

May 2007 Newsletter Edition

Tourette Syndrome Association Rocky Mountain Region

Welcome to the second edition of the Tourette Syndrome Association Rocky Mountain Region email newsletter. The format will be without graphics so that everyone can easily access the information, regardless of a computer's software or age. Please look for local events, legislative updates, lobbying efforts, current events, medical articles, and resources related to TS. And send us your feedback and local updates to kjmatsey@msn.com or info@tsarmr.com.

If you are not able to link directly to websites from this newsletter, copy and paste the address into your browser.

Denver Family Golf Outing:

Hey kids! Do you want to spend a morning learning how to play golf with other kids with Tourettes? Then this is for you! TSA-RMR board member Kacie Curd is working with Colorado's Glenmoor Country Club for a chance to learn some golf skills. Come learn the basics of how to play golf instructed by people that actually play the game. If you already know how to play, then great, come down and we'll help you improve or you can just come and socialize with other kids who have TS as well. No previous experience is required, and if you have clubs that would be preferable, but if not we can supply them for you. It's a great opportunity to acquire a new skill as well as meet and have fun with other families who also are affected by TS. Also, afterwards, there's a hot dog and hamburger lunch completely free. Friends and family are welcome to come and participate or watch as well. The event will be held at 10:00-12:00 on June 18, 2007 at Glenmoor Country Club in Greenwood Village followed by lunch on the patio. Please RSVP with the number of people coming as soon as possible to KLCBlue79@aol.com so that we know how many lunches to make. Also, if there are any dietary needs we need to consider, please let us know. In your RSVP, please let us know if we need to provide clubs for you and your guests or not. Don't miss this wonderful opportunity!

RSVP: KLCBlue79@aol.com

Location: Glenmoor Country Club
110 Glenmoor Drive
Cherry Hills Village, CO 80113
<http://www.glenmoorcc.org/golf/index.html>

Directions: From I-25 take the Belleview exit west about 3 miles. The entrance is on the north side of Belleview.

Dress code: No denim. Collared shirt and Bermuda shorts are required.

Local Support Groups:

Please update your local support group information so that the website can be current. Send your information to kjmatsey@msn.com. Thank you.

Denver - Mothers Night Out

Since setting aside some time for friendships is both difficult and important to do, we would like to schedule a mother's night out. Why don't we try for a mother's get-together? For any moms who can put some free time on their calendars on the evening of June 6th, why don't we meet at Palace Restaurant, 6265 E. Evans Ave. in Denver? Time to meet is 6:30. All are encouraged to come, relax and share. They have great Chinese food and the environment is comfortable for talking. Please e-mail Sallymmallen@aol.com to RSVP.

Denver - Meet in the Park

Let's start our summer off with a get-together in Observatory Park in Denver! Date will be Tuesday, July 10th. Time will be 6:30pm. This is a wonderful time for kids and parents, and teens and adults with TS to reconnect. All ages are welcome. Please bring a drink or snack if you'd like. The park is located at Milwaukee and Evans. In times past we've been at a picnic table on the west side of the park. Looking forward to meeting all who can come! RSVP to Sallymmallen@aol.com.

Advocacy:

Northglenn, Colorado, High School Presentation

Members of the Rocky Mountain Region TSA in Denver gave an informational presentation to a senior high school science class at Northglenn High School May 15, 2007 to acquaint the students with the TSA organization, the cause and symptoms of TS and current treatments. Ten minutes of the video "I have Tourettes but Tourettes doesn't have me" was shown at the end and the students asked good questions as follow-up. Members of the RMR-TSA are available to present to schools, businesses or groups that are interested.

Government Awareness Week –May 28-June 1.

This year, the TSA will be observing the week of May 28 through June 1, 2007 as our national "Government Relations Awareness Week". This will be our Fifth Annual Government Relations Awareness Program and this year we have chosen to observe the entire week instead of just a single day out of TSA's Awareness Month so that each and every member can fully participate locally. The "Government Relations Awareness Week" is a program to help the chapters continue their local government relations campaign—with local, state, and federal elected officials—by meeting with them in their local offices. The national TSA has support material available to help you with visits to your local government representatives. If you would like to plan a visit you can visit the TSA website www.tsa.org/ and click **public policy, TSA Legislative Action Center**.

Sally Allen, TSA-RMR board president, can be reached by email Sallymallen@aol.com for letters requesting appointments, confirming appointments and thanking representatives after the visit.

Training and Advocacy in Washington DC for Chapter Chairs

The new Chapter Chairperson for TSA Rocky Mountain Region, Sally Mescher Allen, and the legislative chair, Mollie Collum, attended the Training and Advocacy weekend in Washington DC in April. Sally and Mollie were able to meet with several aides or members of Congress to advocate for their support for several bills before the Congress. Of interest to TSA is the mental health parity legislation, reauthorization of IDEA, continued funding of the Tourette Syndrome Program at the CDC (two million dollars for the CDC to continue to educate parents, educators and health providers and to expand the scientific knowledge base), and the Genetic Information Nondiscrimination Act of 2007.

Also during the weekend, training included workshops on Functional Behavioral Assessment and Positive Behavior intervention Plan with Susan Conners, TSA Education Specialist; the New IDEA and how it affects students with TS with Kathy Giordano, TSA Advocacy Specialist, Public Relations; Grant Writing; Speakers Bureau; and Special Events. It was a very informative, well organized weekend with many ideas being shared between the different state's chapter chairpersons.

