

Tourette Association of Texas

phone: 281-238-8096 fax: 281-238-0468 toll free: 1-866-896-8484 3919 River Forest Drive Richmond, TX 77406

www.TouretteTexas.org TouretteTexas@aol.com

Thank you for your inquiry to Tourette Texas. You are not alone. Current conservative statistics show 2-3 percent of the population, with one in one hundred (1:100) school age boys and one in three to four hundred (1:3-400) school age girls, are affected by Tourette's syndrome.

Board of Directors

Director of Programs & Development

Sheryl Kadmon, RN Executive Director

Cindy Sacks

Charlie Hart Accountant

Michael Conway

President

Staff

James Poysky, Ph.D.

Vice-President

Christine Hunter, RN, BSN

Secretary

Dianne Migl

Treasurer

Medical Advisory Board

Joseph Jankovic, M.D.

Chairman

Carol Ann Brady, Ph.D. lan J. Butler, M.D. Carlos Guerra, M.D. Joohi Jimenez-Shahed, M.D. Mered Parnes, M.D. James Poysky, Ph.D. Amber Stocco, M.D. Adriana Strutt, Ph.D. Jay Tarnow, M.D. Marcos J. Valdez, M.D. Douglas W. Woods, Ph.D.

Advisory Board

Robert Zeller, M.D.

Robin Morse, J.D.

General Counsel

Catherine Baker Jamie Blassingame, LSSP Sandra Buffolano, M.Ed., LSSP

Carrie Edwards

Rosemary Frederickson, Ph.D., LSSP

Lisa Henry

Christina Johnson, M.D.

Jonathan Kadmon

Kate & Edward Knapek

Amy Lopez

Wendy Marcus-Perez, MSW

Deborah McKim

Sue Page, Ed.D.

Mary Perez, P.T.

Denise Rite

Trish Rubio

Shelley Sekula Gibbs, M.D.

Pam Weaks, M.Ed.

Tammy & Dr. Louis Zegarelli

Enclosed please find:

- · Q & A brochure with general information about T.S. and information about TAA membership. Please note: if you join nationally, you automatically join locally. However, you do not have to become a member to receive any Tourette Texas services.
- Tourette Texas services info
- General Tourette's syndrome facts
- Support group information
- Physician referral
- Specific information regarding tics and other issues
- A teacher packet including:
 - Teacher letter
 - General educational recommendations
 - o Sample child letters for teacher (to be replaced with specific information about your child)
- Volunteer opportunities, sign up for our on-line newsletter, more

We hope you will find the information contained herein supportive. We can assist you in any way necessary to help your family cope with the enigma of Tourette's syndrome.

Remember - your child will almost surely eventually be fine. Statistics prove almost all individuals affected by Tourette's syndrome improve (some dramatically) in adulthood. So there is truly light at the end of the tunnel.

Take heart, educate yourself and contact us at any time.

Sheryl Kadmon, R.N.

Shorel Kadmon

Executive Director



Tourette Association of Texas

phone: 281-238-8096 fax: 281-238-0468

toll free: 1-866-896-8484 www.TouretteTexas.org <u>TouretteTexas@aol.com</u>

P.O. Box 147 Richmond, TX 77406

DESCRIPTION

Tourette's syndrome (TS) is a chronic neurobehavioral (brain-based) movement disorder that begins in childhood. Those affected make motor movements and vocalizations they cannot control. Additionally, many are plagued by Obsessive Compulsive Disorder, Attention Deficit Hyperactivity Disorder and behavioral issues. Today's estimates indicate 3 per center (1 in 33) of children may have Tourette's syndrome. In spite of its high incidence, as of yet there is no cure. The Tourette Syndrome Association of Texas, one of the largest chapters in the country, is a 501(c)(3) non-profit organization. We raise funds to directly assist Texas area families and children in crisis, 24 hours a day, 365 days a year.

MISSION

The Tourette Association of Texas strives to improve the quality of life of individuals with Tourette's syndrome and their families. To this end, we provide on-going community services, practical assistance and support research efforts to cure this devastating disorder.

SERVICES

Educational: In-service programs for professionals, students, parents, and community

Educational programs, conferences, and conventions

Dissemination of information - packets, brochures, telephone

Video-tape and reference library

Referral: **Physicians**

Therapists

Community services

Federal, state and county agencies

Sources of financial aid

Support Groups: Austin

Katy /Sugar Land /West Houston Bryan/ College Station Gulf Coast

Corpus Christi Lubbock

Dallas/Plano North Houston / The Woodlands

Tyler / Longview

East Texas/Golden Triangle Rio Grande Valley Fort Worth San Antonio

Advocacy: Educational and legal empowerment

Counseling: Lay counseling

Professional counseling

Special funding: Patricia Gray Guarno Pranke Educational Scholarship Fund

Weekend children's camping program "du Ballon Rouge"

Tourette Syndrome Movement Disorders Clinic at Baylor College of Medicine and the Learning Support Center at Texas Children's Hospital

Newsletters Brain Bank Program Crisis Intervention

Tourette Texas is a 501(c)3 organization, qualified to receive charitable contributions in accordance with IRS regulations. EIN: 74-2198940

FACTS ABOUT TOURETTE SYNDROME

Answers to Most Commonly Asked Questions

What is Tourette Syndrome (TS)?

It is a complex neurological disorder characterized by tics—involuntary, rapid, sudden movements and/or vocal outbursts that occur repeatedly. TS is often accompanied by obsessive-compulsive disorder (OCD), attention-deficit/hyperactivity disorder (ADHD), poor impulse control, and other behavioral issues. TS typically begins in childhood and can vary widely between individuals, with symptoms ranging from mild to disabling. People with TS often find their own symptoms fluctuating in severity and frequency over the course of their lifetime. Tics can sometimes be suppressed for periods of time, but this may cause discomfort and fatigue.

What are the most common symptoms?

Commonly, motor tics may be eye blinking, head jerking, shoulder shrugging, facial grimacing. Vocally—throat clearing, barking noises, sniffling and tongue clicking. Symptoms change periodically in number, frequency, type and severity—even disappearing for weeks or months at a time.

What is ADHD?

