



NEWSLETTER

May, 2003

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TSA-RMR has a New Website!

In our continuing efforts to provide our members with the most useful, recent, and relevant information, we have launched a brand-new website.

Please take a moment to fill out the contact information form on the website providing all current information. If you have moved, are planning on moving, or have changed any of your contact information - keep us updated. This will allow us to continue to provide you with breaking news and information about upcoming events. Please remember to include your e-mail address and remember to update us when you make changes. Sending information to you via e-mail will be of great assistance in helping us to control the costs of communication.

We welcome any suggestions, comments, and articles of interest, so please be sure to give us your feedback on the new site. It's for you.

Please visit us at: http://www.sensiblenet.com/tsa/home.htm and be sure to check back regularly for new information.

TSA-RMR respects your privacy, and uses your contact information for the sole purpose of providing you with information and services related to TS and TS Spectrum Disorders. We do not, and will not sell or share your information with any third parties.

Comments about the website can be sent to: jerry@sensiblenet.com or tsarmr@att.net

From the President

We recently had an opportunity to work with a member who wanted to give TSA-RMR a very special legacy.

It started with a phone call requesting information on how the member could set up a future financial gift for this Chapter. The member had already done some homework with CPA's and Attorney's, reviewing wills and bequests, gifts of insurance, charitable annuities, and other financial vehicles. After additional evaluations and discussions, the member determined that their best option was to issue a codicil to their existing will. This was done quickly and is safely and confidentially secured in TSA-RMR legal documents.

The member stated that they had received so much help and hope over the years from TSA-RMR, that they wanted to give back to the organization. They hope that their gift will provide help to others who will contact TSA-RMR in the future seeking help. What a wonderful thought and gift.

Consider how you and your family can leave a legacy to TSA-RMR. There are many options and possibilities. Call any time for confidential discussions on this subject.

Have a fantastic summer and be sure to sign up for the very special events coming up in May, August & September!

[Handwritten signature of Loree Vanderhye]

Loree Vanderhye

In This Issue

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News From Around the Country...

The Importance of In-Services for Your Child's Classmates

By Kathy Giordano Reprint from: Western NY TSA Chapter Winter 2002

"Because of her, my life has completely and totally changed". This is taken from a school report that a young girl wrote concerning her struggle with Tourette Syndrome and a person who had presented to the class about this and related disorders. She discussed her difficulties with the teasing from her classmates and the gratitude she feels as a result of an in-service provided to her classmates. There is no better compliment than this.

Many parents are reluctant to have a person discuss Tourette Syndrome with their child's classmates. I understand their reluctance. Typically if a parent makes a request that someone speak to classmates, it is because some of them are teasing the student for symptoms. Parents and students are afraid that admitting the student has a disorder will only give the other students ammunition to increase their harassment and teasing.

However, giving the behaviors a name, and comparing them to things that are familiar such as asthma, diabetes and even hiccups, helps classmates understand. Understanding leads to acceptance and even support. Children can be very accepting if they have the opportunity to hear an honest explanation followed by a chance to ask questions.

Soon after a presentation, the difference in the child's social-emotional life is very often astounding. Typically, teasing is reduced dramatically and frequently, classmates will defend the student against other students' teasing as well as the disapproval of teachers who are not aware of the situation.

In-services are not only important as an antidote to teasing, but also they say to the child with Tourette that he or she does not have to hide symptoms or keep them a secret. Too often secrets are related to shame. Understanding and honestly discussing symptoms can be an important step toward acceptance of having a disorder. Since symptoms can vary, are inconsistent, and are vastly misunderstood, acceptance becomes a very important component to having the student self-advocate for services as he or she gets into high school, college and the work force.

Not telling the classmates allows them to continue to believe that the noises, movements, and behaviors are purposeful and are intended to annoy others as well as disrupt the class. Many teachers feel trapped in a difficult position, needing to defend the child because of their symptoms, but also needing to respect the confidentiality wishes of the child's parents. Students can relate to having hiccups, scratching an itch, or sneezing at inconvenient times. Giving information to the students helps them relate to the uncontrollable symptoms, and helps them gain an understanding.

