



NEWSLETTER - EDUCATION ISSUE

August, 2005

TSA-RMR

7476 East 29th Ave. #158
Denver, CO 80238
720-212-7535
tsarmr@att.net

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This Newsletter is dedicated to Educational matters including information for parents, caregivers and educators. Please share this with others who can benefit from the resources and information listed.

Chapter Changes

Snow White Wardell has stepped down as Executive Director of TSA-RMR. Snow states that she will continue to work on legislative and educational issues for the Chapter. The Board of Directors and members appreciate all the time and effort Snow has dedicated to TSA-RMR and thank her for her contribution. Because of this change, the office has moved back to Denver from Longmont. Please note the new address/phone:

7476 East 29th Ave. # 158, Denver 80238

Phone: 720-212-7535 (e-mail and website remain the same)

New Support Group in Las Vegas!

Las Vegas' first Support Group meeting will be Wednesday, 9/14/05 from 6:30 pm – 8:00 pm at the A.D.D. Clinic, 2373 Renaissance Drive-Las Vegas (Renaissance Center at NW corner of Tropicana & Easter) Contact: Kim Amato 702-877-1786 or 702-810-5180 – RSVP attendance.

Other Support Groups

Denver's next meeting is Wednesday, 8/24/05 from 6:30 pm – 8:30 pm at Observatory Park, Denver. Dr. George Dorry will facilitate a casual discussion group with the adults while the children play in the park. RSVP Loree Vanderhye 303-638-1504 or e-mail tsarmr@att.net.

Mom's Club – Denver, next meeting Thursday, 9/29 at 6:30 pm at The Palace Restaurant, Denver. RSVP to Loree Vanderhye 303-638-1504 or e-mail at tsarmr@att.net

Colorado Springs next meeting is Thursday of 10/20/05 from 7:00 pm – 8:30 PM at the NAMI Offices-510 E Willamette, Colorado Springs. Contacts Rachel Bolenbaugh 719-266-8477 or Jennifer Pearce 719-481-9716 for more information.

Refer to the Support Group section in this Newsletter and on our website for other location contacts.

Upcoming Events

Movement Disorder Symposium – 9/10/05 – New Hope Baptist Church, Denver

Characterizing Disruptive Behavior Patterns – 10/20/05 – Children's Hospital, Denver

Additional information inside ...

WISH LIST

Underwrite Library Materials for Support Groups \$500 each

*Quarterly Newsletters
Printing \$1,800, Postage \$1,200/yr*

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

Volunteers to work at Movement Disorder Symposium



6th Biennial
*Movement Disorder
 Symposium*

September 10, 2005 - 8:15 am – 4:30 pm
New Hope Baptists Church, 3701 Colorado Blvd, Denver

Welcome & Introductions ~ Brian Maass, CBS4 News

Genetic Evolution: The Increasing Role of Genes in the Search for Cures & Treatments ~ Johan Samanta, MD, MDS

Movement Disorder Treatments: Yesterday, Today, & Tomorrow ~ Jayaraman Rao, MD, MDS

The Promise of Translational Research ~ Chris O'Brien, MD, MDS

Caring & Coping - Susan Imke, RN

Change & Transitions – Independent Housing; Medical; Facility Placement ~ Joyce Sedam & Barbara Palmer

Making the Most of Medical Appointments ~ Pinky Agarwal, MD, MDS

Healthy Living through Nutrition & Diet ~ Colleen Gill, RD

Resource Panel ~ Jan Jerome, LCSW, Cari Friedman, LCSW, Maggie Byrnes, LCSW

Legal Issues (Wills/Trusts/Guardianships/Power of Attorney, Social Security) ~ Douglas Joffe, esq. & Ted Peak, esq.

Deep Brain Stimulation Surgery ~ John McVicker, MD, FACS

Movement Disorder Breakout Sessions (by disorder group)

This conference is designed for adults with movement disorders, parents, caregivers, medical professionals, and other interested parties. The event is presented through a partnership between:

Tourette Syndrome Association, Inc. - Rocky Mountain Region, Denver Dystonia Support Group, Huntington's Disease Society of America - Rocky Mountain Chapter, and Parkinson Association of the Rockies

Other Collaborating Organizations: Colorado Essential Tremor Support Group, Restless Legs Syndrome Support Group, The Society for Progressive Supranuclear Palsy

Registration Form

Cost Per Person:
In Advance: \$45.00 Day of Event: \$50.00

Total Charge: \$ _____
 (# Tickets _____ X \$ _____ Per Ticket)

Names of Attendees:

Credit Card Payment: Visa MC

Card # _____

or attach check payable to:

Movement Disorder Symposium

Name as it appears on card:

Exp.Date: _____

Phone # _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

E-Mail: _____

Please select the afternoon breakout sessions you plan to attend below:

Breakout Session # 1 1:30-2:45pm

- A: Emotional Health/Caring & Coping
 B: Changes & Transitions
 C: Productive Medical Appointments
 D: Nutrition/Diet/Speech/Swallowing
 E: Resource Panel
 F: Legal Issues
 G: Deep Brain Stimulation

Breakout Session # 2 3:15-4:15pm

- H. Dystonia
 I. Essential Tremor
 J. Huntington's Disease
 K. Parkinson's Disease
 L. Progressive Supranuclear Palsy
 M. Restless Legs Syndrome
 N. Tourette Syndrome

No confirmations will be sent unless requested Please call with questions or any special needs (303) 830-1839

Lunch Choice: Turkey Beef Ham Veggie

Certificate of Attendance Desired Yes No

Mail to: PAR, 1420 Ogden, Denver 80218
or call 303-830-1839

Tourette Syndrome Disorder

A genetic, neurological disorder characterized by tics – involuntary, rapid, sudden movements or vocalizations that occur repeatedly in the same way. Typically, tics increase as a result of tension or stress, and decrease with relaxation or when absorbed in certain tasks. Sometimes TS is referred to as the “just right” syndrome because people with TS have a need for the tic feel “just right” before the urge of the tic is satisfied. Symptoms include:

- Multiple motor and one or more vocal tics present at some time during the illness, not necessarily simultaneously;
- Occurrence of tics many times a day, nearly every day or intermittently;
- Periodic changes in the number, frequency, type, and location of the tics, and waxing and waning of their severity. Symptoms can sometimes disappear for weeks or months at a time.
- Onset before the age of 18.

Examples of tics:

Motor – Eye blinking, shoulder shrugging, facial grimacing, smelling of objects, twirling, touching, kicking, spitting
 Vocal – Throat clearing, yelping, sniffing, tongue clicking, uttering words or phrases, repeating words and phrases

The range of tics and symptoms are very broad. The complexities of some symptoms are often perplexing and difficult for people to believe that the actions or utterances are involuntary.

Fewer than 15% of people with TS have the symptoms of coprolalia and/or copropraxia; saying obscene words or making obscene gestures.

Tourette Syndrome Spectrum Disorder

- Tourette Syndrome: As described above
- Executive Dysfunctioning: Difficulties with the higher-order systems of the brain that activate, integrate, coordinate, and modulate a variety of other cognitive functions.
- Obsessive Compulsive Disorder (OCD): Obsessions are intrusive thoughts, images, or impulses that provoke anxiety and interfere with normal functioning. Compulsions are behaviors that are used to reduce the anxiety accompanying the obsessions.
- Attention Deficit Disorder (ADD or ADHD) with/without Hyperactivity: Difficulties in focusing, execution, sustaining, encoding, stability, impulsivity, and inattention.
- Phobia's & Panic Disorders: Phobia is an unrealistic fear of something encountered or anticipated. Panic Disorder strikes from nowhere, seemingly “out of the blue” and cause the individual to have sever fright.
- Mood Disorders – Depression & Bi-polar Disorders: Conditions that interfere with the ability to work, study, sleep, eat, and enjoy once pleasurable activities.
- Oppositional Defiant Disorder (ODD): A persistent pattern of negativistic, hostile, disobedient, and defiant behavior in a child or teen without serious violation of the basic rights of others.
- Nonverbal Learning Disabilities & Asperger's Disorder (NVLD & AD): Language fully in tact but an imbalance in thinking, impairment in social interaction, restricted, repetitive patterns of behavior and interests.
- Learning Disabilities: A disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations.
- Sensory Integration: Ability to take in, sort out, and connect information from the world around us.

Rarely are services requested solely for TS. TSA-RMR, physicians and clinicians who consult with individuals and their families who have TS, are generally contacted, when one or more of the complicating associated disorders described here surface and interfere. It is no wonder that educators struggle to understand students who have been diagnosed with TS. Educators may have some knowledge of TS and tics, but not understand how intertwined and complex the TS Spectrum Disorder can be and the difficulties the individual with TS Spectrum Disorder may be having.

Discipline for Children With Disabilities: Questions & Answers from OSEP (Federal Office of Special Education Programs)

Answers to Questions About Discipline Under IDEA

This ideaQUESTS document was prepared by OSEP, and was excerpted from the Final Regulations posted in the Federal Register on March 12, 1999.

Does IDEA contain provisions that promote proactive up-front measures that will help prevent discipline problems?

