



NEWSLETTER - MEDICAL ISSUE

Winter, 2006

TSA-RMR

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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

This Newsletter includes the latest medication list and other medical information for your reference. Please share this with your medical professionals and others who can benefit from the resources and information listed.

On October 20th, 2005, TSA-RMR in collaboration with CO Department of Education presented the "Patterns of Disruptive Behavior-New Perspectives" Conference at Denver Children's Hospital. The conference was a great success with 105 participants from the education, special education and medical communities. Judy Harrigan facilitated the event and the speakers included; Dr. Barkley Clark, Dr. George Dorry, Dr. Kathy Culhane-Shelburne, Dr. Carol Tierney, Dr. Ron Rabin, Lauren Kerstein, LCSW, Molly Cullom, MSCW, Margaret Wilson, and Georgia Harland. None of this could have been accomplished without the organization and planning of Judy Harrigan and Dr. Barkley Clark. Conference attendees stated that this was one of the best conferences they had attended on complex disorders and the behaviors associated with them. Attendees asked that we repeat it at least annually and we hope to do just that!

We are very pleased to introduce members to Mollie Cullom who joined the TSA-RMR Board and became Chair of the Legislative Committee in September. Mollie is a social worker at Cherry Creek Schools, a member of the "Parent Partnership" task force, serves on a Smokey Hill High School feeder area task force for prevention of gang involvement/violence, and is a member of the Renaissance School's Accountability Committee. Additionally, Mollie was a candidate for Colorado House District 39 and will run again in 2006. Mollie brings tremendous background and skills to our organization and we look forward to her involvement with TSA-RMR.

The documentary "I Have Tourette's But Tourette's Doesn't Have Me" debuted on HBO November 12th. The documentary stirred great interest in the media with several news and talk shows interviewing individuals with TS. The exposure has created renewed interest and awareness of TS around the U.S.A. This Chapter has received many calls from families who watched one of the broadcasts only to recognize the symptoms in their own children. Those parents called for support and information including medical referrals for their children. There will be a special showing of this documentary along with professional panel discussion, and support group in Denver, Saturday, March 11, 2006, from 1-5:00 PM. Denver Academy has graciously offered their facilities for this event. They are located at 4100 E. Iliff, 2 blocks east of Colorado Blvd. The event is open to the public and we encourage you to invite your friends, family, educators, and other interested people. A medical panel will discuss TS+ and answer questions and a separate support group-break out area will be provided for children with TS to talk and play. IMPORTANT - PLEASE RSVP - 720-212-7535!!!

CHAPTER SPECIAL EVENTS

COLORADO: Denver Saturday, March 11th ~ 1:00 ~ 5:00 PM
 Denver Academy ~ 4100 E. Iliff Ave, Denver
 Network, support, medical interaction, and showing of the
 documentary; "I Have TS But TS Doesn't Have Me".
 RSVP 720-212-7535 or e-mail tsarmr@att.net

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 Contact Patti Guicheteau at 208-345-7365

MONTANA: Billings: A medical Grand Round presentation on Tourette
 Syndrome will be held at St. Vincent's Healthcare in Billings,
 MT from 12-1:00 pm on June 8, 2006. A support group
 meeting will be schedule on either 6/7 or 6/8.
 Please RSVP at 720-212-7525 and for additional information.

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 vcook@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