Presenting information to classmates can be a tough decision, but an in-service given when children are younger has a better chance of increasing acceptance and supportive behavior from classmates. It also will be sending a clear message to your child that you are not ashamed of him or his disability and neither should he.

**Need Help Educating Your Child's Classmates or Teachers and
School Administrators About TS?**

Call the TSA-RMR office: 303-832-4166



MOVEMENT DISORDER SYMPOSIUM

"HOPE AND PROGRESS"

September 20, 2003 (Saturday) ~ 8:30 AM to 3:30 PM

Mile Hi Church Community Center ~ Lakewood, CO

SAVE THE DATE

Great News for SAT Takers With Special Accommodations

By: Susan Conners, M.Ed

SAT time for high school students looking forward to applying to colleges is one of the most stressful times in a young person's life. Students with TS and/or associated disorders are very much affected by the stress this creates and this will almost always result in worsening of symptoms of all their disorders. A large majority of these students are appropriately classified under IDEA and as a result receive testing accommodations that they desperately need to be able to achieve successful results on these tests. Up until the summer of 2002, these most needed accommodations have been a double edged sword because if a student received the accommodations needed, their test scores were flagged and weighted as such. I have met many a parent of a student with TS who has refused testing accommodations for their child for this very reason.

Scores in these cases were very rarely indicative of the child's innate ability and intelligence. Finally, the U.S. Department of Education has seen fit to eliminate this "flagging weighting" of accommodated SAT test scores. In doing so, they have finally acknowledged what so many of us have known all along, that learning disabilities do not define intelligence. What a tremendous coup for all learning-disabled students!! This country has been far above any other country in leveling the playing field for physically challenged individuals. We mandate handicapped accessibility in all public buildings, students with physical impairments are provided every opportunity to have their needs met and rightfully so, but students with learning disabilities who may have needed just a little extra time, a quiet location, a test recorder had to do so at the expense of their test results being thus highlighted.

SPECIAL SUPPORT GROUP SPEAKERS, PRESENTATIONS, AND EVENTS

Obsessive-Compulsive Disorder & Tourette Syndrome Spectrum Working with the Individual and the Family for better outcomes

Presenter: Dr. Rit Marifiote of the Family Social Learning Center
Tuesday, May 13th - 6:30 PM - 8:30 PM
 Swedish Medical Center - 2nd Floor Meeting Rooms - Denver
 Questions or RSVP: TSARMR Office: 303/832-4166

Tourette Syndrome Awareness Day - Longmont Recreation Center Recreation center activities, play, climbing wall, socializing - Free to TS parents and kids

Sunday, May 25th - 4:00 PM - 6:00 PM
 Longmont Recreation Center - Quail Campus
 310 Quail Rd., Longmont
 Questions or RSVP: Snow White-Wardell: 303/774-9657

Social & Emotional Issues of TS Spectrum Individuals Developing better relationships for you and your family

Presenter: James Petri, MA
Wednesday, May 28th - 6:30 PM - 8:30 PM
 Spirit of Peace Catholic Church
 1500 Hover Rd., Longmont
 Questions or RSVP: Snow White-Wardell: 303/774-9657

Tourette Syndrome Awareness Month: May 15 – June 15

The Lighter Side of TS

By: Tracy Fischer, Sr.

I recently had the "opportunity" to ride a public bus through town. Although my destination was on the edge of town, my through town trip was compliments of RTD. Whenever I ride the bus I always like to sit in front as close to the driver as possible and strike up a conversation to ease my boredom.

As we get to a major street the driver says the name of it into a microphone. "Broadway," says the driver, and about a second and a half later I hear from the back of the bus, "Broadway" in a voice and manner that emulated the driver beautifully. The bus was quite full and I could not tell where the echo came from so I simply dismissed it. A moment later the driver states "Lincoln" into the microphone and again I here "Lincoln" from the back of the bus. I dismissed this one also but after two or three more of these echoes I looked carefully around the bus, not to see who was doing it, rather to see if people were getting annoyed. No one seemed bothered or as if anything unusual was happening at all, but I figured this was simply politeness. The driver also seemed oblivious to the person that was mocking him from the back of the bus.