Yes. Research has shown that if teachers and other school personnel have the knowledge and expertise to provide appropriate behavioral interventions, future behavior problems can be greatly diminished if not totally avoided. Appropriate staff development activities and improved pre-service training programs at the university level with emphasis in the area of early identification of reading and behavior problems and appropriate interventions can help to ensure that regular and special education teachers and other school personnel have the needed knowledge and skills.

Changes in the IDEA emphasize the need of State and local educational agencies to work to ensure that superintendents, principals, teachers and other school personnel are equipped with the knowledge and skills that will enable them to appropriately address behavior problems when they occur.

In addition, the IDEA includes provisions that focus on individual children. If a child has behavior problems that interfere with his or her learning or the learning of others, the IEP team must consider whether strategies, including positive behavioral interventions, strategies, and supports are needed to address the behavior. If the IEP team determines that such services are needed, they must be added to the IEP and must be provided. The Department has supported a number of activities such as training institutes, conferences, clearinghouses and other technical assistance and research activities on this topic to help school personnel appropriately address behavioral concerns for children with disabilities.

Vibrating Watches Help Some People with TS

Rather than a teacher reminding the student with TS to "get back on task", check out the vibrating, pulsating or beeping watches, set to your intervals or with your reminder messages. This could be useful for adults as well as children.

Here is one source, there may be many more;
<http://www.epill.com/vibration.html>

TSA-RMR website:

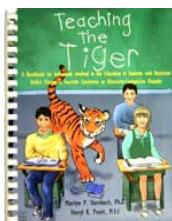
<http://www.sensiblenet.com/tsa/>

TSA – National website:

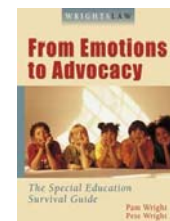
www.tsa-usa.org

Legislative Information:

www.ourchildrenleftbehind.com



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 – 720-212-7535.*

New TS Publications

TSA is pleased to announce publication of two long-awaited print resources, both of which should prove to be extremely valuable to Educators and all who seek understanding and practical information about educating children with TS and related disabilities.

The first, a ***Catalog of Accommodations for Students with Tourette Syndrome, Attention Deficit Hyperactivity Disorder and Obsessive Compulsive Disorder*** (publication ***E125***, or downloadable publication ***E125DD***). It was written by Susan Conners, TSA's Education Specialist, in response to requests from very dedicated teachers who really wanted to help kids with significant symptoms...beyond those addressed in "routine" or basic training programs. It addresses ways complex symptoms can be managed in class, and may help reduce the need to place children out of their classes.

A ***Workbook for Conducting a Functional Behavioral Assessment and Writing a Positive Behavior Intervention Plan for a Student with Tourette Syndrome*** (publication ***E126***, or downloadable publication ***E126DD***) Written by Susan Conners, TSA's Education Specialist with Kathy Giordano, TSA's Advocacy Specialist, gives a progressive, state of the art method for the analysis of behavioral matters. It helps parents, teachers, and team address the identification and management of behavior and symptoms in a systemic way. The material includes not only an overview of the FBA process, but FBA Worksheets, a Positive Behavior Intervention Plan Worksheet and a great deal of practical and useful anecdotal material addressing complex behavioral issues.

Both of these publications are available through our online [catalog](#) of publications (in the Education category), by mail order or for download – go to www.tsa-usa.org. Publications may also be ordered by telephoning TSA at 718-224-2999.

CHARACTERIZING PATTERNS OF DISRUPTIVE BEHAVIOR SEMINAR

The Children's Hospital
Long's Peak Room, Denver

Thursday, October 20, 2005 ~ 8:30 am to 4:30 pm

Educational seminar for school nurses, medical personnel, educators, parents and other adults interested in the subject matter. Topics include:

- Definition of Clinical Pathology "What Do These Kids Look Like"
- ADHD, Tics & ODD Manifested as Disruptive Behavior
- Self Control & Executive Functions
- Anxiety Disorders Manifested as Disruptive Behavior (generalized, socialized anxiety, OCD)
- Mood Disorders (including explosive anger)
- Social Skills Deficits (including non-verbal learning disabilities, Asperger's, Autism, Tourette spectrum)
- Treatments & Interventions (including pharmacology, behavior management techniques, environmental milieu, management strategies)

REGISTRATION

\$75.00 Each Person

Continuing Education Credits Issued

Names of Attendees:

Address: _____

Phone # _____

E-Mail: _____

Lunch Choice: Turkey Beef Ham Veggie

*Clip and mail this form with your
check payable to*

TSA-RMR
7476 East 29th Ave. #158, Denver
80238 Phone: 720-212-7535

Nonverbal Learning Disabilities (NVLD)

A: NVLD can be conceptualized as an imbalance in thinking skills – intact linear, detail oriented, automatic processing with impaired appreciation of the big picture, gestalt or underlying theme.

