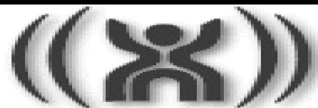 tourette syndrome association, inc.

Rocky Mountain Region **Serving: Colorado, Idaho, Nevada, Montana & Wyoming**

NEWSLETTER Medical Issue November, 2004

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WISH LIST
(approximate cost)

Library Materials for Support Groups $500 each

Training Specialists Expenses to Travel & Train $2,500

Wine Tasting Fund Raising Event $3,000

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

INTRODUCTION
By R. Barkley Clark, M.D.

This medical edition of the Newsletter will cover two broad topics. The first topic will be a review of the highlights of the Fourth International Scientific Symposium on Tourette Syndrome. The second topic will be a review of the recent Federal Drug Administration (FDA) concern about the use of antidepressant medications in children and adolescents.

4th INTERNATIONAL SCIENTIFIC SYMPOSIUM

This remarkable symposium on Tourette Syndrome occurs every five years, and brings together experts in Tourette Syndrome from around the world. This 4th edition occurred on June 25-27, 2004, at the Cleveland Clinic in Cleveland, Ohio, and served as a celebration of the career and contributions of Gerald Ehrenberg, M.D. The Symposium featured some thirty presentations on various aspects of Tourette Syndrome (TS) and associated disorders. This Newsletter will report some highlights and some informational tidbits from the Symposium.

Phenomenology and Natural History of Chronic Tic Disorders

Dr. Jim Leckman of the Yale Child Study Center reminded attendees that tic disorders are primarily disorders of children and adolescents. He reported that the median age of onset of tics is five years of age, and that for every female effected by TS, there will be 3 to 4 males with TS. Most patients with chronic tics report that their worse difficulty ever with tics occurred in early adolescence, and their tics then gradually lessened in frequency and intensity in a linear fashion beginning at about 12 years of age, but most individuals continue with some tics into adulthood. Dr. Leckman also reminded the audience that tics tend to occur in bouts, and added that the mean duration of a bout of tics is approximately nine weeks, with a typical range from one to eighteen weeks in duration. If you wait, the current bout of tics will likely lessen without any specific treatment.

Co-morbidity of Chronic Tics with Other Symptoms and Disorders

Although chronic motor and vocal tics define TS, the non-tic related problems that accompany chronic tics frequently demand much of the attention of the patient, his family, and his health care providers. A number of speakers addressed the issue of the frequency of co-morbidities with TS, and the following represents a synthesis of the information presented by different speakers:

Continued on page 3

Dear Members:

The October 11, 2004 meeting of the Board of Directors resulted in some very important changes to this Chapter, including:

Appointment of Snow White-Wardell as Executive Director of this Chapter. *Snow has been a very affective Board Member and a strong advocate for TSA-RMR for the last two years. As "ED", Snow is responsible for and will manage the day-to-day activities of TSA-RMR including support and services to members.*

Nomination of Georgia Harland to the Board of Directors, in the position of Treasurer*. Georgia is the Accounting Manager at Richfield Hospitality, Inc. Georgia and her family joined the Chapter last summer and have been terrific supporters of our work since then.*

Special thank you to Jeff Barker who served six plus years in the position of Treasurer. *Jeff established the accounting procedures we use today!*

Moving the TSA-RMR business office to Longmont where Snow and her family live.

The names and positions of TSA-RMR Board of Directors are listed on the front page of the newsletter. The Board meets on the 2nd Monday of each month and meetings are open to anyone who wishes to attend. Please call the office for meeting time and place. If you are interested in participating at the Board level, please contact any of the Board at 303-774-7707.

Loree Vanderhye, President

ATTENTION MEMBERS

***New Phone*: 303/774-7707**

***New Fax*: 303/774-7873**

New Address:
500 9TH Avenue Suite 2
Longmont, CO. 80501

***Same Email*: tsarmr@att.net**

Same TSA-RMR website:

http://www.sensiblenet.com/tsa/htm

TSA – National website: www.tsa-usa.org

Legislative Info: TSA – National website: www.tsa-usa.org Click on Public Policy

Dear Members,

I am pleased to accept the position of Executive Director for TSA-RMR, and look forward to meeting and working with all of our members, sponsors and advocates.