It so happened that I was on my way to a TSA-RMR Board meeting at Swedish Hospital and having been a member of the Board for many years, I not only knew what was truly happening but also that I was qualified to diagnose the situation and enlighten the driver. I waited until the bus emptied a bit and then leaned over and asked the driver if he were aware of the echo from the back of the bus and why it was happening? With annoying confidence the driver said, "Sure, I know exactly what it is." I asked him if it bothered him and he told me that it drives him crazy and he wished that the company would do something about it. That was it! I jumped on my soapbox and began my sermon. "The man doing this very likely has a neurological condition in which one of the symptoms is called "Echolalia", causing him to unwillingly repeat what he hears over the speaker and is in no way mocking you or doing anything facetious I said. And further more, I went on, the poor man has seated himself in the very back to do his best not to annoy you and avoid embarrassment, so don't you think that you could have a little understanding for him? A slight smile came over the driver's face and he looked at me and winked. In a kind voice he said, "Sir, I have full understanding of the situation as I told you before and it is you that does not understand." "Really", I said, "Then why don't you enlighten me?" In a mild and polite voice the driver said, "Sir, when I speak into this microphone, it goes on to a tape and then I press this button right here, [he showed me the button], and then it replays what I say on the speaker at the back of the bus."

"I know that, I was just kidding" I said, and I exited the bus and walked the rest of the way.



In their continued support of Colorado non-profit organizations, the Colorado Lottery is anticipating introducing a "Win! Win!" Scratch ticket. In addition to prizes offered,, the game will have a second-chance feature where Win! Win! Tickets can be mailed to the lottery for a second-chance drawing. The players who submit the tickets that are drawn will win a prize, as well as the non-profit listed on the back of the ticket.

The release of the Win! Win! Ticket is tentatively scheduled for November 2003. Information will also be posted on the Colorado Lottery website at www.coloradolottery.com

Work Place Giving Grants

TSA-RMR can only continue to operate and provide services through the generous support of individual and corporate donations. Your employer may donate to non-profit organizations; through matching employee donations, direct contributions or in-kind materials. Contact your HR department and ask what kind of giving program your company has. Then call Laurie Van Sickle at 303-988-3815 and she will do the rest!

Government Employees

If you are a federal, state, county or municipal employee, you can support the work of the TSA as part of your payroll deduction campaign. We are a qualified organization for all campaigns so choose to support TS. If TSA is not listed on your form, write it in and make a difference.

United Way

If you give to United Way, please write in Tourette Syndrome Assoc.-Rocky Mountain Region as your designated recipient. Also, you can request that TSA-RMR be a speaker at your Company's United Way meeting – we would love to present!!

Newsletter Schedule

May & Feb: General Information Issue
 Aug: Education Issue
 Nov: Medical Issue

Board Meeting Schedule

Monthly - 2nd Monday - Swedish Medical Center

Tourette Syndrome Fact:

TSA includes almost 7000 members, approximately 50 Chapters, and more than 300 Support Groups nationwide.

Reprinted from Tourette Syndrome Association, Inc. Website



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 and use your card.

If you do not have a card, call TSA-RMR today and ask to have cards sent to you today!

IMPORTANT NOTE:

BE AWARE WHEN USING YOUR ALBERTSON'S COMMUNITY CARDS DURING CHECKOUT THAT ALTHOUGH THE CHECKER SWIPES YOUR CARD, THE CARDS ARE NOT ALWAYS BEING "READ". ASK YOUR CHECKER TO CONFIRM THAT THE COMPUTER REGISTERED THE CARD SWIPE BEFORE YOU CLOSE OUT YOUR PAYMENT (THE RECEIPT SHOULD ALSO SHOW "COMMUNITY CARD" ON THE TOP).

The returns from Albertson have drastically declined and in checking why, the swiping error was discovered.

