



NEWSLETTER ~ MEDICAL ISSUE

November, 2002

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Announcements!

This issue is dedicated to Medical Issues concerning Tourette Syndrome and Spectrum Disorders. Please share this Newsletter with your medical providers or contact TSA-RMR and ask to have one sent directly to your providers. A Medical Issue will be produced once per year and will include summaries of new and important information. If you have questions that you would like addressed by our Medical Professionals, please forward the questions to TSA-RMR either by mail, fax or e-mail and the Medical Group will attempt to respond. Questions and answers may be included in the general Newsletters as well as the Medical Issue. We will also post information on our website. So, send your questions to TSA-RMR as they come up and we will attempt to provide responses.

Our Chapter continues to grow in member needs and Chapter services. As with our Newsletter format, which now consists of four issues; two general, one education and one medical; we are making changes in our schedules and services for 2003. It is TSA-RMR's goal to provide members the support and services that are wanted and needed, and at the same time, improve member attendance and involvement in TSA-RMR activities. Please check the schedule carefully so you know what is happening and put these valuable programs on your calendars. See page 4.

We are extremely pleased to announce that TSA-RMR received notice that we have been awarded an important Grant from Colorado Department of Education. Our Grant, titled "The Reaching & Teaching Program", consists of training material and video about TS Spectrum Disorder. The Program is on compact disc for easy sharing among schools and families. The Program also includes various follow up material and communication from TSA-RMR throughout the Grant year. The Program will be provided to each school District Director of Special Education and each BOCES in the State of Colorado. Parents and teachers will be able to request the material from the District Director for their independent use as well as training at each school. It is critical that TS parents become active in requesting this material and referring their local teachers to the material. Please share those requests with TSA-RMR so the required Grant documentation can be maintained. This is an important first step in advancing the awareness, acceptance and understanding of TS in Colorado schools. Please help keep this information alive and referenced.

I had the pleasure of attending the TSA National Conference & Presidents Meeting Oct. 30 through Nov. 4, 2002 in Alexandria, VA. It was a wonderful event with excellent speakers and training sessions. Dr. Oliver Sacks (author of "Awakenings", "The Man Who Mistook His Wife For A Hat", to name two), warmed the hearts and minds of everyone with his personal stories and experiences from working with TS individuals over his lifetime. Dr. Ross Green (author of "The Explosive Child") gave hope, ideas and promise to those struggling with explosive children. There were so many wonderful speakers, experiences and so much information available that can't be addressed here because of time and space. Watch for the TSA National Newsletter (if you are a member) for more details.

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Snow Wardell, TSA-RMR Longmont Support Group Leader, also attended the Conference and represented TSA-RMR with our legislators in the four states, as part of a TS visit to "The Hill". In addition, she attended as many programs and presentations as possible. Snow came back to Colorado completely recharged (and somewhat exhausted) as did I. I understand that the next Conference will be held in April-June 2004 timeframe, to allow for better legislative contacts and better weather. I encourage every member, teachers, and medical providers to begin planning now to attend the next conference.

Soon, you will be receiving the TSA-RMR annual local donation card for 2003. Please return the card with your gift to help support the services of this local Chapter. Include any personal updated information such as e-mail addresses, phone numbers, corrections, etc. We are finalizing our new database and receiving accurate information will help us deliver services to you.

Plan now to attend the Movement Disorder Symposium, September 20, 2003 in Denver. This event co-sponsored by Tourette's, Parkinson's, Dystonia & Huntington's, is the only symposium of its kind in the US. Exceptional speakers and workshops are planned. More information will follow in the next few months; get it on your calendar!

Have a wonderful holiday season and we look forward to serving you in 2003! Stay connected and involved with TSA-RMR.

Loree Vanderhye, President

SPOTLIGHT BOOKS OF THE QUARTER

IF YOU HAVE CHILDREN IN SCHOOL - THESE BOOKS ARE A MUST HAVE

**** From Emotions to Advocacy-Wrightslaw:** An excellent and practical "survival guide" that teaches parents and others how to advocate in schools for children with disabilities. You will learn what to expect, how to deal with situations that come up at school, your rights, and how to get the results you want. **In Stock at TSA-RMR – Order Today**

**** Teaching the Tiger:** While other books on these conditions help us to understand the clinical aspects, neurochemistry, genetics and medical treatment of these disorders, **Teaching the Tiger** is uniquely designed to help teachers, parents, students, and relatives maximize the educational plans necessary to help these children. An understanding teacher and an appropriately designed educational plan is a critical part of treating all of these children. **In Stock at TSA-RMR – Order Today**