Attention-deficit/hyperactivity disorder (ADHD) is characterized by the three primary symptoms of hyperactivity, impulsivity, and inattention. There are three "types" of AD/HD. Some patients with ADHD are predominantly hyperactive and impulsive (e.g. can't sit still, always fidget, interrupt others, blurt things out or make inappropriate comments, difficulty waiting turn). Some patients with ADHD are predominantly inattentive (e.g. make careless mistakes, have difficulty staying focused, difficulty following instructions or finishing things, are reluctant to do things that require mental effort, forgetful, daydream). Some patients with ADHD demonstrate a combination of the two. Despite increased social awareness, these behaviors are often attributed to "lack of motivation", "not trying hard enough", or "poor parenting". If not properly treated, symptoms of ADHD can significantly interfere with a patient's academic/occupational, social, and emotional functioning.

What is OCD?

Simply put, obsessive-compulsive disorder is characterized by the presence of obsessions and/or compulsions. Obsessions are intense, intrusive, repetitive thoughts such as concerns about evenness and neatness, unfounded or irrational fears (e.g. becoming ill, hurting someone/self, causing a flood or other catastrophe), perverse sexual thoughts, excessive concern about a body part, excessive concern with morality, intrusive words, phrases, music, or images. Compulsions are meaningless and/or irrational rituals such as checking, counting, cleaning, washing, touching, smelling, hoarding, and repeating. People with OCD often feel that something terrible will happen if they do not perform their compulsions. These symptoms can cause significant distress and often interfere with a patient's focus, concentration, and efficiency.

What is the cause of the syndrome?

TS is thought to be due to an abnormally functioning basal ganglia, the portion of the brain deep inside the cerebral hemispheres that is most responsible for controlling the body's movement. Some studies suggest that abnormal regulation of the neurotransmitter dopamine reduces the ability of the basal ganglia to inhibit behavior. Unfortunately, the symptoms of many patients are wrongly attributed to "habits", "allergies", "asthma", "dermatitis", "hyperactivity", "nervousness" or many other conditions.

Is it inherited?

While the exact cause is unknown, TS appears to be genetically inherited in the majority of individuals. Genetic studies indicate that TS is inherited as a dominant gene, with about 50% chance of passing the gene from parent to child. Sons are three to four times more likely than daughters to exhibit TS.

Is obscene language (coprolalia) a typical symptom of TS?

Definitely not. The fact is that cursing, uttering obscenities, and ethnic slurs are manifested by fewer than 10% of people with TS. Too often, however, the media seize upon this symptom for its sensational effect.

Do outbursts of personal ethnic and other slurs by people with TS reflect their true feelings?

Quite the contrary. The very rare use of ethnic slurs stems from an uncontrollable urge to voice the forbidden even when it is directly opposite to the actual beliefs of the person voicing it.

How is TS diagnosed?

Diagnosis is made by observing symptoms and evaluating the history of their onset. No blood analysis, X-ray or other type of medical test can identify this condition. The TS symptoms usually emerge between 5 and 18 years of age.

How is it treated?

Currently, there is no known cure for TS, but many safe and effective treatments are available to alleviate the symptoms. It is essential that the selection of the therapy is individualized and targeted to the most troublesome symptom. Therefore, a comprehensive evaluation is important, as symptoms associated with ADHD, OCD, or other behavioral difficulties may be more problematic than the tics. Tics usually improve with drugs that block or deplete dopamine or injections with botulinum toxin. Central stimulants, atomoxetine, and drugs that act on the adrenaline system are useful in the treatment of ADHD, impulse control and other behavioral symptoms. Serotonin receptor blocking drugs and other medications are often effective in treating symptoms of OCD. Individuals react differently to the various medications, and frequently it takes some time until the right substance and dosage for each person are achieved. Almost all of the medications prescribed for TS treatment do not have a specific FDA indication for the disorder. In addition, tutoring, counseling, and other interventions may be helpful in addressing academic, emotional, social, and behavioral problems that arise as a result of the impact of TS, OCD, and ADHD on patients' daily lives.

Is there a remission?

Many people with TS get better, not worse, as they mature. In a small minority of cases symptoms remit completely in adulthood.

Do TS children have special educational needs?

As a group, children with TS have a higher incidence of academic or artistic giftedness than the population at large. But problems in dealing with tics, often combined with attention-deficit disorder, obsessive-compulsive disorder and other learning issues may call for special education or 504 assistance. Examples of teaching strategies include: technical help such as tape recorders, alpha smarts or computers to assist reading and writing and access to tutoring in a quiet setting.

How many people are affected?

Between two and three percent of the U.S. population may have TS. In Texas, the estimate is over one-half million people with Tourette's syndrome. TS is 3-4 times more common in males and incidence may be as high as 1 in 100 school age boys and 1 in 300-400 school age girls. All ethnic groups are similarly affected.

What is the prognosis?

In general, people with TS lead productive lives and can anticipate a normal life span. Despite problems of varying severity, many reach high levels of achievement and number in their ranks as surgeons, psychiatrists, teachers, executives and professional musicians and athletes.

What is the Tourette Syndrome Association?

TSA is the only national voluntary health organization dedicated to identifying the cause, finding the cure and controlling the effects of this disorder. Its programs of research, professional and public education and individual and family services are made possible through the generosity of donors. The Tourette Syndrome Association of Texas partners with the national Tourette Syndrome Association. TSA of TX, one of the largest chapters in the country, is a 501(c)3 non-profit organization. We raise private funding to assist area families and children in crisis, 24 hours a day, 365 days a year.

Tourette Syndrome Association of Texas, Inc. phone: 281-238-8096 fax: 281-238-0468 toll free: 1-866-896-8484 e-mail: TouretteTexas@aol.com http://TouretteTexas.org Visit us on Facebook

TSA-TX Services:

Advocacy • Counseling • Education • Referrals • Support Groups Special Funding • Camping Program • Newsletters • Brain Bank Program Crisis Intervention with 24 Hour Emergency Response



Tourette Syndrome Association, Inc.
42-40 Bell Blvd. Suite 205 Bayside, NY 11361-2820
Phone: 718-224-2999 fax: 718-279-9596
e-mail: tsa@tsa-usa.org http://tsa-usa.org



Tourette Association of Texas

phone: 281-238-8096 fax: 281-238-0468 toll free: 1-866-896-8484 P.O. Box 147 Richmond, TX 77406 www.TouretteTexas.org TouretteTexas@aol.com

The Tourette Association of Texas strives to support the medical, educational, social and economic needs of Texans with Tourette's Syndrome and to improve their quality of life. All Programs and services are provided without cost to the recipients, nor do we charge dues of any sort.

