



NEWSLETTER

February, 2003

TSA-RMR

Board of Directors

Governing Board

Loree Vanderhye, President

Co-Chair – Education/Advocacy

Maggie Byrnes, Vice Pres.

Chair-Member Services

Jeff Barker, Treasurer

Chair-Finances

Judy Harrigan, Co-Secretary

Co-Chair-Education/Advocacy

James Gould, Co-Secretary

Chair-Legislative Issues

R. Barkley Clark, MD, Director

Chair-Professional Outreach

Steve Duhon-Thornton,

Director

Chair-Support Groups &
Committee Development

Advisory Board

Tracy Fischer, Director

Ronald Rabin, MD, Director

Lauren Seeberger, MD,

Director

Carol Tierney, PhD, Director

Honorary Board

Paige Vickery

Paula Pattschull, PhD

Diana Blair

Jeanette Cornier

Christopher O'Brien, MD

Douglas Wieder

Thomas Sumners, MD

Nancy Crone (founder)

Staff

Jerry Alley

Education and Advocacy

An EDUCATION & ADVOCACY page has just been launched on the National Tourette Syndrome Association website at <http://tsa-usa.org> Click the "Education & Advocacy" link on the left column or on the homepage feature box. The page has a unique "ASK THE EXPERTS" section featuring SUSAN CONNERS and KATHY GIORDANO responding to questions sent in by website visitors.

Seven new publications, six of which were authored by SUSAN CONNERS are offered to visitors free-of-charge for a limited time only. More are coming!

The purpose of the EDUCATION & ADVOCACY web-page is to provide useful information to parents and families, educators and clinicians, and all those interested in providing the best possible educational experience for students with Tourette Syndrome.

Visitors are invited to visit the page regularly as the ASK THE EXPERTS section will be updated regularly as new questions come in. Visitors are invited to submit specific educational and advocacy related questions at the link on the page.

Questions will be updated on a regular basis (for now once a month). Not all questions will be answered on the web site; some will be answered individually off the site. The site is intended to specifically address Education and Advocacy related issues that will be of general interest to a majority of constituents.

SPECIAL SPEAKERS & PRESENTATIONS COMING TO SUPPORT GROUPS

RSVP – 303-832-4166

February:

Denver 2/11/03

Adult Relationship Survival

Presenter: TBA

Longmont 2/26/03

School Testing Accommodations

Modifications (IEPs, 504's)

Presenter: Cindy Dascher, CO Dept of Ed

May:

Denver 5/13/03

Obsessive-Compulsive Therapies

Presenter: Dr. Rit Marifiote

Longmont 5/22/03

Social & Emotional Issues

Presenter: James Petri, MA

In This Issue

TSA National Website

*Tourette's News and
Stories From Around
the Country*

Support Group Information

A Poem by Jake Arck

*A Story by Leslie
McCarthy*

Product Order Forms

News From Around the World...

A Very Perplexing Syndrome; More Than Nervous Tics, Tourette is Hard to Diagnose and Often Causes Learning Difficulties

Pittsburgh Post-Gazette (Pittsburgh, PA) December 17, 2002

For 42 years, Saralyn Stockton lived with an annoying twitch in her left eye. Her doctors could never explain this involuntary movement. She wrote it off as nervous energy.

Finally, after taking her oldest son to a doctor's appointment after he experienced a mysterious seizure during high school, she had the first clue.

"The doctor said to me 'Do you realize you've been twitching your left eye since you've been here?' " said Stockton, 47. This led to tests that found she had a mild form of Tourette syndrome, a neurobiological disorder characterized by involuntary motor and vocal tics.

She and her husband Steven, 52, eventually learned that three of their four sons also had Tourette. It was a diagnosis that finally explained a pattern of depression, fits of rage and learning problems experienced by the two older boys that had rocked the Upper St. Clair family.

The cause of this genetic disorder that affects more than 3,000 Pennsylvanians is unknown, although there is evidence that it stems from an abnormality in neurotransmitters called dopamine, which are closely tied to alertness and pleasure.

People with Tourette are often portrayed as having Coprolalia, the uncontrolled verbal outbursts of obscenities or ethnic slurs. But this affects fewer than 15 percent of people with the condition. Far more common are related conditions such as Attention Deficit Hyperactivity Disorder, Obsessive-Compulsive Disorder and Learning Disabilities. The complex characteristics of the disorder are the focus of a national push by Tourette advocates for improved educational opportunities.

Congress is considering sweeping changes to the federal special education law called Individuals with Disabilities Education Act, which was last reauthorized in 1997. The act provides free, appropriate public education to eligible children with disabilities.