Newsletter Schedule

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

Board Meeting Schedule

2nd Monday of each month at Swedish Medical Center

THE CLINICAL SPECTRUM OF MOTOR TIC DISORDERS

A recent study of a community sample of 550 elementary aged children (kindergarten thru sixth grade) helps to elucidate the high prevalence of tic disorders in the general population (L.A. Snider, et. al., Pediatrics 110:331, Aug 2002). The researchers observed the children in their classrooms on a monthly basis over an eight-month time frame. Motor tics (vocal tics were not looked for) were observed in a whopping 24% of children on at least one occasion during the eight months of the study. Eighteen percent of all the children had "isolated", transient tics lasting less than three months in duration, and 6% had more "persistent" tics, defined as being observed for longer than a three month period of time. Within the "persistent" group, 25% (1.3% of the entire sample) displayed a "chronic", continuous pattern of ticking over at least 4 months, and 75% (4.8% of the entire sample) of the "persistent" group had a more "episodic", waxing and waning of tics over the duration of the study. Interestingly, the "persistent" group, but not the "isolated" group, displayed significant behavior problems, particularly noticeable in the children with the more "episodic" course, and during the times of their tic flare-ups. The presence of non-facial tics tended to predict a more "persistent" course. Amongst the children with "isolated" tics, the ratio of boys to girls was 2:1, but within the "persistent" group, the ratio of boys to girls was 7.5:1.

One additional, interesting finding was that 75% of all tics occurred in the winter months from November thru February, and only 25% occurred in the period from March thru June. The authors wondered if the winter increase might be related to the increased frequency of upper respiratory infectious illnesses, including Streptococcal Pharyngitis, all of which are known to be more prevalent in winter months.

Certainly, only a very small percentage of children who display tics will go on to have chronic tic disorders like Tourette Syndrome.

TSA-RMR BOARD POSITION OPENINGS

TSA-RMR is accepting nominations for Board Positions for the 2003-2005 term. If you are interested in applying or would like to nominate someone that you feel can contribute, please send a letter of intent and resume to the TSA-RMR office by 1/3/03.

THE 2002 ELECTION WHAT DOES IT MEAN TO TSA?

Excerpt from: Jeremy Scott, Government Relations Specialist-TSA

Governance in 2003 is likely to be marked by continued partisan finger-pointing of the past, making bi-partisan and flexible strategies even more critical. But in the end, President Bush and the Republicans will be operating under a clear voting majority. In this environment it is more important than ever to reach out to your elected officials to educate them about TS. Tell them your personal stories about TS and how the legislation they pass affects you and your family. Remember, advocating advances your cause and builds public trust – policymakers need your expertise.

Call today for your Albertson's Community Partners Card
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!

Ask the Physician

Comments by R. Barkley Clark, M.D., TSA-RMR Board Member & Chair of Professional Outreach Committee.
Dr. Clark is a Psychiatrist in private practice in Denver.

Q: Is Tourette's a neurological/medical disorder OR is it a psychological/behavioral disorder?

A: The simple, and yet very complicated, answer is that Tourette's is BOTH. Tourette's is the prototypical example of a NEUROPSYCHIATRIC DISORDER, meaning that its primary underlying cause is rooted in abnormal brain function, but some of its most troublesome symptoms are emotional and/or behavioral, and life experiences can modify the symptoms of the disorder, for better or for worse.

Q: Is there a "core problem" in Tourette's?

A: Yes, the theme of dealing with "INHIBITING URGES" is a common part of the struggle with Tourette's. Whether it is the urge to move a muscle or perform an action, to make a sound or even speak a phrase or an obscenity, to perform a compulsive ritual in response to a bothersome thought, or to act impulsively without pausing to think sufficiently about the consequences, all can be a part of Tourette's. The ultimate treatment challenge is to either lessen the intensity of the urges, and/or increase the ability to inhibit the action that follows the urge. Real life analogies include inhibiting an itch or squelching a sneeze; they are tough.

Q: What are the cornerstones of treatment for Tourette's?

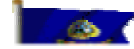
A: Threefold...first and foremost, ongoing education about the nature of the disorder, so that ignorance does not unnecessarily promote shame in the child, and interpersonal conflict between adult caretakers and the child; second, skill building in the areas of self esteem, self control, and stress management; and third, medicine, if needed, to diminish urges and/or enhance the ability to inhibit action.

SUPPORT GROUP



Support Group Meetings Have Changed!

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



Boise, Idaho

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



Colorado

Denver

Special Speakers & Presentations Family Support Group

February 11 and May 13, 2003

6:30pm - 8:30pm

Swedish Medical Center - 501 E. Hampden - Aspen Room

RSVP & Info: Call TSA-RMR 303-832-4166

Men Only Group

Special Speaker & Presentations

February 25 and May 5, 2003

6:30-8:30pm

Swedish Medical Center - 501 E. Hampden - Aspen Room

RSVP & Info: Call TSA-RMR 303-832-4166

Family Support and Men's Group Joint Pot-Luck in the Park! August 10, 2003!

Observatory Park.