Tourette Texas's vital and unduplicated work includes:

Advocacy and Consulting: Providing no-cost professional Consulting, Tourette Texas evaluates the "whole" child or adult to recommend and to assist in implementing appropriate medical diagnosis and management, educational needs and accommodations, social skills, career goals, and/or family interactions. Additionally, we advocate with families, physicians, schools and legal entities to ensure the best interests of our clients are always served.

Education and In-Service: Accurate information about Tourette's syndrome is disseminated to physicians, educators, parents and families and at events throughout the state, such as Health Fairs. In-Service presentations are made to school districts and annual Educational presentations are scheduled across the state at the start of school for college students, parents and young adults.

Medical Assistance Program: Financially strapped, under-insured and non-insured individuals are funded for visits to experienced physicians for diagnosis and management of their T.S. symptoms.

Scholarships and Direct Client Services: Deserving and needy families are provided with scholarships for educational assistance and for other necessities.

Support Groups: Meetings at our thirteen Support Groups around the state provide speakers, support, materials and social interaction for families, children and adults dealing with Tourette's syndrome. Currently, T.S. Support Groups are located in Austin, Bryan/College Station, Corpus Christi, Dallas, East Texas/Golden Triangle, Fort Worth, Houston, Katy, Lubbock, Rio Grande Valley, San Antonio, Tyler and the Woodlands.

Camp du Ballon Rouge: Camp dBR hosts Texas children and teens with Tourette's syndrome to a free (the only free T.S. camp in the nation) three day camping weekend at Camp For All in Burton, TX. For most, this camp is the only time they feel free of prejudice or embarrassment about their symptoms. During its 14th year in 2016, nearly 120 children

enjoyed this unique experience. Not counting the many volunteer hours of our physicians, nurses, psychologist, counselors and other staff, the weekend costs Tourette Texas around \$350 per child.

Family Events and Activities: Tourette Texas hosts across-the-state holiday parties, Summer/Back to School parties, pizza parties at support group meetings, and a November "Museum Day," all free of charge to our very often over-whelmed and under-funded families.

Youth Ambassador Program: Tourette Texas helps sponsor and train children and teens to talk about TS. These young people (ages 13-18) speak about T.S. before their peers at school, sports leagues, Scout troops, camps and after school programs, helping to demystify T.S. and spread awareness.

Tourette Texas works to save the lives of those diagnosed with TS and their families. Until a cure for Tourette's syndrome is found, Tourette Texas will work to provide medical assistance and scholarships; offer social activities and events for children, adults and siblings; educate the public and professionals for heightened awareness, sensitivity, and understanding of the disorder; provide professional "whole person" consulting; and advocate for an improved quality of life for its clients.

*Tourette's syndrome (T.S.) is a complex neurological disorder characterized by motor and vocal tics. Symptoms begin in childhood and cause those affected to make movements and noises they cannot control. While not life-threatening, TS is nonetheless often painful, disruptive and isolating. Many with T.S. also have associated conditions such as Attention Deficit Hyperactivity Disorder, Obsessive Compulsive Disorder, and/or learning disabilities. While it is believed to be genetic, the exact cause of the symptoms is still unknown. Studies indicate up to 3% of the population, with approximately 1 in every 100 school age boys and 1 in every 300-400 school age girls, may be afflicted with Tourette's. Although symptoms usually diminish in adulthood, T.S. is considered a lifelong disorder.



For more information, call 281-238-8096; email TouretteTexas@aol.com; visit our website at www.TouretteTexas.org; and "LIKE" us on Facebook at TouretteTexas.

Your TAX-DEDUCTIBLE CONTRIBUTIONS are always welcome.

Tourette Texas is a 501(c)(3) charitable organization, qualified to receive donations in accordance with IRS regulations. EIN: 74-2198940.

TOURETTE TEXAS SUPPORT GROUPS



The following support group leaders and individuals have agreed to accept telephone calls concerning Tourette's syndrome. Although all phone volunteers are well versed in TS, their comments reflect their personal background with TS and do not necessarily reflect the views of the Chapter. For further information, contact the support group leader, visit our website at www.TouretteTexas.org, email us at TouretteTexas@aol.com or call the office at 281-238-8096. All meetings are FREE of charge unless noted.

AUSTIN SUPPORT GROUP

Contact: Kate or Edward Knapek

Email: katecrow17@gmail.com

Meetings: Seton Medical Center

1201 West 38th Street McFadden Auditorium

First Tuesday of most months; 6:30 - 8 pm. NO January/July meetings.

CONCURRENT CHILDREN'S GROUP - Siblings welcome.

Occasional Adult Only meetings.

BRYAN / COLLEGE STATION SUPPORT GROUP

Contact: Steve at Brazosvalleytourettes@gmail.com

Meetings: Peas in a Pod Learning Center

2033 Harvey Mitchell Pkwy S College Station, TX 77840

Quarterly meetings; 6:30 - 8 pm. NO January/July meetings. CONCURRENT CHILDREN'S GROUP - Siblings welcome.

CORPUS CHRISTI SUPPORT GROUP

Contact: Mary Perez at (361) 816-3272

Email: mary-l-perez@sbcglobal.net

Meetings: Driscoll Children's Hospital

3533 S. Alameda Street

Out-Patient Rehabilitation -- Library

Quarterly meetings; 6:00 to 8:00 pm. NO January/July meetings. CONCURRENT CHILDREN'S GROUP - Siblings welcome

DALLAS / NORTH TEXAS SUPPORT GROUP

Contact: Amy at amwa@swbell.net 214-207-5019

Meetings: Brookhaven College

3939 Valley View Lane Farmers Branch, TX 75244-4997

Bldg. X, Rooms X3005 and X3006

Second Saturday of most months; 10:00 am to 12:00 pm. NO January/July meetings.

CONCURRENT CHILDREN'S GROUP; Siblings welcome.

Occasional Adult Only meetings.