MEDICATIONS PRIMARILY FOR TREATMENT OF TICS

9-2005

Medication Class	Generic Name	Brand Name	Usual Daily Dosage Range	More Frequent Side Effects	Additional Notes
Alpha Adrenergic Agonist	Clonidine	Catapres	0.05 – 0.5mg	Sedation, irritability, dizziness, headache, early AM awaking	May have efficacy across a broad spectrum of TS associated symptoms beyond tics; often need 3-4 doses per day; can be helpful for delayed sleep onset
	Clonidine Skin Patch	Catapres TTS-1, 2, or 3	Patch changed every 5 days	Same as above, plus local skin rash under patch	Simplifies life, if rash does not develop
	Guanfacine	Tenex	0.5 – 5.0 mg	Sedation, irritability, dizziness, headache	Compared to clonidine, less sedating, and only 2-3 doses per day
<u>Second Generation (“Atypical”) Antipsychotics</u>	Risperidone (RIS)	Risperdal	0.25 – 4.0 mg	Sedation, weight gain, neuromuscular symptoms, blood sugar and/or lipid problems, hormonal changes (inc. breast engorgement)	“Atypicals” are primarily for tics, but can also help emotional instability and anger/aggression. “Atypicals” have less risk of tardive dyskinesia than neuroleptics.
	Olanzapine	Zyprexa	2.5 – 30mg	Same as RIS, but without breast changes	An effective medicine, but big problems with weight gain
	Ziprazidone (ZIP)	Geodon	20 – 240 mg	Initial agitation at lower doses, sedation, neuromuscular symptoms, EKG changes, no breast changes	Same as RIS, but does <u>not</u> usually cause significant weight gain! EKG needs to be monitored.
	Quetiapine	Seroquel	25 – 800 mg	Same as RIS, but less weight gain, and no breast changes	Helpful for sleep
Third Generation Antipsychotics	Aripiprazole	Abilify	2.5 – 30 mg	Initial restlessness/agitation	Like ZIP, less weight gain, and fewer metabolic and neuromuscular problems
<u>First Generation Antipsychotics (Neuroleptics)</u>	Haloperidol	Haldol	0.25 – 10mg	Sedation, weight gain, neuromuscular symptoms, tardive dyskinesia, hormonal changes, emotional blunting	For years, the “gold standard” for tic suppression, but many find the side effects intolerable
	Pimozide	Orap	0.5 – 10mg	Same as above, plus EKG changes	EKG needs to be monitored
High Potency Benzodiazepine	Clonazepam	Klonopin	0.25 – 2.0mg	Sedation, disinhibition, irritability	Not often used as “stand alone” medication, because of risk of habituation with continuous use over weeks.

MEDICATIONS PRIMARILY FOR TREATMENT OF ATTENTION DEFICIT DISORDER SYMPTOMS

9-2005

Medication Class	Generic Name	Brand Name	Usual Daily Dosage Range	More Frequent Side Effects	Additional Notes
<u>Psychostimulants</u> (Gold Standard for ADHD)	Methylphenidate (MPH)	Ritalin, Metadate, Methylin	5 – 80mg	Headache, stomachache, loss of appetite, disturbed sleep, irritability, moodiness, increase tics, agitation, sedation	Single dose lasts 2-4 hours
	d-methylphenidate	Focalin	2.5 – 40mg	Same as MPH	Can work when MPH is not tolerated or efficacious
	Intermediate duration MPH	Ritalin SR Metadate ER, Methylin ER	20 – 80mg	Same as MPH	Single dose lasts 4-6 hours; Not predictable release
	Long duration MPH	Concerta Metadate CD Ritalin LA	18 – 72mg 10 – 80mg 10 – 80mg	Same as MPH	Single dose lasts 8-12 hours
	Long duration d-methylphenidate	Focalin XR	10 – 40mg	Same as MPH	Single dose lasts 8-12 hours
	Dextroamphetamine	Dexedrine, Dextrostat	2.5 – 40mg	Same as MPH	Single dose lasts 3-5 hours
	Intermediate duration Dextroamphetamine	Dexedrine Spansules	5 – 40mg	Same as MPH	Single dose lasts 4-6 hours; Not predictable release
	Mix of amphetamine salts (Available as generic)	Adderall	5 – 40mg	Same as MPH	Single dose lasts 5-7 hours, Approx. 75% of elementary age children can get through school day on single AM dose
	Long duration Adderall	Adderall XR	5-40 mg	Same as MPH	Single dose lasts 8-10 hours
<u>Norepinephrine Reuptake Inhibitor</u>	Atomoxetine	Strattera	1.0-1.8 mg/kg/d	Same as MPH; sedation; less risk of tics increasing; rare reports of liver injury	Single AM dose can last until bedtime
<u>Novel Antidepressants</u>	Bupropion	Wellbutrin SR & XL	100 – 400mg	Same as MPH	Seizures associated with doses above 450 mg per day
<u>Tricyclic Antidepressant</u>	Desipramine (DMI)	Norpramin	10 – 300mg	EKG Changes, sedation, dry mouth, weight gain, heart rate and blood pressure changes	Heart rate, blood pressure and EKG should be monitored
	Nortriptyline	Pamelor	10 – 150mg	Same as DMI	Same as DMI
	Imipramine	Tofranil	10 – 300 mg	Same as DMI	Same as DMI
<u>Wakefulness Promoting Agent</u>	Modafinil	Provigil	85 – 425 mg	Similar to Psychostimulants	FDA approval studies underway
<u>Alpha Adrenergic Agonists</u>	<i>Same as the treatment for TICS</i>				