Actors Dreyfuss and Draper Call on Congress for Action on Tourette Syndrome; Children Affected by TS May Explain the Syndrome Best

DATELINE: Mar. 05, 2003; WASHINGTON, DC; INTERNET WIRE

The Tourette Syndrome Association (TSA) held a Congressional Luncheon yesterday to educate congressional members and their staff about a \$1.5 million appropriation in the Department of Health and Human Services Budget, for an education and research program on Tourette Syndrome (TS). Funding was authorized for the TS initiative under the Children's Health Act in 2000, but money has never been allocated. Actors Richard Dreyfuss and Polly Draper lent their voices to a line up of TSA members who placed their personal struggles with TS into context, for an audience of about 60.

"TS is the most common unknown disorder," said Fred Cook, president of the TSA board, "but the TSA is a place that all Americans can turn to when the disorder has been diagnosed." A neurological condition, TS is characterized by involuntary motor and vocal tics. Those affected by the syndrome often find themselves subject to societal misperceptions due to a lack of understanding about Tourette's.

"In just the past few minutes, members of this audience have learned more about TS than most medical staff know," said Dr. John Walkup of John Hopkins University. "TS has moved from a disease of the mind to a disease of the brain, and now we are seeing a whole shift in the research efforts related to the syndrome."

"Tourette's makes people make weird sounds and weird movements, but people with Tourette's are not weird," said Polly Draper of how her 7 year-old son matter-of-factly stopped two girls the same age from teasing him.

TS has become a personal mission for celebrities Draper and Dreyfuss.

Dreyfuss' godson, 15-year-old Jackson Kramer, later took to the microphone and relayed a compelling story. Growing up, Jackson wore kneepads to protect his joints from injury related to a motor tic that forced his knees to involuntarily bang together. "'Where are your skates?' people would always ask me," said Jackson. "'No skates,' I would reply, 'I just have TS.'"

The TSA Philosophy: Don't Follow Legislation, Shape it!

By Jeremy Scott, Government Relations Specialist – TSA

The introduction of new legislation can have a major impact on you and your family and your participation is crucial. This is why the Tourette Syndrome Association is pleased to introduce a new resource available online to its members – public policy information.

A recent Pew Internet and American Life Project study shows more Americans are going online, actively contacting their elected officials and seeking out government information, and TSA is a part of this growing trend. To help members become more personally involved in the political process, TSA has included on its Web site all the necessary tools and information to communicate effectively with your federally elected officials.

TSA PUBLIC POLICY SECTION INCLUDES:

- Government Relations Committee and Advocacy Statement
- TSA legislative priorities
- TSA position statements
- TSA advocacy statements
- Current legislation that affects TS
- Issues action alerts, where members can take action
- Congressional links

These tools enable members to educate themselves on issues important to TS; identify their federally elected Senators and Representatives; and communicate their views to their lawmakers. Please check the Web site frequently for updates and requests on how we can all work together to influence public policy. www.tsa-usa.org



CONGRATULATIONS JOSHUA!!!

Joshua Wardell (my son) received the Longmont Youth Asset Award, for being a positive and inspirational role model in our community. His father and I are very proud of him. He will design a tile to be added to the Youth Asset Award Wall at the Longmont Recreation Center. We hope it will be available for viewing during our Tourette Syndrome Awareness Community Day at the recreation center.

*Sincerely,
Snow & Jim Wardell (proud parents)*

Summer Camps for Kids with TS

TS Camp Organization – Chicago 773-465-7536
www.tourettecamp.com

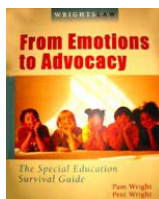
Camp Courage of Iowa – Monticello 319-465-5916

Other online resources:

www.aca-camps.org
www.camping.org
www.parentsoup.com
www.summertimecamp.org

Recommended Reading

From Emotions to Advocacy - The Special Education Survival Guide



(Wright & Wright)

This book is a practical "survival Guide" designed to teach you how to advocate for children with disabilities. Learn advocacy skills – how to organize, plan, present, and prepare. Learn how to organize the child's file, write SMART IEP goals and objectives, and measure progress objectively. Learn to create paper trails, write persuasive letters, and maintain control in school meetings. Includes worksheets, forms, sample letters.