There are several important objectives that are critical to improving the services that we offer as a volunteer health organization. These include:

- Programs that will help parents advocate for their child at school, understand the IEP process, and know their rights, so that students with TS+ may fully participate in and have access to an appropriate education;
- Continue our efforts to stay informed about legislative issues that affect people living with TS+, and encourage our elected officials to hear our voice;
- Distribute literature to the health care community that will help doctors with the early and accurate diagnosis of TS+, and have doctors inform the families of TSA-RMR and the support services we offer.
- Provide 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 visit our website for additional information www.sensiblenet.com/tsa/home.htm and to learn more about our mission at TSA-RMR. Each of you can help move our efforts forward. Thank you for your continued support and efforts on behalf of those with Tourette Syndrome Spectrum Disorders.

Sincerely, Snow White-Wardell

Co-morbidity of Chronic Tics with Other Symptoms and Disorders - continued

ADHD	50-60%
Oppositional Behavior	50-60%
Conduct Disorder (CD)	15%
CD with hx of psychiatric hospitalizations	35%
Problems with Anger/Rage	35-40%
Any Anxiety Disorder	50-70%
Obsessive Compulsive Symptoms	60%
Obsessive Compulsive Disorder	25-40%
Any Mood Disorder	50-60%
Major Depression	20-50%
Bipolar Mood Disorder	10-25%
Self Injurious Behavior	30-40%
Problems with Social Skills	20-30%
Trichotillomania	10%
Sexually Inappropriate Behavior	6%

Genetics of Tourette Syndrome

The genetics of TS is a topic of intense research investigation. Dr. David Pauls of Harvard Medical School described his work, as well as the research of the TS International Consortium for Genetics. Dr. Pauls believes that a number of different genes likely underlie the genetics of TS, and he sited evidence for a common genetic basis for TS, chronic tic disorders, and Obsessive Compulsive Disorder (OCD). In looking at the first degree relatives of probands with TS, Dr. Pauls has found that the risk for TS in males is 15%, the risk for TS in females is 3%, the risk for OCD in males is 7%, and the risk for OCD in females is 15%. In addition, the first degree relatives of probands with both TS and ADHD have approximately a 16% risk for ADHD, compared to an occurrence of 3-4% in the relatives of probands with TS, but without ADHD, and in controls.

Neurobiology of Tourette Syndrome

A number of presentations involved studies of the neurobiology of TS. Jonathan Mink, M.D., of the University of Rochester School of Medicine reviewed some of the complex functioning of the Basal Ganglia. He pointed out that many researchers now think of the Basal Ganglia as functioning to facilitate focused and desired behaviors, while inhibiting other unwanted or potentially competing behaviors. Dr. Mink hypothesizes that TS is related to Basal Ganglia dysfunction that results in a failure of behavioral inhibition. He reminded the audience that the TS Spectrum commonly includes tics, ADHD, and OCD, and that all of these conditions share impaired inhibition of unwanted behavior as a common feature.
Neuro-imaging studies of the brains of individuals with TS have revealed a 5-8% decrease in the volume of the caudate nucleus compared to the caudate volume in control subjects. In addition, a smaller caudate size on MRI before the age of 14 years tends to predict the more severe persistence of tics after 16 years of age.

Continued on page 4

Volunteers of the Quarter: **All of the volunteers who helped with the TSA-RMR office relocation. I hope we do not have to move again for another ten years!**

"When you carry out acts of kindness you get a wonderful feeling inside. It is as though something inside your body responds and says, yes, this is how I ought to feel."
Author: Harold Kushner

New Treatments for Tourette Syndrome

The most interesting new information on medical treatment options for TS came in private conversations with attendees at the Symposium. A number of physicians in charge of university based TS Clinics reported their antidotal findings of encouraging results with the use of aripiprazole (*Abilify)* at a dose of from 5-10 mg per day for both tic suppression and for mood stabilization. Aripiprazole is the newest second generation antipsychotic (SGA), and it is purported to have stabilizing effects on dopamine and serotonin receptors that make it good as an antipsychotic and as a mood stabilizer.

Most importantly, aripiprazole is reported to have significantly less propensity to promote weight gain, and significantly less propensity to promote the elevations in blood sugar and blood lipids that have become such a concern with the use of many SGA agents. Open label studies of aripiprazole for TS are currently in the process of being funded.