Actor Richard Dreyfuss, whose godson was born with Tourette Syndrome 15 years ago, has gone on a publicity campaign urging that Tourette be recognized as a "separate and distinct disability." "Educators continue to mistakenly see Tourette as a behavioral or conduct disorder, which results in the improper placement of many of these children," he said. "Eligibility for special services and accommodations should be based on the presence of symptoms that compromise school performance," he said. "In many cases, as it stands now, a child must first fail before qualifying for services."

What's wrong with me?

There is a 50/50 chance of Tourette being passed through the genes, and the condition is three times more common in men than in women. As in Saralyn's case, many parents do not know they have the gene, said Sue Levi-Pearl, vice president for Scientific and Medical Programs for the national Tourette Syndrome Association.

One of the more perplexing problems with Tourette is the difficulty in diagnosing the condition. The Stocktons' first hint of a problem surfaced when their oldest son, S. Douglas, entered elementary school in the Upper St. Clair School District. Tests showed he had an above-average IQ, but he had a short attention span. He often became so bored in his kindergarten class that he would lay down on the floor and cried. Although he had tested as gifted by the time he entered third grade, the quality of his work varied as he progressed through elementary and middle school. Entering his freshman year at Upper St. Clair High School, S. Douglas found it increasingly difficult to concentrate not only on schoolwork, but small tasks. He experienced a seizure after a soccer practice during his sophomore year, which eventually led to diagnosis a year later of Tourette, as well as attention deficit hyperactivity disorder and obsessive compulsive disorder.

Dr. Imad Jarjour, a neurologist at Allegheny General Hospital, said Tourette is hard to diagnose for many reasons. The tics and other symptoms may be dismissed as nervous habits. Care from many different doctors and insurance issues also may contribute.

The Stocktons' second-oldest boy, Evan, 18, displayed the most severe symptoms of Tourette, which included the outbursts of profanities and slurs. With his hand and facial tics and attention problems, learning in the structured environment of a classroom became almost impossible. School officials worked with the Stocktons to develop a customized plan for Evan. But teachers didn't always follow it, his parents said. Nor did the district develop a behavior plan that would have helped teachers handle his classroom disruptions.

Continued on page 3...

Continued from page 2

"The teachers thought it was easier to send him to detention than work with Evan's circumstances," Saralyn Stockton said. Mary Lou Reaver, executive director of the Pennsylvania Tourette Syndrome Association in Gettysburg, Adams County, who tried to intervene on the Stocktons' behalf, said the staff refused to accept the severity of the boy's disabilities. "Like many kids with Tourette, this young man was good-looking and appeared normal because he could hold his tics in he appeared so normal in school they refused to believe the report by psychologists that he needed special help. He did need it. "

Frustrated at school, he got involved in petty crime and turned to drugs. The Stocktons ended up sending him during his junior year to the Total Learning Center, a special school in the North Hills that could address his needs. He spent his senior year at Parkway Technical School, and graduated from Upper St. Clair High School last spring. He hopes to attend a technical school.

The third child, Sean, 15, has so far escaped the disorder, but Ryan, 12, began showing Tourette symptoms when he reached the fourth grade. He was having attention problems and displayed verbal outbursts and a mouth tic.

S. Douglas, now 22 and a senior in college, continues on Ritalin, which keeps him focused, but the family has battled their insurance company because it typically doesn't cover the medication for people over 18. A regimen of antipsychotics, antidepressants and other medication for the three boys costs the family more than \$3,000 a year. The Stocktons hope that their experiences with S. Douglas and Evan will prepare them for the perils that may lie ahead for Ryan. "We want to get to the point where the kids can lead a normal life," said Steven Sr., who has involved the boys in Scouting as a way of achieving that goal.

Saralyn, a part-time wedding planner, recently organized a support group for parents of children with Tourette syndrome. It helps her to meet with other parents who have experienced the same difficulties and challenges. "It's such a devastating diagnosis. Tourette is such a complex disorder," she said. "We want families to know that there are others out there facing the same issues."

AN ADOLESCENCE MADE EVEN HARDER

Byline: S. Douglas Stockton

Pittsburgh Post-Gazette December 17, 2002

Imagine your eyes rolling back inside your head, uncontrollably and without warning. Then your fingers begin to stretch and your tongue begins to curl up. Equally perplexing, try to understand how it is that a person with a gifted-level I.Q. was incapable of performing beyond remedial levels of academic performance. Even some of the best medical doctors in the area could not provide an explanation. This was the ordeal that I faced through most of my high school years. As it is for so many adolescents, high school was a difficult and tumultuous time in my life. I was dealing with many of the typical concerns of youth -- trying to wear the latest fashions, worrying about girls and trying desperately to fit in. However, I also performed poorly academically. As I entered my senior year in high school, I ranked near the bottom of my graduating class. In fact, throughout high school, my grades displayed a truly random pattern of achievement --an A here, a D there and the occasional C. With this pattern, my troubles expanded during my sophomore year.