"A superb reference, very highly recommended reading for all parents of children in need of adapted or special education services... Filled with tips, tricks, and techniques and an immense wealth of resources, from Internet sites and advocacy organizations to worksheets, forms, and sample letters." Midwest Book Review

"The Wright's have given families a clear roadmap to effective advocacy for their children. We award their work the Exceptional Parent Symbol of Excellence."

Phone today to order your copy, or fill out the publication order form and mail or fax to us.

SUPPORT GROUPS

Support Group Meetings Have Changed!

Meetings for the Longmont & Denver Area Family & Denver Men's group now meet Quarterly. Check Schedules & RSVP !!

Boise, Idaho

2nd Tues of Month: Meeting Time: 7:00-9:00pm
Location: St. Alphonsus Regional Medical Center.
Contact: Patti Guicheteau 208-345-7365; call for updates and information.

Denver, Colorado

**SPECIAL PRESENTATION: Dr. Rit Marifote
May 13, 2003** 6:30pm - 8:30pm
Swedish Medical Cnt - 501 E. Hampden - Aspen Rm
RSVP & Info: Call TSA-RMR 303-832-4166

Men Only Group

May 5, 2003 6:30-8:30pm
Swedish Medical Cnt - 501 E. Hampden - Aspen Rm
RSVP & Info: Call TSA-RMR 303-832-4166

SUMMER PICNIC - Potluck in the Park! August 10, 2003

Observatory Park. Look for more information in your summer Newsletter!

Longmont, Colorado

**SPECIAL PRESENTATION: Dr. James Petri
February 26 and May 22, 2003** 6:30-8:30pm
Spirit of Peace Church – 1500 Hover Rd, Longmont
RSVP: Contact, Snow Wardell 303-774-9657

Monument, Colorado

Twice per month – Friday's 10:00am-12:00pm at the Monument Library Call TSA-RMR for details.

Kalispell, Montana

Contact: Patricia DiStefano 406-755-8498 Informal discussion groups only--call for information.

Support group contacts have agreed to accept calls and assist in providing information, their comments reflect their personal background and experiences with TS and do not necessarily reflect the views of this chapter.

PUBLICATION ORDER FORM

Please return complete page with your check to:
TSA-RMR – 2020 South Oneida #19, Denver, CO 80224

Dysinhibition Syndrome (Wood & Comings) (Rage in adults/children)	\$25 x ___ = \$ _____
Tourette Syndrome & Human Behavior (Comings) softback	\$40 x ___ = \$ _____
Search for the TS & Human Behavior Genes (Comings)	\$30 x ___ = \$ _____
ADD Kaleidoscope-The Many Faces of Adult ADD (Comings)	\$25 x ___ = \$ _____
**From Emotions to Advocacy (Roadmap to services at schools)	\$30 x ___ = \$ _____
Ryan, A Mother's Story of Her Hyperactive/TS Child (Hughes)	\$10 x ___ = \$ _____
Hi, I'm Adam: A Child's Book of TS (Buehrens)	\$ 5 x ___ = \$ _____
Echolalia: An Adult's Story of TS (Seligman)	\$12 x ___ = \$ _____
Don't Think About Monkeys: Stories by People w/TS	\$13 x ___ = \$ _____
Adam & The Magic Marble (Buehrens)	\$ 7 x ___ = \$ _____
What Makes Ryan Tic? A Family's Triumph over TS & ADHD	\$15 x ___ = \$ _____
The Gene Bomb	\$25 x ___ = \$ _____
**Teaching The Tiger (TS/ADHD/OCD teaching techniques)	\$35 x ___ = \$ _____
Video - Twitch & Shout Documentary with TSA-RMR Panel	\$35 x ___ = \$ _____
Video - Bending the Rules - Parent's Guide-	\$10 x ___ = \$ _____
TS Identification Card	\$ 1 x ___ = \$ _____
<i>Add Postage & Handling (under \$25 = \$5.00, over \$25 = \$7.00)</i>	\$ _____
2003 Subscription to TSA-RMR Newsletter	
(includes one TSA-RMR T-Shirt Size _____)	\$ 25.00
Other Contribution Toward _____	\$ _____
Total Enclosed:	\$ _____



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

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