Updated Physician's Referral Listing and Medications Primarily For Treatment of Tics now available.

Please call the TSA-RMR office 303-774-7707

LEGISLATIVE ACTION ALERT

1. Go to www.tsa-usa.org
2. Click onto Public Policy
3. Click onto Legislative Action Center
4. Go to the Legislative Action Link & click the purple "here"
5. Scroll down to Action Alert and click onto "House-Senate Conference Committee on IDEA Reauthorization Appointed"
6. Read the Public Policy Information section
7. Enter your zip code in the little box that says Take Action Now
8. This will bring up your senators and representatives
9. Type in Subject (Reauthorization of IDEA)
10. Read the letters (two of them - one for House, one for Senate) and personalize them -- this works better than everyone using the same letter. Talk about your family, your child, the successes due to flexible teachers, the failures and difficulties caused by inflexible teachers and ineffective and inappropriate punishment, etc.
11. Fill out your name in the section at the bottom and then click the send message

NOW encourage your relatives and others to do the same. We know that many of you have waited a very long time to respond to Congress about the reauthorization of IDEA. The time is now! Our children need our voice.

Thank you from the Legislative Chair

CONCERNS ABOUT THE USE OF ANTIDEPRESSANTS IN CHILDREN & YOUTH

Since antidepressant medications (ADs) in general, and selective serotonin reuptake inhibitors (SSRI's) in particular, are often part of the medical treatment of individuals with Tourette Syndrome, the recent concern and investigations by the Federal Drug Administration (FDA) into the use of ADs in children and adolescents deserves the attention of this Newsletter.

The Risks

To start, it should be noted that the FDA has previously approved the use fluoxetine for children 8 years of age and older for Major Depression, and has also approved the use of fluvoxamine, sertraline, fluoxetine, and clomipramine for the treatment of Obsessive Compulsive Disorder in children and adolescents. All other uses of antidepressants in children and youth are "off label".

The current concern about ADs began in June 2003 when the British Department of Health warned physicians in the UK to avoid the use if paroxetine (*Paxil)*, an SSRI, for the treatment of depression in individuals 18 years of age and younger. The warning was made following a British government review of pharmaceutical company studies on the efficacy of paroxetine for the treatment of depression in youth. The government review of those studies pointed to a previously unnoticed finding that a small percentage of youth (perhaps 1-1.5%) during the initial weeks of treatment with paroxetine developed what appeared to be new symptoms suggesting an increased risk for suicidal behavior.

In February 2004, the FDA initiated its own investigation into the safety of SSRI's in children and adolescents. After reviewing some 24 drug trials, with 9 different antidepressants, involving some 4,400 children and youth with a variety of diagnoses, the FDA concluded that treatment of youth with antidepressant medications was associated with approximately a 1.5- 2% risk of new, treatment emergent, suicidal ideation and/or self injurious behavior with intent to die. No completed suicides have been reported. On October 15, 2004, the FDA directed manufacturers of all antidepressants (regardless of drug type or class) to include a "Black Box Warning" on all product labeling, alerting health care providers and consumers of a potential risk of increased suicidal thinking and/or behavior in children and adolescents newly treated with any antidepressant, for any reason.

Defining Safety

The safety concerns expressed above about treatment emergent "suicidality" is one side of the coin. The safety of any drug is a relative concept depending upon the risk of harm attributable to the natural history of the disorder afflicting the patient, combined with the anticipated benefits of the treatment (presumably, lessened harm to the patient), along with the potential risk of treatment emergent adverse events posed by applying the treatment to the patient. The opposite side of the coin involves the risk to the individual posed by the afflicting condition. Consider the following:

1. Major Depression affects 2.5% of preadolescents, and some 5-8% of adolescents, not to mention 20-50% of individuals with Tourette Syndrome;
2. Depression is the single most important factor in adolescent suicide (Brent, 2004);
3. Suicide is the 3rd leading case of death in persons age 10-24 years in the U.S.;
4. The risk of completed suicide in 15-19 year olds has decreased from 11/100,000 in 1990, to 8/100,000 in 2001, in part related to the increased number of depressed youth being treated with antidepressants (Olfson, 2003).