B: It is not nearly as common as language-based learning disabilities, but this may be a phenomenon created by environmental demands (i.e., our societal demands for precision skills in reading assure that even the most subtle language-based LD cases are identified).

C: Typically social/psychiatric concerns are raised before academic problems are identified.

D: While the overlap is not complete, NVLD children may meet the criteria for Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), Asperger's Disorder, or Schizotypal Personality.

Asperger's Disorder (AD):

Language skills are fully intact.

A: Qualitative impairment in social interaction, including:

1. Failure to use non-verbal social skills (i.e. eye contact, gestures, body posture, facial expressions).
2. Developmentally inappropriate peer relationships.
3. Lack of spontaneous sharing of enjoyment and interests with other people.
4. Lack of social and emotional reciprocity.

B: Restricted, repetitive and stereotyped patterns of behavior, interests, and activities:

1. Preoccupation that is overly intense and narrow.
2. Inflexible adherence to non-functional or peripheral routines.
3. Stereotypic or repetitive motor movements.
4. Persistent preoccupation with parts of objects.

These problems taken together (A plus B) present significant challenges in the lives of people with AD as they attempt to live in a "neurotypical" world and meet the expectations of others. There is no general language delay. There is no severe global cognitive impairment.

Suggestibility & Perseveration . . .

During a recent school and family advocacy presentation, a striking example occurred of how highly sensitive individuals with TS are to suggestion and perseveration.

Mark (not his real name) is 16 and struggles with all the complexities of TS, OCD, ODD, ADD and much more. Mark's TS is quite severe and currently includes coprolalia and spitting. The advocacy covered the normal TSA-RMR program but was geared to Mark's needs and included showing the video "Twitch & Shout".

Mark was in and out of the room during the program, wanting to be there, but stressed to the max with the situation. While in the room during part of the video, Mark became highly stimulated by some of the individuals with TS shown in the film. During the viewing, Mark's coprolalia and spitting became uncontrollable, and when certain individuals in the video would reappear, and before they said or did anything, Mark immediately began ticcing. It seemed the mental suggestion of what was to come caused Mark's tic's to become intense. It also appeared that Mark perseverated on the situation, and trying not to tic only made the situation worse.

Fortunately, we were able to review and discuss what had just been witnessed. The experience seemed to explain what had happened to Mark in his previous school environments; when he would see certain people or enter a classroom expecting certain people, his tics would increase. The school director had described Mark's TS attacks as directed at certain people and situations. In the Director's opinion, Mark's behavior was intentional, purposeful, and had nothing to do with TS and in fact was bad behavior! At the conclusion of the program, many of the people present had a better understanding of Mark and how he struggled every minute of every day. As always, it is extremely difficult for "non TS" people to really understand and believe the complexities of TS, but I feel we had a positive impact in this situation.

Support Group Contacts & Schedules

Denver: Wednesday, 8/24/05 - 6:30 pm – 8:30 pm Observatory Park- btwn Evans & Warren / Milwaukee & St. Paul RSVP to Loree Vanderhye 720-212-7535 or tsarmr@att.net (meet at tables near swings/climbing bars/basketball)

Denver - Mom's Club: Thursday, 9/29 at 6:30 pm at The Palace Restaurant, 6265 East Evans, Denver. RSVP to Loree Vanderhye 720-212-7535 or e-mail at tsarmr@att.net

Colorado Springs: 3rd Thursday of each Month beginning 10/20/05 from 7:00 pm – 8:30 PM Meeting: NAMI Offices-510 E Willamette - Contact: Rachel Bolenbaugh 719-266-8477 tsacospgs@bolenbaugh.net

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

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

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

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

Las Vegas: 2nd Wednesday of each Month beginning 9/14/05 from 6:30 pm – 8:00 pm Meeting Location: A.D.D. Clinic, 2373 Renaissance Drive-Las Vegas (Renaissance Center at NW corner of Tropicana & Easter) Contact: Kim Amato 702-877-1786 or 702-810-5180 – RSVP attendance

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.

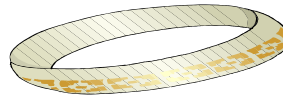
DESIGNATE TSA-RMR ON YOUR UNITED WAY CONTRIBUTION FORM

Write in Tourette Syndrome-Rocky Mountain Region 720-212-7535
on the form in "other" category

A GIANT THANK YOU to those who already do this!



IT IS HERE!



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**
We are looking for sponsors to help us purchase the bracelets.
If you want more information, contact the TSA-RMR office
720-212-7535 or email: tsarmr@att.net

Return Address

Stamp