One fall evening, after a rigorous soccer practice, I climbed into my mother's minivan and couldn't keep my eyes from rolling into the back of my head. My tongue was rolling backward into my mouth, causing me to produce a sort of huffing sound. My mother and I were both unnerved, and we visited our family pediatrician. He was equally confounded and referred me to a local pediatric neurologist.

After a standard neurological evaluation, the results of which indicated that my brain and nervous system were functioning well within a normal range, the doctor began the arduous process of narrowing down his diagnosis. I underwent a series of medical tests including blood work, EEGs (scans of brain wave activity), and even an MRI scan of my brain. However, even when the most advanced neurological diagnostic equipment was used, the mystery only intensified. Test after test failed to find anything wrong with my brain or my central nervous system. By all accounts, I was a perfectly normal and healthy individual. My pediatric neurologist then referred me to another specialist, a pediatric neuro-ophthomologist, hoping that perhaps this highly trained individual could pinpoint the cause.

Finally, I was diagnosed with a mild form of Tourette syndrome. At the same time, I also received a diagnosis of attention deficit hyperactivity disorder, a neuropsychological disorder that often occurs with Tourette. Suddenly, everything began to make perfect sense: the uncontrollable muscle tics, the sheer physical pain that I would feel when faced with tasks requiring sustained mental attention (such as high school classes), and my inability to achieve at an academic level consistent with my above-average intelligence level. I was finally able to receive treatment that would enable me to achieve at my fullest potential.

It has been almost four years since I graduated from high school, and my life could not be more different. With continued treatment, and a sense of determination, I will graduate from college with a perfect 4.0 grade point average.

Following graduation, I plan to attend graduate school, where I will train to become a clinical psychologist. In so doing, it is my sincerest hope that I will be able to help those individuals suffering from unknown afflictions, as I once did, so that they too can experience success in their lives, and can strive, as I have, to reach their fullest potential.

Help Waiting in Wings; Actor plans workshops for Tourette Syndrome kids

Newsday (New York, NY) January 6, 2003

Any actor can tell you: Show business is tough.

Frank Senger of Astoria is one of the lucky ones. "I've been able to make a living as an actor for 16 years," Senger said. "But it's not always easy."

Senger, 48, has appeared on popular TV programs including "Law and Order" and "Third Watch," as well as some films. And he is particularly proud of his stage work, which includes productions at New York's Public Theatre and The Kennedy Center in Washington, D.C. But like most thespians, in the lean years he has taken other jobs to supplement his income. Senger's jobs leaned toward helping others: He has been a coordinator for the picking up and delivering of food to the homeless for the Queens Interfaith Hunger Network, and he has worked for We Can, a non-profit organization that helps homeless people earn money by redeeming empty bottles and cans. He also has taught acting in city public schools.

This year, Senger would like to teach acting to young people who have Tourette syndrome. He's in the early stages of planning these workshops and is coordinating with the main office of the Tourette Syndrome Association in Bayside to target children and teens who might benefit most from such a program.

Senger has TS. Although he displayed symptoms of the disorder throughout his childhood, he wasn't diagnosed until his teen years. "Prior to my diagnosis, I was considered a disruptive kid," he said. "Very little was known about TS back in the 50s and 60s." Like most children with TS, he suffered humiliation because of his tics. He spent much of his early years isolated from his peers.

Complicating matters was the fact that his TS also manifested itself in the form of coprolalia, the involuntary uttering of inappropriate words. "Imagine how the nuns in my school felt about that," he said. "I spent many a school day locked away in the cloak room."

It was acting that turned Senger's life around. A junior high teacher in his hometown of Springfield, Ill., encouraged him to audition for a class play. "I'd always loved to imitate actors on my favorite TV shows," Senger said. "When I actually got a chance to act in a play, I was hooked."

Not only did his first performance build Senger's self-confidence, it allowed him to complete a project for one of the first times in his young life. "TS does not have to stand in the way of anyone's dreams," Senger said. "I'd like children to discover that first-hand."