FORT WORTH SUPPORT GROUP

Contact: Tammy Zegarelli

Email: ts.ftworth@gmail.com

Meetings: Baylor All Saints Medical Center at Fort Worth

1400 Eighth Avenue Fort Worth 76104

Faxel Conference Room

Second Saturday of most months; 5:30 pm to 7:30 pm. NO January/July meetings.

CONCURRENT CHILDREN'S GROUP; Siblings welcome

GULF COAST SUPPORT GROUP

Contact: Jamie Blassingame jj01ut2005@gmail.com 281-755-7555

Jonathan Kadmon jkadmon@gmail.com

Meetings: Memorial Hermann Southeast Hospital

11800 Astoria Blvd. Houston, 77089

Quarterly meetings, starting in February; 6:30 pm to 8:00 pm CONCURRENT CHILDREN'S GROUP; Siblings welcome

Serving Pearland, Galveston, Clear Lake, Friendswood, Dickinson, Texas City, Manvel,

La Marque, Santa Fe, Alvin, League City, Channelview and more.

KATY/SUGAR LAND/WEST HOUSTON SUPPORT GROUP

Contact: Brenda Johnson

Email: Brenda.Johnson@cfisd.net

Meetings: Memorial St. Catherine Hospital

Bluebonnet Conference Room, Second Floor

701 Fry Rd. Katy 77450

Second Wednesday of most months; 7:00PM. NO January/July meetings.

CONCURRENT CHILDREN'S GROUP; Siblings welcome

LUBBOCK AREA SUPPORT GROUP

Contact: Pam Weaks Email: pzweaks@yahoo.com

Meetings: Covenant Neuroscience Institute

3610 22nd St. Lubbock, TX

3rd Floor Library

Second Sunday of most months, 2:00 pm - 3:30pm. NO January/July meetings.

CONCURRENT CHILDREN'S GROUP; Siblings welcome

NORTH HOUSTON/THE WOODLANDS/SPRING SUPPORT GROUP

Contact: Lisa Henry Email: lmhenry888@gmail.com

Meetings: Memorial Hermann The Woodlands

9250 Pinecroft The Woodlands, TX 77380

Conference Center Room A/B and E/F

Second Thursday of <u>every other month</u> (starting in February), 7:00 pm to 8:30pm. CONCURRENT CHILDREN'S GROUP; Siblings welcome

RIO GRANDE VALLEY SUPPORT GROUP

Contact: Christina Johnson, M.D. 956-458-2417

Email: cpj.mission@gmail.com

Meetings: Mission Regional Medical Center

900 S. Bryan Road Mission, TX 78572 Classrooms A & B

Meets quarterly; 6:00 PM. NO January/July meetings. DAY and TIME may vary. Contact Christina for details.

CONCURRENT CHILDREN'S GROUP; Siblings welcome. Se habla Espanol.

SAN ANTONIO SUPPORT GROUP

Contact: Wendy Marcus-Perez at 210-479-3740

Email: pod1098@aol.com

Meetings: Methodist Healthcare System

8109 Fredericksburg Rd. at Datapoint

Conference Rooms B and C

First Tuesday of most months; 6:30 PM. NO January/July meetings.

CONCURRENT CHILDREN'S GROUP; Siblings welcome

TYLER/LONGVIEW SUPPORT GROUP

Contact: Denise Rite

Email: tourettetyler@gmail.com

Meetings: East Texas Center for Independent Living

4713 Troup Highway Tyler, TX 75703

Tentative Third Saturday of every other month (starting in February); 1:00 to 2:30 PM.

DAY and TIME may vary. Contact Denise for details.

CONCURRENT CHILDREN'S GROUP; Siblings welcome. Free parking.

EAST TEXAS/GOLDEN TRIANGLE SUPPORT GROUP

Contact: Carrie Edwards at (409) 837-2406

Email: tcedwards@windstream.net

Meetings: Held <u>intermittently</u> in rotated locations.

Please contact Carrie or watch web site for updated meeting dates and locations.

Includes Colmesneil, Orange, Jasper, Beaumont, Lumberton, Diboll, Livingston, Nacogdoches and more

The views and recommendations expressed by speaker(s) at these support group meetings are not necessarily endorsed or promoted by Tourette Texas or the Tourette Association of America. The speaker's views are provided for your information only.

New support groups are considered for other Texas cities. <u>If you are interested in starting a group in your area</u>, please contact Sheryl Kadmon, Executive Director of TSA of Texas, at 281-238-8096. Training, materials and support are provided.



PHYSICIAN REFERRAL — AUSTIN, TEMPLE AREAS

Ezam Ghodsi, M.D.
Dilip J. Karnik, M.D.
Jeffrey Kane, M.D.
Jeffrey S. Kerr, M.D.
Michael S. Reardon, M.D.
Karen Richards, M.D.
Pediatric Neurology
'Specially for Children
One Children's Place
1301 Barbara Jordan Blvd., Suite 200
Austin, TX 78723
Phone: 512-628-1850

Patrick Nolan, M.D., Ph.D.

Austin Diagnostic Clinic 12221 N MoPac Expy Austin, Texas 78758 Phone: 512-901-4061

Email: info@adclinic.com

Effective 1/2014 also at Steiner Ranch:

5145 FM 620 North Austin, TX 78732-1815 E. Darrell Crisp, M.D.
Patricia Stewart-Foulks, M.D., F.A.A.P.

Pediatric Neurology Scott & White Clinic 2401 South 31st Street Temple, TX 76508 **Phone:** 254-724-2288

OTHER SPECIALISTS

Gail Allen

Parenting Coach & Family Communication Specialist 2214 Lindell Avenue Austin, TX 78704 Phone: 512-476-7999

Patrice Brumley. M.Ed., BCB, LPC-1 Neurofeedback, Board Certified in Biofeedback Samaritan Center for Counseling 8956 Research Blvd., Bldg. 2 Austin, TX 78758 (512) 451-7337, ext. 236 www.samaritan –center.org Edward Scholwinski, Ph.D./Pres/CEO School & Family Institute

1205 Highway 123, Suite 204 San Marcos, TX 78666

Phone: 512-392-9441/800-511-0162

Fax: 512-392-9448

www.schoolfamilyinstitute.com ed@schoolfamilyinstitute.com

Ann Conolly, B.S. Special Education
Tutoring, Reading & Cognitive Training
5450 Bee Cave Road, Suite 3B
Austin, TX 78746
(512) 657-0126
(512) 777-5044 fax
ann@apluslearningtexas.com
www.apluslearningtexas.com



PHYSICIAN REFERRAL — DALLAS, FORT WORTH, PLANO, TYLER

Janet Collins, M.D.

