



**tourette syndrome
association, inc.**

Rocky Mountain Region

Serving: Colorado, Idaho, Nevada, Montana & Wyoming

NEWSLETTER

General Issue

February, 2005

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WISH LIST

- ↪ **Fund the Quarterly Newsletter**
 - **Printing \$1,800/year**
 - **Postage \$1,200/year**
- ↪ **Fund the "Reaching & Teaching In-Service Program" Expenses & Materials \$300 ea (in CO) Call for out of state \$**
- ↪ **Computer Tech Help**
- ↪ **Literature Cubby for the office**
- ↪ **Volunteers for Fundraising**

Database, Statistics & Funding Facts

The Center for Disease Control (CDC) collects and publishes TS statistical database information gathered from our parent organization, Tourette Syndrome Association-National-NY. When you read statistical statements such as; "there are 100,000 individuals diagnosed with TS in the United States", you are reading the results of the CDC's data gathering. These statistics are referenced in medical journals, books, and appeals for funding or grants.

In the past, Tourette Syndrome Association-National-NY's database information has been limited to those who contacted them directly, or from information supplied to them by Chapters such as ours (TSA-RMR). With every Chapter operating under different database systems, the information collected has been very understated and inaccurate (if done at all).

Late 2004 brought major improvements to the TSA computer systems whereby more compatible database systems were developed and Chapters (including TSA-RMR) began forwarding database information to TSA-National-NY. TSA-National-NY now has the ability to provide much more realistic and accurate information to the CDC. That will ultimately offer better research opportunities, funding support and support services to TSA members and the public.

Shortly, you should receive correspondence from TSA-National-NY. Please respond to the request for information and join the TSA-National-NY membership. You can direct part of your contributions to TSA-RMR (your Chapter) by noting it on the donation form on the prepaid return envelop provided.

Loree Vanderhye, President

**11TH BIENNIAL MOVEMENT DISORDER SYMPOSIUM
"HOPE & PROGRESS"**

September 10, 2005 - Denver Location TBA – Info: tsarmr@att.net
Mark your calendars for this special one day event.
Outstanding presentations; Latest Research and Medicine, Emotional Health, Holistic Therapy, Caring & Coping, Resources, Insurance Issues & Legal Assistance. Excellent vendor products, material, books and more!

Dear Members,

Happy New Year, and welcome to our new members! This year promises to be a busy year for TSA and the chapters. Your Rocky Mountain Region chapter is growing rapidly, and with that growth, we are in need of additional volunteers. We need people to organize fundraisers, arrange in-services to schools, facilitate support group meetings, mentor a child, and consider participation on our Advisory or Governing Board. TSA is an all-volunteer organization. We operate and depend on fundraisers, donations, and in-kind gifts, to continue the important objectives that are critical to improving the services that our volunteers strive to offer people with Tourette Syndrome Spectrum Disorder. Our efforts include:

- Programs that help parents advocate for their child at school, understand the IEP process, and know their rights;
- Informing members about legislative issues that affect people living with TS+;
- Distributing literature to the health care community that assist in the early and accurate diagnosis of TS+;
- Support and services to individuals and families who are now and will be in the future, diagnosed with and affected by Tourette Syndrome and the associated bio-neurological disorders that often accompany TS.

I encourage you to contact the TSA-RMR office to learn more about our mission and get specific information on how YOU can be a TSA-RMR VOLUNTEER! If each of us can do a little, together we will accomplish much. Please help move our efforts forward. Thank you for your continued support.

Sincerely, Snow White-Wardell

BEST-SELLING "SPECIAL NEEDS" AUTHOR IN DENVER

Best-selling author and Pediatrician Mel Levine, M.D. will be at the "Book Beat Luncheon" at the Denver Athletic Club, 1325 Glenarm Place, Denver, Wednesday, February 9, 2005 at 12:30 p.m.

The cost is \$20.00 For reservations, call Katie Walters at 720-931-6810 or e-mail at kwalters@denverathleticclub.org

Dr. Levine will talk about his latest book, "Ready or Not, Here Life Comes". The book addresses how today's society makes it difficult for kids to grow into productive adults and what we can do about it.