Conferences of Interest for Members:

1. Susan Conners, Education Specialist, Presenting in Montana

There is an opportunity for medical and educational professionals to attend an education program on Tourette Syndrome in Montana. Susan Conners, TSA Education Specialist, will be presenting an education program Tuesday June 5th in Miles City and Wednesday June 6th in Glasgow. This is being offered by the TSA-CDC Partnership. Unfortunately Susan Conners will have to leave directly after each presentation to travel to the next and so will not be available for a TSA-CDC family program. For additional information please contact Patricia DiStefano 404-755-8498

2. What Is the Road a Student with Traumatic Brain Injury Travels? *Emotional, Behavioral and Cognitive Transitions*

DATE OF CONFERENCE: Friday, September 21, 2007

PLACE OF CONFERENCE: The Wildlife Experience
10035 South Peoria
Parker, CO 80134

Interested, or have questions, please call Sharon Thorson at (303) 805-2502 or email thorfam@rmi.net

Resource for reading difficulties:

A member of the Rocky Mountain Region TSA in Denver would like to highlight two resources for any one who has dyslexia or vision problems. Sally Mescher Allen, Sallymmallen@aol.com, a Denver parent of a high school student with Tourette Syndrome and dyslexia, has experience in obtaining books (popular and the classics) on tape from the Colorado Talking Book Library in Denver, and textbooks for academic classes from Reading for the Blind and Dyslexic "RFB&D", national headquarters in Princeton, NJ. Colorado Talking Book Library can be reached at 303-727-9277 or www.cde.state.co.us/ctbl. You can also check your local state for their talking book library. RFB&D can be reached at 800-221-4792 or www.rfb.org. RFB&D requires an individual or school membership and most any textbook through graduate school can be obtained. Both organizations are updating their technology to make the books on take more portable and easier to use. There are also other laptop adapted reading systems available locally.

Articles of Interest to Members:

UCLA Study on Friendship Among Women

A landmark UCLA study suggests friendships between women are special. Scientists now suspect that being with our friends can actually counteract the stress most of us experience on a daily basis. A landmark UCLA study suggests that women respond to stress with a cascade of brain chemicals that cause us to make and maintain friendships with other women. In fact, says Dr. Klein, it seems that when the hormone oxytocin is released as part of the stress responses in a woman, it buffers the fight or flight response and encourages her to tend children and gather with other women instead. It may take some time for new studies to reveal all the ways that oxytocin encourages us to care for children and share time with other women. We can be tempted to let go of women friendships in our busy lives but the researchers feel that the study shows that friendships are a source of strength and healing.

Taylor, S., Klein, L.C., Lewis, B. P., Gruenewald, T. L., Gurung, R.A. R., & Updegraff, J. Female Responses to Stress: Tend and Befriend, Not Fight or Flight" Psychol Rev , 107(3):41429.

Make some new friends, sign up for the Denver area Mom's dinner on June 6th

IDEA Update:

With the reauthorization of 2004 IDEA there are some changes families should make themselves aware of. This update was addressed by Kathy Giordano at the Leadership Training Conference in Washington DC this April.

THE GOOD:

- Strongly encourages pre-in service and professional development for all individuals working with the student;
- includes words "functional" and "developmental" regarding evaluations, writing an IEP;
- students with behaviors which are determined to be a manifestation of their disability should be provided an FBA (Functional Behavioral Assessment), a PBIP (Positive Behavior Intervention Plan), and support, not punishment;
- continued emphasis on early identification;
- emphasized FBA with positive behavior interventions;
- it is not necessary that student fail in order to be eligible for special education support;
- Tourette is listed under **Other Health Impaired**;
- IEP meeting not required to make changes to IEP. If new tic begins, it should be easier to get it inserted into the IEP for the student's benefit.**

THE BAD:

- removing Short Term Goals on IEP's (states may decide to retain them);
- parents are responsible for legal fees of school if parents lose in Due Process;
- IEP meeting not required to make changes to IEP. Parents must not agree to changes before careful consideration is given. Parents must still give permission.**

EXCELLENT WEBSITE FOR IDEA:

<http://idea.ed.gov/explore/home> Families can type in a word and it will search and bring up the regulations or statute. It also connects to state regulations.

Advice on advocacy from Kathy Giordano (TSA Advocacy Specialist)

"I continue to believe that the best advocacy for students with TS is changing attitudes by way of educating educators. I use the 'laws' when I need to and when it works. Generally my approach is to focus on getting the school to see a child as a student who wants to be successful but is not able due to symptoms. RESPECT, UNDERSTANDING AND POSITIVE SUPPORT ARE DIFFICULT TO LEGISLATE."

RMR-TSA has the power points from the following talks at Leadership Training in Washington DC:

<<*FBA & Writing Positive Behavior Intervention.pdf*>>

<<*Discipline & Manifestation Determination.pdf*>>

<<*IDEA-OHI-press-release 6 .pdf*>>

<<*Occupational Therapy 4-07.pdf*>>

The above IDEA advocacy points are from the IDEA. They are available by download for families from our website.

Resources at your fingertips:

Tourette Syndrome Association, national website: <http://www.tsa-usa.org/>

Rocky Mountain Region Chapter website: <http://www.tsarmr.com/>

Email: info@tsarmr.com

National legislative updates, write to your representatives:

http://capwiz.com/tsa/index_frame.dbq?url=http://capwiz.com/tsa/home/

Board Members:

The TSA-RMR Board Members for 2007 are as follows:

Sally Allen, Chairperson

R. Barkley Clark, MD, Vice Chairperson & Medical Committee Chairperson

Georgia Harland, Treasurer

Donna Davies, Vice Chairperson & Fund Raising Committee Chairperson

Lorraine Alcott, Secretary

Mollie Cullom, Member, Legislative Committee Chairperson

Kathy Matsey, Member

Kacie Curd, Junior Member

Loree Vanderhye, Advisory Board Member

Ron Rabin, MD, Advisory Board Member

Carol Tierney, PhD, Advisory Board Member