Look for more information in your summer Newsletter!

Longmont

Special Speakers & Presentations

Family Support Group

February 26 and May 22

6:30-8:30pm

Spirit of Peace Church – 1500 Hover Road, Longmont, CO

RSVP: Contact, Snow Wardell 303-774-9657

Monument

Twice per month – Friday's 10:00am-12:00pm at the

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. 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.

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.

IS THERE AN ASSOCIATION OF STREPTOCOCCUS WITH TICS & OCD?

The issue of so-called Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infections (PANDAS) has been a hot topic of research in the last ten years. This line of research has stemmed from the well-known association of anti-Beta-hemolytic streptococcal antibodies with the occurrence of Sydenham's Chorea in some children with late occurring sequellae to Acute Rheumatic Fever and previous infection with Group A Beta-hemolytic streptococci (GABHS). When careful clinical observations were made of children with Sydenham's, a significant percentage were found to have "adventitious" tic-like movements, and/or obsessional worries and even compulsive, ritualized behaviors. Subsequent research, primarily at the National Institutes of Health under the direction of Susan Swedo, M.D., has defined a significant minority of children with tics and/or Obsessive Compulsive Disorder (OCD) who seem to have symptoms brought on by, or acutely worsened by, GABHS throat infections, the so-called group of children with PANDAS (S.E. Swedo, et. al., Am. J. Psychiatry 155:264, 1998).

Dr. Swedo's work has elucidated the clinical presentation of these children. They are typically young (often less than 6 or 7 years old at onset of symptoms), have a very abrupt onset to, or very abrupt worsening of, their tics and/or OCD, have a rather episodic course to their symptoms with periods of marked worsening and periods of substantial improvement, all associated with the presence of GABHS Pharyngitis, as evidenced by either positive throat cultures and/or serologic evidence of infection with GABHS. Another very interesting aspect of these children is their tendency to display a variety of other associated neuropsychiatric symptoms during the periods when their tics and/or OCD flare-up, including moodiness, anxiety symptoms, sleep disturbances, enuresis, and symptoms that for all the world look like Attention Deficit Hyperactivity Disorder; these associated symptoms tend to remit when the tics and/or OCD symptoms remit. Of great interest is the first preliminary report of a small group of children with PANDAS for whom treatment of an acute exacerbation of symptoms with anti streptococcal antibiotics reduced the morbidity of their symptoms (M.L.Murphy, Arch Ped Adol Med, 156:356, 2002).

At the present time, no one knows how frequently PANDAS occurs within a population of children with tics and/or OCD, but the research to date would suggest that the prudent approach would be to obtain throat cultures and serial Antistreptolysin O (ASO) titers or Antistrep DNAase B titers in any child with either an early age of onset of tics and/or OCD, a "saw-tooth"/episodic course to the child's symptoms, a history of acute exacerbations of symptoms within the context a febrile illness and/or pharyngitis, and especially if there appears to be associated, episodic changes in mood, anxiety levels, sleep, and/or disruptive behavior. Children with evidence of GABHS infection in association with an exacerbation of either tics and/or OCD should then be treated with a full course of antibiotics to eradicate GABHS as the initial part of any more traditional treatment protocol for tics or OCD.

UPDATE ON MEDICAL TREATMENTS FOR TOURETTE ASSOCIATED SYMPTOMS

In October 2002, the American Academy of Child and Adolescent Psychiatry held its Annual Scientific Meeting. Dr. Larry Scahill of the Yale Child Study Center provided a wonderful review of the latest medical treatments for Tourette's Disorder. Highlights from his review follow:

GENERAL: As always with Tourette Syndrome, medical treatments need to be focused at specific target symptoms that cause sufficient disability and/or distress to warrant a medical intervention. Typical Tourette associated target symptoms might include tics, Attention Deficit Hyperactivity Disorder (ADHD), obsessive compulsive symptoms, mood and/or anxiety symptoms, disruptive behavior, and difficulties with anger management. Each targeted symptom should be rated at baseline for frequency, intensity, and levels of subjective distress, and then ratings tracked over time with treatment interventions to determine "costs vs. benefits". For most targeted symptoms, a 30% to 50% improvement is considered significant.

TICS: The mainstays of treatment for the suppression of motor and vocal tics continue to be the dopamine-2 blockers for moderate to severe tics, and the alpha adrenergic agonists for mild to moderate tics. There are now three controlled studies that support the use of the "atypical" neuroleptics risperidone [1-3.5 mg/d divided bid (Scahill 2002 & Dion)] and ziprasidone [20-40 mg/d divided bid (Sallee)], with an expected level of symptom improvement in the 35-50% range. Because of a more favorable side effect profile (particularly, a lower incidence of short and long term extra pyramidal side effects), the "atypical" agents are now more favorably accepted by both patients and physicians than the older "typical" neuroleptics, particularly haloperidol and pimozide, the latter two of which were seen as the "gold standards" for tic suppression for many years.