For more about Dr. Levine, visit his website:
www.allkindsofminds.com

Support Groups & Contacts

Denver, CO 3rd Wednesday of each Month 6:30-8:30 PM Contact: Loree Vanderhye 303-638-1504 or tsarmr@att.net

Colorado Springs, CO 3rd Tuesday of each Month 7:00-8:30 PM NAMI Offices-510 E Willamette
Contacts: Rachel Bolenbaugh 719-266-8477 Jennifer Pearce 719-481-9716

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

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

Gillette, WY **Contact:** Vicki Cook 307-682-9732 vcCook@vcn.com

Kalispell, MT **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.
If you are interested in forming a support group, contact the TSA-RMR office, 303/774-7707 for details.
We need facilitators in Nevada!*

IDEA REAUTHORIZATION 2004

Summary of Changes Affecting Students with Tourette Syndrome

The Individuals with Disabilities Education Act (IDEA) reauthorization bill was passed by both the House and the Senate and signed into law on December 4, 2004. Although some protections from the prior law were removed, the reauthorized current law contained some important gains for children with Tourette Syndrome.

TSA will keep apprised of how the Federal and State regulations are composed, and whether funding will be provided to support the positive initiatives that have been added to IDEA as well as how the potentially negative parts will be interpreted and administered.

Below is a summary of some of the changes that will most directly affect students with TS. For more details on these changes, please refer to TSA Nationals Public Policy on the web site: www.tsa-usa.org. When Federal Regulations are finalized (mid-2005), TSA will update summary information reflecting changes in IDEA regulations.

DISCIPLINE

Functional Behavioral Assessments and Positive Behavior Intervention Plans were retained in the reauthorized law. Additionally, throughout IDEA, schools will need to provide support not only for academic progress, but also for functional and behavioral goals. This is critically important when supporting students with TS. Other critical changes include...

STAY PUT

In the past; a student with a disability would remain in his current educational placement, pending an appeal for alleged violations of the school code that may result in a removal from the student's current education placement for more than 10 days. Previously, this "stay put" was only denied if a weapon, other dangerous activities or drugs were involved. Stay put was critically important...

PROFESSIONAL DEVELOPMENT

There are new guidelines that schools provide *"high-quality, intensive pre-service preparation and professional development for all personnel who work with children with disabilities to improve the academic and functional performances"*. This will significantly assist in providing the vitally important in-services for teachers and support staff...

EARLY AND POSITIVE INTERVENTION

IDEA 2004 supports whole-school approaches regarding early interventions and positive behavior interventions, which have been extremely effective approaches in educating all students—particularly those with disabilities such as TS. Acceptance and understanding typically reduces stress...

FLEXIBLE IEP MEETINGS

IDEA encourages parent participation at IEP meetings by allowing phone conferencing, video conferencing and other alternative means of them participating in the meeting. Minor changes will be able to be made to a student's IEP without reconvening the entire IEP team...

THREE YEAR IEP'S

IDEA provides the opportunity for up to 15 states to develop an optional three year IEP for students instead of the annual review that is currently mandatory. Parents will need to be aware that this is an option...

SHORT TERM GOALS

Short term goals will no longer be required on a student's IEP for the vast majority of students. The only students who will have these essential road marks will be those whom the IEP team has designated as requiring alternate assessments which No Child Left Behind (NCLB) has determined to be only those students with the most significant cognitive disabilities...

COLLABORATIVE RELATIONSHIP

A general emphasis of IDEA 2004 is on providing opportunities that encourage an atmosphere of collaboration between schools and parents. One way this is demonstrated is in supporting the federally funded Parent Training and Information Centers to increase this aspect of their focus...

TRANSITION SERVICES

IDEA emphasizes transition services (preparing the student for life after high school) and redefines them to focus not just on academic achievement but also the functional development of the student. Again, the words "functional development" is included which can be critically important for children with TS...

USE OF FUNDING FOR SUPPORTING NON-DISABLED STUDENTS

School districts may use up to 15% of funding provided by IDEA for students without disabilities who require additional academic and behavioral supports to succeed in a general education environment. This will allow schools to use funding to support students who may require minimal support...

DEFINITION OF LEARNING DISABILITY

IDEA maintains the definition for "specific learning disability." However, schools will no longer be able to claim that the only way they can provide this classification is if the child has a severe discrepancy between achievement and IQ scores. Parents and advocates will need to be aware of the specific language...