MEDICATIONS FOR TS ASSOCIATED PROBLEMS (Depression, anxiety, OCD, mood lability)

9-2005

Medication Class	Generic Name	Brand Name	Usual Daily Dosage Range	More Frequent Side Effects	Additional Notes
Selective Serotonin Reuptake Inhibitors (SSRI's)	Fluoxetine (FLXT)	Prozac	5 – 80 mg	Agitation, tremulousness, headache, stomach upset, diarrhea, disinhibited behavior, sleep problems, sexual dysfunction	The SSRI's are "broad spectrum" agents for depression, anxiety, OCD, & anger. 1-2% of starts associated with disturbing agitation and risk of self injury; Fluoxetine, Paroxetine, Citalopram, & Fluvoxamine available as generics
	Fluvoxamine	Luvox	25 – 300mg	Same as FLXT	Same as FLXT
	Paroxetine	Paxil	5 – 60mg	Same as FLXT	Same as FLXT
	Sertraline	Zoloft	12.5 – 200mg	Same as FLXT	Same as FLXT
	Citalopram Escitalopram	Celexa Lexapro	5 – 60mg 2.5-30 mg	Same as FLXT	Same as FLXT Lexapro a close relative of Celexa
Novel Antidepressants	Bupropion	Wellbutrin SR & XL	100 – 400 mg	Headache, irritability, agitation, stomach upset, sleep disturbance	For depression & ADHD; Not helpful for anxiety; doses above 450 mg per day associated with seizures
	Venlafaxine	Effexor XR	37.5 – 300 mg	Irritability, sleep problems, increased BP	For depression and/or anxiety
Tricyclic Antidepressant	Clomipramine	Anafranil	25 – 250mg	Same as for other tricyclics (see under treatment for ADD)	Good for treatment resistant OCD, but more side effects than for SSRI's
Mood Stabilizer	Divalproex	Depakote	250 – 3,000mg	Sedation, tremor, stomach upset, hair loss, weight gain	Used for severe mood instability or "Bipolar" symptoms; regular blood monitoring necessary; some concerns about occurrence of polycystic ovaries in females
Second & Third Generation Antipsychotics	Same as for treatment of TICS				Helpful for severe, explosive anger, and for treatment resistant OCD

Physician & Professional Referral List

Tourette Syndrome Association maintains a Professional Referral List (PRL) that is available to members upon request. If you are interested in recommending a physician, therapist, learning specialist, lawyer, or others to be included on the PRL, please forward their information to us at this Chapter. The information will be processed and TSA will send a letter inviting them to the PRL.

TOURETTE SYNDROME ASSOCIATION LAUNCHES CME AND ALLIED PROFESSIONAL EDUCATION COMPONENTS ON WEBSITE

Beginning Friday, November 4th 2005 TSA initiates a CME (Continuing Medical Education) program and resource materials for Medical, Allied, and Education Professionals on the TSA website. Those who seek access to the materials will be asked to provide professional credentials and contact information before being provided with a password.

Contact TSA at 718-224-2999 or www.tsa-usa.org and click on "Medical Education".

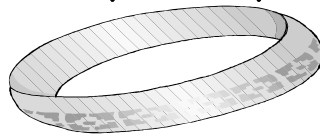
Through its partnership with the U.S. Centers for Disease Control (CDC), TSA has been presenting a series of programs directed to Medical and Allied Professionals; another group of programs is directed to Education/School Based Teachers and Clinicians. In furtherance of this effort, and to make these valuable resources available to a wider audience, many of the materials provided to the participants in the live programs are now being mounted on the website.

The first postings to tsa-usa.org are of medical and education materials, including videos, and current medical and scientific articles. In the future, TSA will be posting additional website educational materials for those affected by TS, educators, allied professionals and clinicians, as well as additional CME programs.

The CME presentation, of John Walkup, M.D., Division of Child and Adolescent Psychiatry Johns Hopkins, Baltimore, MD was filmed at Downstate Medical Center in New York on July 22, 2005. Dr. Walkup is also the current Chairman of TSA's Medical Advisory Board. Viewers of the CME program (video and slides) will, in accordance with CME requirements, be required to complete an Evaluation form and submit it for processing for 1.5 CME credits.

A new sidebar button choice, "Medical Education", has been set up to begin the registration process to access the new materials.

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.