In addition, controlled studies support the alpha-adrenergic agonists clonidine [0.1-0.3 mg/d divided t-qid (TS Study Group)] and guanfacine [1-4 mg/d divided b-tid (Scahill 2001)] for mild to moderate tics, with an expected level of symptom improvement in the 30-35% range.

Recent, small, controlled studies also suggest that desipramine (Spencer), pergolide (Gilbert), and baclofen (Scahill 2002) have significant tic suppressing properties, but mecamlamine and nicotine patches do not (Scahill 2002).

ADHD: Various combinations of impulsive behavior, attentional problems, and low frustration tolerance can result in very significant disability in 50-60% of patients with chronic tic disorders, such as Tourette Syndrome. For years, psychostimulant medications were "forbidden" in patients with ADHD and tics (or even in patients with family histories of tic disorders) for fear that psychostimulants "caused" tics to appear and even persist over time. There is now controlled evidence to suggest that many patients with tics and ADHD can effectively be treated for ADHD with the standard psychostimulant medications (i.e. dextroamphetamine and methylphenidate containing compounds) without aggravating their tic disorders, either in the short term or over the long term (T S Study Group & Gadow). When and if tics do flare up with exposure to a psychostimulant (in perhaps 20-40% of patients), the tics can be expected to return to previous baseline levels upon withdrawal of the offending medication. There is also some evidence to suggest that pre-treatment of patients with alpha adrenergic agonists before cautiously, slowly introducing the psychostimulant will allow an even greater number of patients to benefit without the aggravation of tics. The bottom line is that, for many patients, psychostimulant remain the "gold standard" of treatment for ADHD, even in the presence of tics (up to 80% of patients with ADHD respond favorably to one or another psychostimulant).

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Treatments - continued from page 6

When psychostimulant are not tolerated, controlled studies support the effectiveness of non-stimulant treatments for ADHD in the presence of tics, but with treatment efficacy generally in the range of 50-70%. Evidence supports tricyclic antidepressants (Spencer), bupropion, clonidine (T S Study Group), and guanfacine (Scahill 2001) as second line therapeutic agents.

In addition, great interest is being expressed about the pending FDA approval in 2003 of atomoxetine, a non-stimulant, nor epinephrine reuptake inhibitor that has already been tested in some 3,000 patients with ADHD (AACAP Meeting 2002). Single morning doses of 1.2 mg/kg/d were significantly effective in reducing all ADHD symptoms and improving social and family functioning, with treatment effectiveness just beneath the treatment effectiveness of psychostimulants, and generally above the effectiveness of the current second line medications for ADHD. So far, atomoxetine does not appear to aggravate tics.

References for this Medical Treatments Update

- Dion, Y., et al., J Clin Psychopharm., 22:31, 2002
 Gadow, K., et al., Arch Gen Psychiatry, 56:330, 1999
 Gilbert, D., et al., Neurology, 54:1310, 2000
 Sallee, F., et al., JAACAO, 39:292, 2000
 Scahill, L., et al., presented at AACAP, San Francisco, Oct. 2002
 Scahill, L., et al., Am J Psychiatry, 158:1067, 2001
 Spencer, T., et al., Arch Gen Psychiatry, 59:649, 2002
 TS Study Group, Neurology, 58:527, 2002

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 surface and interfere. It is no wonder that providers and educators struggle to understand individuals who have been diagnosed with TS Spectrum Disorder. 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 the Disorder may be having. It is our responsibility to inform and educate the public about this complex neurological disorder.

TS IN THE NEWS

The Longmont Police Department received a presentation on TS and 50 copies of "Recognizing Special Needs: A Police Officer's Field Guide to Selected Disabilities". Snow Wardell, TSA-RMR Longmont Support Group Leader presented the information to the Police Department and found them to be very interested and appreciative. In fact, Commander Tom Ericson said "they plan to purchase more booklets so they can have one in the hands of every police officer". Joe Southern of the Longmont Daily Times also attended the presentation and wrote an article in The Daily Times. A special thank you to Snow for her determination and commitment to this special project.

We need this information at every police department in every state!

TAX DEDUCTIBLE! I want to make a 100% tax deductible gift to help TSA- RMR, a 501©(3) organization, create awareness, understanding and acceptance of this complex, bio-neurological disorder.

\$25 \$50 \$75 \$100 \$250 \$500 *Make checks payable to TSA-RMR*

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Please notify the following person of my gift: Name: _____

Address: _____ City: _____ State _____ Zip: _____

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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	\$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	\$35 x ___ =	\$ _____
Handbook of Rights to Special Education in Colo.(Legal Ctr)	\$10 x ___ =	\$ _____
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TS Identification Card	\$ 1 x ___ =	\$ _____
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