MEDICATIONS

Schools will be prohibited from requiring that a child obtain prescription medication as a condition of attending school, receiving an evaluation or receiving services...

EVALUATIONS

Evaluations must determine the levels of academic achievement, and related developmental needs of the child. The focus is not strictly on the academic needs of the child. IDEA also includes that evaluations must be conducted within 60 days of receiving parental consent...

Thank you from the Legislative Chair

**TOURETTE SYNDROME ASSOCIATION (TSA) & CENTER FOR DISEASE CONTROL (CDC)*****PRESENTS GRAND ROUNDS AT DENVER CHILDREN'S HOSPITAL***

Physicians and allied medical professionals are invited to attend Grand Rounds at Denver Children's Hospital - Pediatric Department - Friday, May 5th - 12:30 p.m. – 1:30 p.m.

- Expert training in Tourette Syndrome, differential diagnosis, information about latest treatments including medications, case management, and common co-morbid conditions
- CME approved credit
- Attendees will receive a comprehensive CD-DVD featuring practice parameters, important published papers, and four useful videos

Presenting physician will attend a separate TSA family meeting for members of this chapter. Members may wish to invite their own doctors to attend if they are not able to attend the TSA & CDC Grand Rounds.

Contact TSA-RMR for additional details 303/774-7707 or tsarmr@att.net

*The following essay was written by a young man with TS, he included it with his college application.
His parents provided a copy, and agreed to share it with TSA-RMR.*

I hope his inspiring words leave a place on your heart just as it did on mine. Snow White-Wardell, ED



I sit in class, the first day of school. I look about at the new faces around me, trying to suppress the urge to blink, or flinch, or contort my body as I sit stifled in my chair. "What will they think of me?" I wonder. I begin to fidget in my seat, attempting to resist the urge to release myself, a moving mass of fury. Finally, I cannot stand it any longer; I look to my left, blink my eye and slightly twist my mouth. I breathe a sigh of relief, looking about the classroom at my new classmates' reactions, fearing the worst. A few kids glance at me, and look casually away. Perhaps Tourette's isn't as big a deal as I expected it to be.

While I do occasionally incur sideways glances or somewhat curious stares from my classmates because I have Tourette Syndrome, it has proven to be much less of a hindrance than I ever imagined it would. While it does warrant a few stares and even a rare question, my fears about allowing my Tourette's to show itself in public almost always prove unfounded. Tourette's has significantly formed me into who I am today, and will likely continue to do so for the rest of my life. I owe almost all of my most valuable personality traits in some way to Tourette Syndrome. Because of it, I feel I am much more accepting of the differences in others than I otherwise would be. I have learned through the knowledge I have of myself that no person can be judged by outward appearances, and that the boy dubbed "freak" or "loner" (or perhaps both) is often funnier than the class clown, stronger than the class jock, and smarter than the class genius, even if he may not seem so at first glance. I have learned through my own experience that often the most intriguing characters are those hidden behind inch-thick glasses or nose piercing and black nail polish.

Because of my acceptance and understanding of others, I have often found that people do not care that I have Tourette's and are more than willing to extend this same acceptance to me. Although I may strain to restrict myself from jerking my head to the side while sitting in a movie theater, as soon as I give in and fulfill my urges, I find that my fears are without basis. My friends continue watching the movie, seemingly unfettered. How did they not notice that, I wonder to myself incredulously. However, as I grow and become more aware of the feelings of my friends and family regarding my Tourette's, I have begun to realize that they do notice my small bursts of tics; it is out of their acceptance that they do not show it. I have learned to realize that in life, there is little use in fearing the inevitable, the unavoidable little risks one must take each day; one must simply face these obstructions and make the best of the situation at hand. I have discovered that I cannot stop Tourette's; however, I have realized that the less I show that it hinders me; the less others will think it hinders me as well.

By: Ted McCarthy

**"Our children are living messages
we send into a time and place we will never see."**

~Author Unknown

YES! I want to make a tax deductible donation to help TSA-RMR (a 501[c]3 org), create awareness, understanding and acceptance of this complex, bio-neurological disorder.

\$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
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**NEW ADDRESS &
TELEPHONE**

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