't line math problems up correctly to name a few. Being unable to write is extremely interfering to classroom performance. Homework takes them twice as long, test are never finished on time, math problems are wrong because they were not lined up properly and the level of frustration grows and grows each time they must put a pencil or pen in their hand.

*TS and OT - continued*

So, how does an OT fit into this picture? Some of you may even be wondering what is an OT. **An OT is an Occupational Therapist** whose job it is to see that children with disabilities of any kind learn to function to their optimum potential. **I always strongly encourage any parent of a child with TS to request an evaluation by the school's occupational therapist including a sensory integration evaluation** to determine the extent to which this disability is impacting on their educational performance. OT's traditionally work with children with fine motor impairments to help them improve first and foremost their fine motor skills, but even more importantly to determine what adaptations need to be implemented in the classroom setting to assist the child with this problem. Below is a list of very useful accommodations that can be in the child's IEP or 504 Plan to address these issues:

- ♦ The use of a word processor is a reasonable and necessary accommodation.
- ♦ Occupational Therapy Intervention / Sensory Integration Evaluation.
- ♦ Tests/reports given orally. Waive time limits on tests.
- ♦ Shorten assignments.
- ♦ Verify all homework assignments to make sure they were copied accurately.
- ♦ Standardized tests answers written directly in the test booklet and transferred onto answer sheet by teacher or assistant
- ♦ Provide graph paper to help line up math problems or allow child to turn paper sideways.
- ♦ Do not penalize students for poor handwriting. Provide alternatives for doing tests, assignments, etc. (orally, taped).
- ♦ Do not penalize for spelling errors. Encourage the use of spell check.
- ♦ Provide class notes rather than having the student copy from the chalkboard or overhead.

Having said all of the above, I also must add a caveat to all of this good advice. It is not at all uncommon that school based OT evaluations miss the problem of fine motor difficulties with children with TS because they tend to give a very short writing sample. I recently worked with a young girl with very obvious (to me, at least) fine motor difficulties. When tested by the school OT, no disability was found. When I asked to see the writing sample that the OT had asked for during the evaluation, I was shocked to see that the child had only been asked to write his name and one other sentence. The sample demonstrated fairly good handwriting. Most kids with TS can write a few sentences with decent handwriting. However, this quickly falls apart as their hand begins to cramp and the handwriting deteriorates. I then had the classroom teacher put together a portfolio of longer writing samples from the child in question which quickly demonstrated her inability to write neatly, stay on the line, space appropriately between words and keep even margins. Her math papers showed uneven addition and subtraction columns and therefore answers that were incorrect. You also need to know that school based OT's are not always trained to perform sensory integration testing.

When either of these situations occurs; 1) the school based OT evaluation does not find any fine motor difficulties and/or 2) the the school OT does not evaluate for sensory integration difficulties, you have the right as a parent to respectfully disagree with the OT evaluation and request that the school do outside OT testing at their expense. And even more importantly, if your child is exhibiting any of the signs of sensory defensiveness listed at the beginning of this article and if the school does not perform sensory integration evaluations, you have the right to request that it be performed by an outside OT at the district's expense.

Children with sensory modulation difficulties will often experience periods of over or under arousal. Behaviorally this manifests itself as poor coping mechanisms, withdrawal from activities, increased aggression toward others, increased frustration and/or anxiety when confronted with situations perceived as overwhelming or threatening. Children with these issues may also attempt to maintain control over their environment to a very extreme degree, becoming inflexible and stubborn. Their inappropriate behavior may be driven **not** by an emotional need, but rather a physical one.

The good news is that children with these difficulties usually respond well to occupational therapy. The therapy should focus on the underlying sensory processing and modulation problems.

To summarize, if this article seems to have been written about your child, you must immediately become best friends with the school Occupational Therapist. Seriously, follow the procedure outlined herein, have your child properly evaluated and you may soon see a very different child.



## Oppositional Defiant Disorder

(From an article by James Keim: "The Strategic Therapy of Oppositional Behavior")

Many of our kids with TS have symptoms of oppositional defiant disorder, and for us as parents, this can be more of an issue than the tics. Symptoms include chronic anger, defiance, blaming others for mistakes, being touchy or easily annoyed, annoying others, and swearing or using obscene language. We feel that we are always battling with our kids, and conventional discipline strategies often fail. We feel isolated and powerless, blame ourselves, and feel confused because often our kids are model citizens away from home! It helps to realize that these kids are handicapped in their ability to be flexible and handle frustration; the only thing harder than living with them is BEING them. Some thoughts:

The oppositional child or teenager often behaves as if they have the authority of adults, not kids, and tend to argue with adults as if arguing with peers. Sometimes, in response, the adult begins to behave less like a parent and more like a peer vying for power. What the parent doesn't know is that the power struggle is the payoff for the kid, not the outcome! The person with the power in a confrontation is the person who:

- ♦ Determines the TIMING of the confrontation;
- ♦ Decides the CONTENT AND DIRECTION of the communication during the confrontation;
- ♦ Determines the MOOD of the confrontation; and
- ♦ Decides the OUTCOME of the confrontation.