Lynne Rosen, a therapist at the Brooklyn Heights office of the Tourette Syndrome Association, believes the physical movements involved in acting benefit youngsters who may have pent-up energy. In addition, she believes that by focusing on acting, they will be more relaxed and thus less apt to have tics. In fact, that's how Senger believes acting helped him. Having TS has prepared him for some of the less pleasant aspects of acting. "Rejection is such an intricate part of show business. ... I got accustomed to rejection at a young age. I'm more capable of handling the ups and downs of this industry because of my early experiences living with TS," he said.

"I'd like to find funding somewhere to enable me to offer these classes for free, or at low cost, for children who would benefit from the workshops. ... For children with TS, I think acting can build self-esteem," Senger said. "I also like to introduce everyone to great dramatic literature, which they otherwise might never read."

I AM AN INCREDIBLE COMIC ARTIST

by: Jake Arck - Denver, CO

I am an incredible comic artist
I wonder if I will grow up to be a comic artist
I hear the paper and pencil calling me to draw
I see those two items waiting for me to approach them
I want to draw so bad, but there's a problem
I am an incredible comic artist

I draw pictures and cartoon characters in my mind
I feel the presence of what I want to draw
I touch the pencil and look at the paper
I worry that I will get in trouble for drawing during class
I cry at taking a chance of doing this
I am an incredible comic artist

I understand what will happen if I do this
I say nothing to myself
I dream of what I could be drawing
I try to ignore the pencil and paper
I hope that I will not get in trouble
I am an incredible comic artist

"Jake is a happy 13 year old with Tourette Syndrome and the "typical" disorders that accompany it; most notably, OCD. He is in 7th grade in a public school and enjoys a wealth of friends. Jake was required to write a poem for his humanities class. Poetry, writing and general communication are not his strength, however, from the depths within came this incredible poem that has taught our family so much and gave us remarkable insight into the mind of a kid with TS."

Freddy and Dani Arck

Newsletter Schedule

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

Board Meeting Schedule

Monthly - 2nd Monday - Swedish Medical Center



Call today

**...for your Albertson's
Community Partners Card
303-832-4166**

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!**

From Emotions To Advocacy

*"A superb reference, very highly recommended reading for all parents of children in need of adapted or special education services.. Filled with tips, tricks, and techniques and an immense wealth of resources, from Internet sites and advocacy organizations to worksheets, forms, and sample letters .." **Midwest Book Review***

*"The Wright's have given families a clear roadmap to effective advocacy for their children. We award their work the **Exceptional Parent Symbol of Excellence.**"*

In stock at TSA-RMR – see page 8

A TRIBUTE TO MY SON

By: Lesley McCarthy – Littleton, CO

My son Ted, has TS. He was assessed when he was about ten and has had hundreds of different tics through the years. His manifestations are mostly facial, head and neck – but he has had body and vocal tics as well. Obsessive Compulsive Disorder is also a factor. In the last few years his reading has become affected – he reads a line and then needs to read part of it backwards. Obviously this makes reading difficult, time-consuming and comprehension is affected as well.

Ted will soon be 18 and in the past 8 years we have tried “just about” all-legal medications available in the US, with only a few short-termed successes.

Ted has faced the many challenges of public and peer inquisitiveness and sometimes ridicule with grace, humor and intelligence. He himself, says he is a much more tolerant person – not only of others, but also of himself, for having to deal with TS on a daily basis. Ted has a wonderful close-knit group of friends that have grown up with him and their acceptance of Ted – with his many and varied tics and quirks throughout the years – will always be a source of joy to me. They are great kids. Ted is a delightful guy – kind, goodhearted, generous, intelligent, hardworking and very self-driven. Throughout his years at Arapahoe High School (Littleton Public Schools) he has been on the cross-country team and this year is one of the Captains. He was MVP for his grade freshman, sophomore and junior years. He is in the top 2% of his class (graduating this May). I’m not sure of his academic ranking at present, but I think he’s in the top 10 students (of 500+). His GPA for the seven semesters (so far) stands at 4.0+. He has been honored with two scholarship semi-finalist awards; the Colorado Boettcher Foundation and as a National Merit Scholar. He is well liked by his peers and teachers – as well as neighbors, family and friends. He plays and teaches piano; plays guitar (a little); skis and rock climbs. He’s a pretty typical senior!

I thought you would like to hear about someone who has overcome some of the stigma and problems associated with TS. His outlook on life may inspire others. His college essays were on Tourette syndrome.

Ted has applied to Brown, Amherst, Wesleyan, Oberlin, Vassar, University of Rochester-New York, Dartmouth and University of Colorado. He plans on studying Neuroscience, English and Music.

He really is a great guy!

