



NEWSLETTER

Spring/Summer, 2006

TSA-RMR

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TSA-RMR will be phasing out the

printed Newsletter and replacing it with a PDF version that will be e-mailed to members who's address are on file with us, and posted on our website. Please confirm your e-mail address with us today at tsarmr@att.net.

A GREAT DAY FOR TSA

On August 4, 2006, Judit Ungar Chairperson of National Tourette Syndrome Association, Inc., was invited to a private Department of Education meeting in Washington DC, in which they announced the new regulations for the Individuals with Disabilities Education Act (IDEA). I am so happy to let you know that Tourette Syndrome will now be listed as a disability under the category of Other Health Impaired (OHI). This new classification is the result of over two decades of vigorous advocating by TSA and our members.

TSA is distributing a news release this afternoon to every national newspaper, magazine, TV and radio news programs, news and education websites and trade publications, targeting education and public policy editors, as well as placing a website story on the TSA home page and an extensive newsletter story for the Fall issue.

This is a tremendous victory for all children with TS - now they will get the appropriate services they need to help them reach their full potential in school and make their lives so much easier when dealing with teachers who do not understand TS.

Although many children with TS may be classified under the OHI category (or should have been), TS was not specifically listed. A copy of the release is on the TSA website at www.tsa-usa.org.

Denver Mini Conferences & Networking

Denver has held two very successful mini-conferences and plans more in the next few months. To receive timely notices for the meetings, please confirm that the correct and current e-mail address is on file with TSA-RMR. Drop us a confirming e-mail at tsarmr@att.net.

Upcoming events and topics:

- Social Skills (responsibilities, friendships, self advocacy)
- Family Relationships (couples, siblings, outside support)

Program includes; panel discussion, speakers, general support group, breakout for children to play and adults to learn.

GET READY FOR SCHOOL

Prepare a one page synopsis of your child's IEP and distribute it to each teacher and service provider involved with your child. If your child doesn't have an IEP, the synopsis will still provide tremendous help and understanding for the teachers.

Synopsis of IEP for John Q Tourette (Example)

Classification:	Other Health Impaired (OHI) – Tourette Syndrome, ADHD, OCD
Diagnosis:	Tourette Syndrome, ADHD, Obsessive Compulsive Disorder, Anxiety Disorder, Sensory Integration Difficulties, Fine Motor Impairment, Visual Motor Impairment
Services:	Occupational Therapy, Shared Aide, Consultant Teacher Services, Counseling
Strengths:	Very bright, excellent reader, eager to learn and do well in school, very interested in science, enjoys public speaking
Problem Areas:	Math Handwriting and other fine motor activities Short attention span Sensory overload in noisy, chaotic environments (cafeteria, auditorium) Interfering tics associated with Tourette Syndrome Organization Gross motor deficits Difficulty with motor planning with both fine and gross motor activities Interfering obsessions and compulsions
Accommodations:	Frequent breaks from class to release tics Daily journal/communication log between home & school Assignments verified by teacher Long range assignments broken down into smaller parts Reduction in length of homework assignments Instructions repeated and reread for clarification Preferential seating up front to the side of classroom Reminders to help refocus when inattentive Extended time for tests and testing in a quiet location Alternatives to long written assignments and use of a computer Check out by teacher aide at the end of the day of back pack and take home folders Occupational therapist to meet with PE teacher to set up appropriate modifications Assistance with organization Teacher aide assistance in less structured classes such as PE, Art, Music, etc. Positive Behavior Intervention Plan
Things to Avoid:	Seating too close to other children because of tics and sensory issues Being in the middle of a line – John is much better at the beginning or the end

INDEPENDENT EVALUATIONS

*by Kathleen J. Giordano
TSA Education Advocacy Specialist*

Students with TS can have numerous difficulties that cause them to be less than successful in a number of different areas of academic achievement. Therefore, advocacy must always include requesting evaluations for any suspected disability in order to determine if supports need to be provided by the school. Learning challenges that are left undiagnosed will most likely lead to an increase in stress for the student. The importance of early recognition and support is paramount because stress generally makes symptoms worse which often results in academic failure. Failure is stressful and a situation then develops that very often cannot be easily turned around.

Studies and experience indicate that early recognition and intervention for difficulties due to TS works best. Areas of suspected challenges can be found on this site's Education/Advocacy webpages and include:

- Learning Disabilities
- Dysgraphia (writing difficulties)
- Sensory Integration Deficits (is the child hypersensitive to light, sounds, touch, smell or taste? Do they have excessive need to touch, smell, or chew?)
- Processing Delays (Do they require extra time to process verbal request? Visual request? Do they require extra time to process a visual cue?)
- Executive Dysfunction (Do they get overwhelmed easily, have poor long term or short term planning, poor organizational skills, get stuck with multiple tasks requests?)

If a parent believes there are educational difficulties which have not been identified by school evaluations, they can request an outside and independent evaluation. According to Federal Individual with Disabilities Education Act, the school has two options. The first option is to provide the funding for the evaluation. The second is to take the parents to a hearing (See explanation below).

The following is an excerpt from Discover IDEA CD 2002. (Offered through IDEA Partnerships, at www.cec.sped.org – it is a [wonderful resource](#). They will also send you a [free](#) CD that replicates all the information of the web page by requesting one from that site. All of the information provided on that site was produced by IDEA PARTNERSHIPS and was approved by U.S. Department of Education Office of Special Education Programs):

"Parent right to evaluation at public expense"

(1) A parent has the right to an independent educational evaluation at public expense if the parent disagrees with an evaluation obtained by the public agency.