As the argument progresses and tension mounts, the child increasingly focuses on the PROCESS, while the adult is increasingly focused on the OUTCOME.

The job of the adult is to choose the TIMING of the confrontation when he/she (and the child) are calm, not angry; this may mean physically leaving the situation if the child follows you around insisting you talk to them. Deciding the CONTENT AND DIRECTION of the discussion is easier if you have set limits, rules, and consequences (and put them down on paper for the child to see) BEFOREHAND; nonverbally handing the child this list can de-escalate the situation. Monitor your own MOOD at the onset of (and during) the confrontation. And finally, what do you want the OUTCOME to be?

Remember, for the oppositional child, the ARGUMENT is the payoff, not the outcome. If you refuse to join the fight, you win; if you get into it, the child wins.

Our job as parents is to set the limits and make decisions on rules and consequences, but equally important is also to reward, reassure, soothe, protect, spend positive time with them, and let them know that we know that sometimes, just putting one foot in front of the other is a major feat!

## Support Group Contacts & Schedules

**Denver:** 8/18/2004 & 9/15/04 6:30-8:30 PM Observatory Park- btwn Evans & Warren / Milwaukee & St. Paul  
Contact: Loree Vanderhye 303-638-1504 or tsarmr@att.net (meet at tables near swings/climbing bars/basketball)

**Colorado Springs:** 4<sup>th</sup> Thursday of each Month 8/26/2004 7:00-8:30 PM NAMI Offices-510 E Willamette  
Contacts: Rachel Bolenbaugh 719-266-8477 Jennifer Pearce 719-481-9716 tsa-cospgs@bolenbaugh.net

**Longmont:** TBA Contact: Snow White-Wardell 303-774-9657 or jwardel@msn.com

**Boise:** 7:00-9:00 PM Boise Public Library-Marion Bingham Room-715 S. Capital Blvd.  
Contact: Patti Guicheteau 208-345-7365

**Gillette:** 9/30/04 7:00 PM Campbell Cnty Library-2101 S. 4J Rd Contact: Vicki Cook 307-682-9732 vcook@vcn.com

**Kalispell:** Informal Meetings Contact: Patricia DiStefano 406-755-8498

*Support Group contacts have agreed to accept calls and assist in providing information.*

*Their comments reflect their personal background with TS and do not necessarily reflect the views of this chapter.*

**YES!** I want to make a tax deductible gift to help Tourette Syndrome Association, Rocky Mountain Region, a 501[c]3, create awareness, understanding and acceptance of this complex, bio-neurological disorder.

\$50    \$100    \$500 Bronze    \$1,000 Silver    \$2,500 Gold    \$5,000 Platinum

Donor name: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_  
 Home Phone: ( ) \_\_\_\_\_ Work phone: ( ) \_\_\_\_\_  
 E-Mail: \_\_\_\_\_

- Check payable to the TSA-RMR (Tourette Syndrome Association, Rocky Mountain Region)
- Note any special use for your gift \_\_\_\_\_
- If your employer has a matching gift program, please enclose the completed forms required by your company, or name of the company contact.
- I want to become a member of TSA, send me the forms.

*Unless requested otherwise, your name may be listed in TSA-RMR Newsletters as a contributor*

*Tourette Syndrome Association, Inc.-Rocky Mountain Region, attempts to offer support group opportunities, literature, information and assistance to individuals with Tourette Syndrome and its associated disorders, their families, interested friends and supporters. TSA-RMR DOES NOT provide medical advice, nor do they promote, endorse, or recommend any product, therapy, or institution. Study and check all drugs, treatments, therapies and products carefully and speak with your physicians and pharmacists. Statements and opinions expressed in this Newsletter and at support groups or in any other information are not necessarily those of TSA-RMR*



Rocky Mountain Region  
 2020 S. Oneida St. # 19  
 Denver, Colorado 80224

Phone: (303) 832-4166  
 Fax: (303) 861-0515  
 E-Mail: [tsarmr@att.net](mailto:tsarmr@att.net)  
 Website: <http://www.sensiblenet.com/tsa/home.htm>

**NON PROFIT  
 ORG  
 U.S. POSTAGE  
 PAID  
 DENVER, CO  
 PERMIT 2745**