Psychiatry 8226 Douglas Ave., Suite 805 Dallas, TX 75225

Phone: 214-361-7009 Fax: 214-373-3404

Michael S. McLane, Psy. D.

Clinical Neuropsychology 12880 Hillcrest Road, Suite 110 Dallas, TX 75230

Phone: 972-620-1225 Fax: 972-620-4393

Robert S. Chudnow, M.D. Anthony R. Riela, M.D. Gerald M. So, M.D. Texas Child Neurology 1708 Coit Rd., Suite 150

Plano, TX 75075 Phone: 972-769-9000 Fax: 972-769-0035

www.texaschildneurology.com

RESEARCH

James A. Bibb. Ph.D.

Assistant Professor Department of Psychiatry The University of Texas Southwestern Medical Center 5323 Harry Hines Blvd., NC5,410 Dallas, TX 75390-9070

Phone: 214-648-4168 Fax: 214-648-1293 Roy D. Elterman, M.D.
Steven Linder, M.D.
Kazi Majeed, M.D.
David B. Owen, M.D.
Dallas Pediatric Neurology Associates
Pediatric Neurology
Medical City Dallas, Suite A307

7777 Forest Lane
Dallas, TX 75230-2507

Phone: 972-566-8600 Fax: 972-566-8601

Ray Scardina, M.D.

Trinity Mother Frances Health System 3300 So. Broadway, Suite 102

Tyler, TX 75701 Phone: 903-593-1786

Madhavi Thomas, M.D.

Serving adults and children North Texas Movement Disorders Institute 2004 Bedford Road, Suite 100 Bedford, TX 76021

Phone: 214-432-7549 Fax: 214-432-6137

Laura Wu, M.D.

Neurology/Movement Disorders

ETMC Neurological Institute/Tyler 700 Olympic Plaza, Ste. 850 Tyler, TX 75701

Phone: 903-594-2958

SCHOOL PSYCHOLOGY

Rosemary Frederickson, Ph.D., LSSP

Lewisville Independent School District 136 W. Purnell Street Lewisville, TX 75057

Phone: 469-948-8552 Fax: 972-350-947



PHYSICIAN REFERRAL — HOUSTON, KATY, GALVESTON, THE WOODLANDS

Joseph Jankovic, M.D.

Neurology Baylor College of Medicine 7200 Cambridge Street, Ste. 9A Houston, TX 77030

Phone: 713-798-7438 Fax: 713-798-6808

Ian Butler, M.D.

Pediatric Neurology UT Health Science Center Prof. Bldg. 6410 Fannin, Suite 500 Houston, TX 77030 Phone: 832-325-6516

Fax: 713-512-2248

--or--

Medical Plaza at Memorial Herman Hospital 1120 Medical Plaza Dr., Suite 120 The Woodlands, TX 77380 832-325-6516 Every other Thursday, 1-5pm

Joohi Jimenez-Shahed, M.D.

Neurology Baylor College of Medicine 7200 Cambridge Street, Ste. 9A Houston, TX 77030

Phone: 713-798-7438 Fax: 713-798-6808

Dana Kober, M.D.

Pediatric Psychiatry -Medication/HRT/CBIT Legacy Community Health Baker-Ripley Clinic 6500 Rookin Bldg. B, 2nd Floor Houston, TX 77074 Phone: 832-548-5000

William Ondo, M.D.

Neurology/Movement Disorders UT Health Science Center 6410 Fannin Street, Suite 1014 Houston, TX 77025 Phone: 832-325-7080

Joshua Rotenberg, M.D., M.M.S.

Neurology-Children & Adolescents; Sleep Medicine for all ages Memorial City Medical Plaza I 902 Frostwood Dr., Suite 210 Houston, TX 77024

Phone: 713-464-4107 (877-770-8677 toll free)

www.neurosleep.org

Mered Parnes, M.D.

Pediatric Neurology / Movement Disorders 6701 Fannin Street Clinical Care Center, Suite 1250 Houston, TX 77030 Phone: 832-822-1750

Fax: 832-825-1717

John Slopis, M.D.

Pediatric Neurology 1515 Holcombe Blvd. #431 Houston, TX 77030 Phone: 713-792-2121

Jay Tarnow, M.D.

Child, Adolescent and Adult Psychiatry The Tarnow Center for Self-Management 1001 West Loop South, Suite 215 Houston, TX 77027

Phone: 713-621-9515

PHYSICIAN REFERRAL—HOUSTON CON'T.

Christopher R. Thomas, M.D.

Psychiatry UTMB

Room 3.22, Graves Bldg. D-25 Galveston, TX 77555-0425

Phone: 409-747-9667

Daniela M. White, M.D.

Child, Adolescent and Adult Psychiatry 5225 Katy Freeway, Suite 650 Houston, TX 77007

Phone: 713-426-3100 Fax: 713-426-3102 Douglas W. Woods, Ph.D.

Professor & Head of Psychology/C-BIT Texas A&M University

4235 TAMU 515 Coke Street College Station, TX 77843

Phone: 979-845-2540 / 979-845-2581

Robert Zeller, M.D.

Pediatric Neurology / Movement Disorders

6701 Fannin Street, Suite 1250

Houston, TX 77030 **Phone:** 832-822-5046

THERAPISTS WITH EXPERTISE IN T.S.

Carol Ann Brady, Ph.D. Patrick Brady, Ph.D.

2211 Norfolk St. #500 Houston, TX 77098

Phone: 713-526-6085

Lyle Cadenhead, M.D.

Phone: 713-942-2330

Bilingual

Scottie Holton, M.Ed., LPC

16300 Katy Freeway, Suite 100

Houston, TX 77094

Phone: 281-398-7070

Fax: 281-492-2751

Maren Jones, Ph.D.