Teenager's Odd Chromosome Points To Possible Tourette Syndrome Gene

www.sciencemag.org SCIENCE VOL 310 14 OCTOBER 2005 CREDIT: J. LABELSON ET AL., SCIENCE
A bad break that apparently gave a young boy Tourette syndrome may turn out to be a lucky break for researchers studying the neuropsychiatric disorder.

Tipped off by a suspicious chromosomal rearrangement, a team led by geneticist Matthew State at Yale University Medical School reports on page 317 that it has identified a gene that the researchers believe causes Tourette syndrome when mutated. Although the gene is responsible for at most a small fraction of Tourette cases, it's the best lead yet in tracking down the genetic contributors to the syndrome. "This gives us a key clue to the potential biological pathways that are altered in this disorder," says neurologist Daniel Geschwind, director of the center for autism research at the University of California, Los Angeles (UCLA).

Traditional genetic analyses of people with Tourette and their families have fingered a half-dozen chromosomal regions that appear to be involved in the syndrome, which causes as many as 1 in every 100 people to involuntarily move or make sounds (*Science*, 3 September 2004, p. 1390). But difficulties in pinning down susceptibility genes in those regions led State to take a different approach. He has been looking in people with the syndrome for chromosomal breaks and rearrangements that might implicate specific genes.

A little over a year ago, a geneticist associated with a consortium organized by the Tourette Syndrome Association (TSA) told State about a boy who had an inversion in chromosome 13: A portion of his chromosome had an orientation opposite that of normal chromosomes. The boy was the only member of his family with Tourette syndrome and the only one with the inversion.

State and his colleagues found three genes close to the breakpoints of the inversion. Two had no plausible connection to Tourette syndrome, but the third immediately drew their attention. Known as *Slit and Trk-like family member 1 (SLITRK1)*, it was related to a group of genes known to be involved in neuronal growth, guidance, and branching.

To test the gene's association with the syndrome, State and his colleagues sequenced *SLITRK1* in 174 people with Tourette. They found one person with a missing nucleotide in the gene that resulted in a truncated protein. State's medical school colleague Nenad Sestan then cultured mouse neurons that expressed either the regular *SLITRK1* gene or the version with the missing nucleotide. The cells with the normal gene grew significantly longer dendrites—the portions of the cell that reach out to receive nerve impulses—than did neurons with the mutated gene. Although the link to Tourette syndrome remains to be determined, the gene appears to have a "functionally important" role in neuronal growth and differentiation, says Sestan.

Among the 174 people with the syndrome, State, Sestan, and their colleagues also found two unrelated individuals who had a change near the coding region of the gene. The change altered a binding site for a short RNA molecule, or microRNA, that regulates expression of the gene. And both the microRNA and *SLITRK1* are expressed in portions of the brain thought to be involved in Tourette syndrome.

State suspects that mutations in or near *SLITRK1* can cause Tourette syndrome when they block or reduce the expression of the gene during development. "This finding needs to be replicated," he says. "But we have multiple lines of evidence pointing to the involvement of this gene."

Other researchers warn that the findings, although interesting, remain tentative. "Each piece of the evidence is intriguing but not on its own conclusive," says UCLA geneticist Nelson Freimer. "To what degree can the pieces be combined to make a persuasive case? Opinions will differ on that."

To try to resolve the matter, TSA has given funding to State, Sestan, and their colleague neurobiologist Angeliki Louvi to produce a mouse in which *SLITRK1* has been knocked out and to study how the *SLITRK1* protein functions. "If it holds up, it's a giant leap for Tourette research," says neuropsychiatrist Neal Swerdlow of the University of California, San Diego, School of Medicine.

—STEVE OLSON

Steve Olson is a writer in Bethesda, Maryland.

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# TSA NATIONAL CONFERENCE

**April 6 – 9, 2006   Hilton Hotel   Alexandria, Virginia**

- General Sessions: Medical Track ~~ Education/Advocacy Track ~~ Adult/Young Adult Track
- Youth Programs: National Air & Space Field Trip & Historical Sights Tour ~~ Chat Groups ~~ Self Confidence Building ~~ Motivational Drum Circle
- Teen Programs: Private Tour of the Capital ~~ Teen Peer Ambassador Self Advocacy Program ~~ Confidence Building ~~ Classroom Tips & Strategies ~~ Motivational & Rap Chat Session
- Outstanding speakers and facility
- Go to the TSA website for more information and registration: [www.tsa-usa.org](http://www.tsa-usa.org)



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