MOVEMENT DISORDER SYMPOSIUM

“HOPE AND PROGRESS”

September 20, 2003 (Saturday) ~ 8:30 AM to 3:30 PM

Mile Hi Church Community Center ~ Lakewood, CO

(Put this on your calendar – additional information in future mailings)

Dear Members:

We hope you enjoy this Newsletter with articles from around the US; a wonderful poem by Jake Arck that is amazingly insightful and speaks for many TS children; and a letter from Leslie McCarthy about her son Ted that is fantastic and hopeful for all parents! Thank you to all contributors! We would love to publish your stories too, please send them in along with your comments and ideas. Send us a letter, or an e-mail and you may see them in an upcoming issue!

In the last Newsletter, we announced that TSA-RMR received a Grant from Colorado Department of Education to distribute TS information to every District Director of Special Education in the State of Colorado. The distribution of a CD and other material is now underway. Ask the Special Education Director in your child's school to request a "loan" of the material for presentation to the educators and staff at your school. Your participation and communication is very important to further the use of TSA educational material in schools. (Additional copies can be purchased at TSA-RMR). Be part of the presentation and provide TSA-RMR information of your experiences.

We have a new office staff member; Jerry Alley. Jerry joined us in January and brings an extensive technology and marketing background. He has goals of developing broader internet and web-site capabilities for TSA-RMR and general support of our operations. Jerry replaces Pete Bernal who took a new position that did not allow for the part time work with TSA-RMR. Pete promises to continue to help us on various projects that come up in the future.

Thank you to everyone who sent in donations during our annual campaign. Your gifts are greatly appreciated! TSA-RMR continues to struggle and operate on a very limited budget. Only with the support of members, special family gifts, corporate giving and grants like the one described above, will our member services and organizational capabilities continue and grow. There are many ways to give; ask your employer what grants or matching gifts they offer – consider including TSA-RMR in your will; make monthly or quarterly donations; let TSA-RMR be the beneficiary of an event or party. Need ideas? Call us, we are happy to help!

Loree Vanderhye, President



SUPPORT GROUPS

Support Group Meetings Have Changed!

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

Boise, Idaho

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

Denver, Colorado

Family Support Group

February 11 and May 13, 2003 6:30pm - 8:30pm
Swedish Medical Cnt - 501 E. Hampden - Aspen Rm
RSVP & Info: Call TSA-RMR 303-832-4166

Men Only Group

February 25 and May 5, 2003 6:30-8:30pm
Swedish Medical Cnt - 501 E. Hampden - Aspen Rm
RSVP & Info: Call TSA-RMR 303-832-4166

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

Observatory Park. Look for more information in your summer Newsletter!

Longmont, Colorado

Family Support Group

February 26 and May 22, 2003 6:30-8:30pm
Spirit of Peace Church – 1500 Hover Rd, Longmont
RSVP: Contact, Snow Wardell 303-774-9657

Monument, Colorado

Twice per month – Friday's 10:00am-12:00pm at the Monument Library Call TSA-RMR for details.

Kalispell, Montana

Contact: Patricia DiStefano 406-755-8498 Informal discussion groups only--call for information.

Support group contacts have agreed to accept calls and assist in providing information, their comments reflect their personal background and experiences with TS and do not necessarily reflect the views of this chapter.

PUBLICATION ORDER FORM

Please return complete page with your check to:
TSA-RMR – 2020 South Oneida #19, Denver, CO 80224

Dysinhibition Syndrome (Wood & Comings) (Rage in adults/children)	\$25 x ___ = \$ _____
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 (Roadmap to services at schools)	\$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 (TS/ADHD/OCD teaching techniques)	\$35 x ___ = \$ _____
Handbook of Rights to Special Education in Colo.(Legal Ctr)	\$10 x ___ = \$ _____
Video - Twitch & Shout Documentary with TSA-RMR Panel	\$35 x ___ = \$ _____
Video - Bending the Rules - Parent's Guide-	\$10 x ___ = \$ _____
TS Identification Card	\$ 1 x ___ = \$ _____
<i>Add Postage & Handling (under \$25 = \$5.00, over \$25 = \$7.00)</i>	\$ _____
2003 Subscription to TSA-RMR Newsletter	
(includes one TSA-RMR T-Shirt Size _____)	\$ 25.00
Other Contribution Toward _____	\$ _____
Total Enclosed:	\$ _____



Rocky Mountain Region
 2020 S. Oneida St. # 19
 Denver, Colorado 80224
 Phone: (303) 832-4166
 Fax: (303) 861-0515
 E-Mail: tsarmr@att.net
 Website: www.geocities.com/tsarmr

**NON PROFIT
 ORG
 U.S. POSTAGE
 PAID
 DENVER, CO
 PERMIT 2745**

TSA-RMR Newsletter