Phone: 713-526-6085

Richard Newman

Phone: 713-850-1980 ext. 308 Runs high school group in Katy

Patricia Perrin, Ph.D.

Phone: 713-622-3999

James Poysky, Ph.D.

Parenting strategies for oppositional &

argumentative children

Neuropsychologist 21384 Provincial Blvd.

Katy, TX 77450

Phone: 281-829-1599

Fax: 713-264-8607

www.katychildpsychology.com

Julie Sherman, Ph.D.

Psychologist/Biofeedback/Neurofeedback

Beaumont, TX

Phone: 409-225-5796

Adriana M. Strutt, Ph.D., ABPP-CN

Neuropsychologist

Baylor College of Medicine

7200 Cambridge Street, Ste. 9A Houston,

TX 77030

Phone: 713-798-8678

David Wood, Ph.D.

Phone: 713-526-6085

PHYSICIAN REFERRAL—HOUSTON CON'T.

DIAGNOSTICS AND TESTING

James Poysky, Ph.D.

Includes testing for school problems

Neuropsychologist

Katy Child Psychology Associates, PLLC

21384 Provincial Blvd.

Katy, TX 77450

Phone: 281-829-1599

Fax: 713-264-8607

www.katychildpsychology.com

Bonnie Brookshire, Ph.D.

Phone: 713-664-5838

Linda Ewing-Cobbs, Ph.D.

Phone: 713-500-8300

BIOFEEDBACK / NEUROFEEDBACK

Vicki Jones, LCSW

2211 Norfolk St., Suite 140

Houston, TX 77098

Phone: 713-523-0628

www.smarterway.com

Julie Sherman, Ph.D.

Psychologist/Biofeedback/Neurofeedback

Beaumont, TX

Phone: 409-225-5796

TUTORING

Gittel Tanenbaum

Academic Tutoring Services www.HoustonMatchCoach.com Elementary, Middle, High School Math, Geography, History, SAT, ACT, Reading, Essays, more

Phone: 713-417-6867

DIETICIAN

Margaret Farnsworth, MA, RD, LD

The Methodist Hospital 6565 Fannin Street, BB1.011 Houston, TX 77030

Phone: 713-441-2147



PHYSICIAN REFERRAL — SAN ANTONIO, CORPUS CHRISTI, RIO GRANDE VALLEY

SAN ANTONIO

Eric Pappert, M.D.

Teen and Adult Neurology 2379 N.E. Loop 410 San Antonio, TX 78217

Phone: 210-656-2333

Jeslina Raj, Psy.D.

Comprehensive Behavior Intervention for Tics (CBIT)
Be Well Center
University of Texas Health Science Center at San Antonio
Department of Psychiatry
7703 Floyd Curl Drive
San Antonio. TX 78229

Juan Ramirez-Castaneda, M.D.

Neurology – Movement Disorders University of Texas Health Science Center 8300 Floyd Curl Drive, MC 7883 San Antonio, TX 78229 Phone: 210-450-0500

Fax: 210-450-0500

Phone: 210-562-5413

Jorge A. Saravia, M.D.

Pediatric Neurology 2829 Babcock Rd. San Antonio, TX 78229 **Phone:** 210-614-3657

Tracy Schillerstrom, M.D., P.A.

Child & Adolescent Psychiatry 2135 Babcock Road San Antonio, TX 78229 **Phone:** 210-614-7070

APPOINTMENTS: 210-614-0300 ext 2100 (ask for Nathan)

Subhashie Wijemanne, M.D.

Neurology – Movement Disorders University of Texas Health Science Center 8300 Floyd Curl Drive, MC 7883 San Antonio, TX 78229

Phone: 210-450-0500 Fax: 210-562-9366

CORPUS CHRISTI

Marcos J. Valdez, M.D., P.A. Child Neurology / Sleep Disorders Driscoll Children's Hospital 3533 S. Alameda Street Corpus Christi, TX 78411

Phone: 361-694-6747 Fax: 361-808-2070

Carol DeLine, M.D.

Pediatric Neurology Driscoll Children's Hospital 3533 S. Alameda Street Corpus Christi, TX 78411 **Phone:** 361-694-6747

Fax: 361-808-2070

Amy Bowers, LCSW

Counseling 5866 S. Staples, Suite 316 Corpus Christi, TX 78413 361-442-7923

EL PASO

Boris Kaim, M.D. Psychiatry / Sleep Disorders 2311 N. Mesa St., Ste. F El Paso, TX 79902 Phone: 915-544-6400

Categories of Tics

Motor Vocal (phonic)

Simple Simple Complex

Motor Tics

Simple:

Abrupt, sudden, single or repetitive, isolated movements occurring out of a background of normal activity

Examples:

Blinking, transient eye deviations, nose twitching, mouth and jaw movements, head jerks, shoulder shrugs, finger movements, abdominal muscle contractions.

Complex:

Coordinated patterns of sequential movements, slower and longer, may resemble normal movements but are inappropriate, instance and timed.

Examples:

Touching, throwing, hitting, jumping, kicking, squatting, hand gesturing, grabbing, copropraxia, echopraxia, head shaking, facial grimacing, trunk-pelvic gyrating, and bending movements.

Vocal (phonic) Tics

Simple

Single sounds or noises

Examples:

Throat clearing, grunting, sniffing, squeaking, coughing, barking, humming, screaming, whistling, blowing, sucking.

Complex:

Verbalizations

Examples:

Coprolalia, echolalia, palilalia

Vocal Tics II

Linguistically meaningful utterances

"Shut up"

"Oh, ok"

"Now you've done it"

Speech atypicalities

Unusual rhythms, tones, intensity of speech (especially loud), stuttering, or "baby talk"

Phenomenology of Tics

- Involuntary
- · Waxing and waning in frequency, intensity, and distribution
- May be volitionally suppressed (temporarily) through intense mental effort
- · Exacerbate with stress, excitement, fatigue, boredom, and heat exposure
- · May be suppressed during mental or physical tasks requiring intense concentration
- Are characterized by suggestibility

AND CHAPTER Helping Children & Changing Lives

Generic Academic and Behavioral Accommodations/Modifications

(are appropriate for almost every student with T.S.—either 504 or OHI)

I. Episodic Issues

(Tourette's syndrome waxes and wanes and changes over time with no measure of predictability.)