Continued on page 6

The Treatment for Adolescents with Depression Study (TADS)

Thankfully, along comes TADS (TADS Team, 2004), which compares the treatment efficacy of fluoxetine (flxt) and/or Cognitive Behavior Therapy (CBT) verses placebo in the treatment of over 400 youth ages 12-17 with Major Depression over a period of 12 weeks of treatment. Importantly, the study was funded by the NIMH, and not by pharmaceutical companies with a vested financial stake in the outcome. The findings of TADS are remarkable:

1. Depressed adolescents were rated much or very much improved by the different treatments at the following rates:

Combined flxt plus CBT	70%
Flxt alone (mean dose 30 mg/d)	60%
CBT alone (15 structured sessions)	43%
Placebo	35%

2. The rate for some suicidal ideation in the depressed youth decreased from 30% of depressed patients at baseline to 10% of patients at the end of treatment, with the combined flxt and CBT having the best outcome;
3. 1.6% of depressed youth made a definite suicide attempt after starting treatment, and some 7.5% of depressed youth engaged in some type of self injurious behavior after starting treatment. The rate of self injurious behavior was two times higher in individuals receiving flxt, compared to individuals not receiving flxt.

So, in summary, it appears that the treatment of Major Depression in adolescents with medications alone, and with medications plus structured psychotherapy, are both effective treatments. In addition, a small percentage of depressed youth engage in self harm behaviors after starting treatment, and the rate of self harm behavior is twice as common in depressed youth treated antidepressant medication compared to depressed youth not getting antidepressants.

Recommendations When Using Antidepressants in Children and Adolescents

1. Be sure that families are made aware of non-medicinal, evidenced based treatments, as well as proven medical treatments;
2. Be sure that families are made aware of the evidence that does support an increase in self injurious behavior and perhaps suicidality in a small percentage of youth taking antidepressant medications early in the course of treatment, or when changes are made in dosages;
3. Provide families with written lists of signs and symptoms to watch for, including increases in suicidal thoughts, urges to injure oneself, and any self harm events;
4. Provide families with written information to call in the event of new or increasing anxiety, agitation, irritability, impulsive behavior, restlessness, activation, or elation;
5. Maintain at least weekly contact with the patient and family for one month, or for as long as dosage changes are being made.

References for Antidepressants in Youth

1. Brent, D., NEJM 1598-1601, Oct 14, 2004.
2. Olfson, M., et. al., Arch Gen Psych, 60:978-82, 2003.
3. TADS Team, JAMA 292:807-820, Aug 18, 2004.
4. Vitiello, B., et. al., NEJM 1489-91, Apr 8, 2004.

Medical information prepared by R. Barkley Clark, M.D

Support Group Contacts & Schedules

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

Colorado Springs: 4th Thursday of each Month 7:00-8:30 PM NAMI Offices-510 E Willamette

Contacts: Rachel Bolenbaugh 719-266-8477 Jennifer Pearce 719-481-9716 tsa-cospgs@bolenbaugh.net

Longmont: Times/Dates vary **Contact**: Snow White-Wardell 303-774-9657 or jwardel@msn.com

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

Gillette: 7:00 PM Campbell Cnty Library-2101 S. 4J Rd **Contact:** Vicki Cook 307-682-9732 vcook@vcn.com

Kalispell: Informal Meetings **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.

CONFERENCES AND EVENTS

2005 INVISIBLE CHILD CONFERENCE
Saturday January 22, 2005
Contact: Harriet Austin
Harriet@invisiblechild.org

2005 PEAK INCLUSIVE EDUCATION CONFERENCE
January 27-29, 2005
Denver, Co.
Contact: PEAK Parent Center
info@peakparent.org

2005 42nd ANNUAL LDA INTERNATIONAL CONFERENCE
March 2-5, 2005
Reno, NV.
Contact: www.ldanatl.org

2005 11TH BIENNIAL MOVEMENT DISORDER SYMPOSIUM
September 10, 2005
Denver Location to be announced
Contact: tsarmr@att.net

Under the direction of Drs. Ross Greene and Stuart Ablon, the **CENTER FOR COLLABORATIVE PROBLEM SOLVING** provides clinical services, training, and consultation to assist education, mental health, and medical professionals and parents in understanding and implementing the Collaborative Problem Solving (CPS) approach. www.explosivechild.com http://www.allkindsofminds.com by Dr. Mel Levine

YES! **I want to make a tax deducible 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**

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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

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