(2) If a parent requests an independent educational evaluation at public expense, the public agency must, without unnecessary delay, either-

(i) Initiate a hearing under §300.507 to show that its evaluation is appropriate; or

(ii) Ensure that an independent educational evaluation is provided at public expense, unless the agency demonstrates in a hearing under §300.507 that the evaluation obtained by the parent did not meet agency criteria."



As we hoped and expected, "I Have Tourette's But Tourette's Doesn't Have Me" received TWO Emmy nominations.... One for **Outstanding Children's Program** and one for **Outstanding Cinematography For Nonfiction Programming - Single-Camera Productions**... Below is the complete listing for each category including our competition... TSA will begin promoting the nominations and campaigning for voters to recognize this amazing program... Hooray!

Outstanding Children's Program

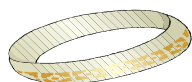
1. Classical Baby 2 • HBO • HBO Original Programming - Producers TBA
2. High School Musical • Disney • Salty Pictures/First Street - Films/Disney Channel - Producers TBA
3. **I Have Tourette's But Tourette's Doesn't Have Me • HBO • Tourette Syndrome Association with HBO Documentary – Films - Producers TBA**
4. Nick News With Linda Ellerbee: Do Something! Caring For The Kids Of Katrina • Nickelodeon • Nickelodeon Studios with Lucky Duck Productions - Producers TBA

Outstanding Cinematography For Nonfiction Programming - Single-Camera Productions

1. All Aboard! Rosie's Family Cruise • HBO • Sceneworks Productions and KidRo Productions in association with HBO Documentary Films - Maryse Alberti, Dir of Photography - Sandra Chandler & Beth Wichterich, Camera
2. Baghdad ER • HBO • Feury/Grant Productions and Downtown Community Television Center in association with HBO Documentary Films - Jon Alpert, Director of Photography - Matthew O'Neill, Director of Photography
3. Children Of Beslan • HBO • HBO Documentary Films in association with the BBC - Dirk Nel, Director of Photography
4. **I Have Tourette's But Tourette's Doesn't Have Me • HBO • Tourette Syndrome Association with HBO Documentary – Films - Buddy Squires, Director of Photography**
5. Rome: Engineering An Empire • The History Channel • KPI Productions, Inc. for History Television Network – Productions - Jeremiah Crowell, Director of Photography

These nominations will bring further awareness and education about Tourette Syndrome and continue to keep this program in the public eye. The winners will be announced at the 58th Annual Creative Arts Emmy Awards on Saturday, August 19.

"I Have Tourette's But Tourette's Doesn't Have Me" is available from the TSA website at <http://tsa-usa.org>. The DVD includes the 27-minute documentary as well as a half an hour of extras with Tourette Syndrome experts as well as some additional footage unaired on HBO.



ORDER YOUR BRACELETS - IT IS HERE AND IN STOCK!

*TSA now has our very own awareness bracelet! The design is similar to the Lance Armstrong one, but ours is Teal colored, and inscribed with the word: **INSPIRE**
Order some for your family and friends today - they are only \$1 each!
720-212-7535 or email: tsarmr@att.net*

*Thank you to those of you who have returned your annual donation to TSA-RMR and to those of you who designated TSA-RMR on your United Way contributions at work.
If you have not yet sent in a donation for 2006, please do so today.*

CHAPTER SPECIAL EVENTS

COLORADO:

Denver - Mini Conferences & Other Events

Denver Academy - 4100 E. Iliff Ave, Denver

720-212-7535 or e-mail tsarmr@att.net

Send us an e-mail to be added to the list for notices.

Colorado Springs 3rd Thursday of each month - 7-8:30 PM

NAMI Offices-510 E. Willamette.

Contact: Rachel Bolenbaugh 719-266-8477 or

tsacospgs@bolenbaugh.net

IDAHO:

Boise 10/15 - Call for details!!!

Contacts: June Sparks 208-388-1616 or junetsparks@cableone.net

Stephanie Hoffman 208-376-3409 or shoffman3409@msn.com

MONTANA:

Billings: None - please contact TSA-RMR if you are interested in starting a group.

Kalispell: Contact Patricia DiStefano 406-755-8498

NEVADA:

Las Vegas: Contact Kim Amato 702-877-1786 or

702-810-5180

WYOMING:

Gillette: Contact Vicki Cook 307-682-9732 or vcCook@vcn.com

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.

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

The Denver Mom's Group met again recently and had a great time. Get on the e-mail list so you receive notices and invitations of future events.

⚡ A Product for Sensory Problems ⚡

An underwear product called Underarmour seems to provide relief for people with Sensory issues. One mother reported that her child likes the silky feel of the Underarmour shirts. He can wear it under his school uniforms to eliminate the discomfort from the shirt and problems when tucking the shirt in.

PRL (Professional Referral List) Outreach Program

TSA's goal is to identify professionals throughout the entire chapter, especially the more remote areas, who may be interested in learning more about TS. We want to build our referral list and need your help.

Please forward the names and pertinent information on any medical, educational, legal, or other professionals with whom you have experience, or you feel would be receptive to learning more about TS. We will follow your referral with a letter to the professional(s), video's, and response form for them to complete and return to us. The end result will be an increased number of professionals who are knowledgeable about TS. Please e-mail your referrals to tsarmr@att.net. Thank you!



Rocky Mountain Region
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Website: <http://www.sensiblenet.com/tsa/home.htm>

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