- A. Plan for worst case scenario be proactive.
- B. Practice flexibility with academic and behavioral expectations, especially when symptoms are exacerbated.

II. Tics

(Parents - please write a symptom list to present. Update as tics change.)

- A. Increased movement in classroom
- B. Extended time for test taking.
 - 1. Increased difficulty testing due to blinking, hand, shoulder and torso movements
- C. No timed tests
 - 1. Increased anxiety increases tics
- D. Safe place to discharge tics or emotions
 - Pass to Nurse or other previously designated area
- E. Preferential seating back of classroom close to door

III. Dysgraphia

(Over 90% of all boys with T.S. are dysgraphic)

- A. Decrease all paper and pencil tasks
- B. Provide notes (student must still attempt note taking)
- C. Provide copy of homework assignment
- D. Fill-in-the-blank overheads and worksheets
- E. Use of keyboard/computer whenever possible
- F. iPad
- G. Allow dictation: Scribe at home/school if necessary

- H. Shorten assignments without changing content
- I. Extended time to complete assignments
- Allow oral responses
- K. Allow voice-activated computer typing programs

IV. ADHD

(Intrinsic disorganization)

- Special Homework Plan will avoid a string of zeros (Mom will need to check binder every day at first)
 - 1. Extra home set of textbooks
 - 2. Parent-generated emails Tuesday and Thursday regarding assignments due and/or missing
 - 3. Extended time (1-2 days) to complete missing assignments without penalty
- B. Short structured breaks
 - 1. Laminated pass for one three-minute break per 20 50 minutes
- C. Allow increased movement in classroom
- D. Single instruction or directive

V. Obsessive Compulsive Disorder (OCD)

- A. Allow routines which are not disabling or intrusive, e.g., flipping light switch, sharpening pencil
- B. Provide compensatory strategies/objects for annoying behavior:
 - 1. Soft object on end of pencil for tapping
 - 2. Place in front of line and instruct to keep one arm length between others for compulsive touching
 - 3. "Chewelry" for chewing shirts, pencils or other objects
- C. Assess inattention (intrusive thoughts seriously disrupt learning)
- D. Avoid direct confrontation. Use redirection whenever possible to prevent obsessive-compulsive neuro-rigidity "oppositionality."
- E. Provide transition time. (Allows brain to disengage and engage.)
- F. Provide reassurance for worries, fears or extreme perfection.

VI. <u>Tactile Issues</u>

Hypersensitivity to noise and crowds

A. Early dismissal from classroom (2-3 minutes)

B. Use of earphones, earplugs, darkened glasses during designated times

VII. <u>Directives for Implementation of Behavioral Accommodations</u>

Contained classroom is not necessary nor appropriate to implement.

- A. Planned ignoring tics
 - 1. Tics will worsen if attention is focused on them (increasing anxiety)
 - 2. Pass to Nurse for a short time if tics are overwhelming or disruptive
- Use calm, quiet voice for directives and corrections (Child is neurologically over stimulated; quiet voice will help refocus)
- C. Avoid direct confrontation. Use redirection whenever possible to prevent obsessive-compulsive neuro-rigidity "oppositionality."
- Transition time both physically and for directives (Allows brain to engage and disengage from tasks)
- E. Stepwise directives and rules
- F. Provide structure and clear understanding of expectations with flexibility for waxing and waning of symptoms
- G. Provide increased supervision in unstructured settings, i.e., lunch, P.E. and recess
- H. Quiet area to regroup/gain control when over-stimulated
- I. Use positive reinforcement
- J. Do not apply immediate consequences (whenever possible) after escalated behavior has occurred. Wait until child has calmed before disciplining. (Will avoid continued or rapid re-escalation.)

VIII. Education of peers and school staff

The Golden Rule: Avoid academic frustration, utilizing appropriate accommodations and by teaching compensatory strategies.

Goal: Always move the child to the norm.

** Remember that stress exacerbates all symptoms and behaviors **

The Tourette Association of Texas 3919 River Forest Drive Richmond, TX 77406

281-238-8096 * 866-896-8484 * 281-2380468 fax TouretteTexas@aol.com www.TouretteTexas.org

Generic Academic and Behavioral Accommodations/Modifications

8/29/2015

Debunking myths and misconceptions about Tourette Syndrome and Tic Disorders

by Dr. Kevin McNaught, Executive Vice President, Research and Medical Programs, Tourette Association of America

Movies and the media often characterize or portray Tourette Syndrome and other Tic disorders as conditions defined by emotional outbursts and uncontrollable vocal obscenities. This mainstream depiction has led many to dub Tourette the "cursing disorder." Yet, Tourette is not an emotional disorder and only a small subset vocalize socially unacceptable words or phrases. These widespread misunderstandings have served to alienate those living with TS while stunting efforts to accurately define the condition as a treatable neurological disorder, rather than an emotional or behavioral disability.

Ranging from a lack of awareness of the complex and varied nature of its symptoms to the misreporting of its prevalence rate, parents, teachers, children and even some physicians are not aware of the FACTS about Tourette Syndrome and Tic disorders. I've outlined the most common myths and misconceptions surrounding Tourette on behalf of the Tourette Association of America and hope that you'll help us advocate and reinforce the FACTS.

Myth #1: Everyone with Tourette Syndrome (TS) blurts out obscenities.

FACT: While frequently portrayed in the media as a common symptom of TS, in reality the excessive and uncontrollable use of foul or obscene language, known as coprolalia, only affects 10% of individuals with TS. For those who do have coprolalia, the outbursts they experience are completely involuntary and they often try to mask the obscenities. This myth is important to rectify as it often leads to prejudices against people with TS.

Myth #2: Everyone who has tics also has TS.

FACT: Tic conditions are part of a spectrum that ranges from simple, temporary tics lasting for a few weeks or months, to situations where there are multiple complex tics in one or more parts of the body and which can be permanent. Within each situation, there is also a range of severity from mild and infrequent to severe and disabling. In order to be diagnosed with TS, an individual must have a history of a number of motor tics and at least once vocal tic, with tics being present on and off for more than a year. In contrast, a person may have a diagnosis of "chronic motor or vocal tic disorder" where either but not both types of tics are present for at least 1 year.

Myth #3: People with TS can control their movements and sounds if they really want to.

FACT: The physical and vocal tics associated with TS are thought to be the result of altered brain structure and function and are thus involuntary (like a sneeze) or uncontrollable. Some individuals have the ability to temporarily interrupt the expression of their tics, but this is unusual and is not lasting. With behavioral therapy, some people can learn to manage their tics, but successful response to behavior therapy does not mean the tics were a behavioral issue rather than a neurological problem.

Myth #4: If I can't see the tics, they must be doing better.

FACT: Individuals with TS, especially children, may temporarily suppress tics and other symptoms with or without behavior therapy in order to fit in or feel "normal." While symptoms evolve over the years and some tics come and go, a lack of visual tics does not mean an individual is "doing better" or "cured."

Myth #5: TS is caused by stress or an unhappy childhood.

FACT: While stress can worsen the symptoms of TS for certain individuals, it is not the cause of TS. The precise cause remains unknown; however, current studies indicate that TS likely has a significant genetic component (meaning it is likely inherited). Prenatal, perinatal, autoimmune, and environmental factors may also contribute to or modulate the development of TS.

Myth #6: Tics only occur in children.

FACT: Although TS and tics are more frequently seen in children, these conditions occur in all age groups. Indeed, while childhood tics can decline as an individual gets older, many adults live their entire life with persistent tics which can range from mild to severe. However, in order for an individual to receive a diagnosis of TS, the tics must begin prior to the age of 18.

Myth #7: People with TS suffer from mental illness.

FACT: Although often treated by psychiatrists, Tourette is not a mental or psychiatric illness. Rather, it is a movement disorder that often occurs along with other psychiatric conditions such as obsessive compulsive disorder, attention deficit hyperactivity disorder, anxiety, etc.

Myth #8: People with TS are not as intelligent as others.

FACT: Individuals living with TS are as intelligent as those who do not have TS. However, a portion of people with TS do also have learning disabilities or other comorbidities such as OCD, ADHD and anxiety disorder. For this reason, if tics and other associated learning disabilities interfere with an individual's ability to perform in school or gain social acceptance, adjustments may be needed to create a learning environment conducive to the individual's needs.

Myth #9: People with TS can't lead normal lives.

FACT: While TS can have a profoundly negative impact on the lifestyle of some individuals, others can lead rich and fulfilling lives. Many people with TS are high-achievers, and find that their tics tend to subside when they are concentrating hard on a task. This accounts for the fact that people with TS have gone on to become successful musicians, surgeons and athletes among many other notable professions.

Myth #10: TS is more common among certain ethnic groups than others.

FACT: TS does not affect one racial or ethnic group more than another.

Kevin St. P. McNaught, Ph.D., is Executive Vice President for Research and Medical Programs at the Tourette Association of America, the only nationwide organization serving the Tourette community. The Association works to raise awareness, fund research and provide on-going support. Dr. McNaught guides the development, implementation and management of the Association's medical, scientific and therapeutics research and forges collaborations with the pharmaceutical industry. In addition, he oversees the Association's external advisory boards and serves as liaison with government agencies addressing childhood brain disorders.

To learn more visit: www.tourette.org or www.TouretteTexas.org

EXPECT THE UNEXPECTED

by Carol Ann Brady, Ph. D.

As a clinical psychologist it is often my privilege to work with youngsters who have been diagnosed with Tourette's syndrome. Because of diverse, and an often unpredictable range of symptoms and their involuntary origin, my approach must necessarily be different. I must often train myself never to go by the book and, most importantly, to expect the unexpected. Tourette's syndrome is a complex neurobehavioral movement disorder characterized by involuntary movements and sounds called tics. The onset of symptoms must occur between the ages of two and 21, they must wax and wane, and they must be present throughout a period of more than one year. Additionally, most children will exhibit co-existing behavioral problems including obsessive/compulsive disorder, attention deficit disorder with or without hyperactivity, and aggressive and oppositional behaviors. They may also be learning disabled. Although the clinician may expect vocal tics and motor movements to some degree, what often is more subtle and interwoven are the psychological and behavioral problems that co-exist with Tourette's syndrome. These vary by individuals, but again will often include attentional problems, lack of impulse control, irritability, oppositionalism, obsessiveness, and compulsiveness. Also included may be more classic signs of anxiety and depression or over-involvement with sexual content, with all the above leading to not winning friends and influencing people, particularly during the teenage years.

On a day-to-day basis, a Tourette's child is often besieged by a myriad of demands saying to him, "control yourself". So many have despondently retorted, "I cannot". Oftentimes school and parents misunderstand that the associated symptoms are part and parcel of the syndrome. The significance of this is to expect that the child may be able to control or behave as youngsters can in all other areas with the exception of the motor and vocal tics. As I have come to understand from the youngsters who have trained me so well in their disorder, it is all intrinsically interwoven and part of the same syndrome. Interestingly enough, unlike the child who clearly suffers from an emotional problem, the Tourette's youngster may be horrified or otherwise upset that there is absolutely no control. While he or she may have a well-developed conscience, there may be occasions of seeming oblivious to any type of punishment. In essence, these children simply do not react in the usual way to traditional techniques.

For most children with bad behavior, behavior modification will be applied in which a contingency of time-out is given at the onset of inappropriate behavior and then the behavior will remediate. With Tourette youngsters, however, I find that, unless they can finish the thought, deed, or activity they are engaged in, they cannot interrupt that chain to move on to a new one. In the playroom, I often observed this. Often a story is compulsively reported over again many times before the issue can be dropped. This has the feel of a demanding, and sometimes one assumes, spoiled youngster who cannot deal with not getting his or her own way. It is, I think, not so much not getting their own way that drives these children as it is that they cannot give up on an idea or thought until it reaches some natural conclusion.

Unfortunately, sometimes the conclusion is for the grownups around them to become extremely upset to the point where a new problem moves into the arena, that being the upsetness of the parent over-shadowing and overwhelming the child's immediate particular need. Constant reprimands result in a vicious cycle. When thwarted, often a temper tantrum will ensue much to the annoyance of parents and teachers. So many times I have seen these youngsters on the way out the door say, "We must go to the toy store after the session", "We must have a friend over", or "I insist we take an extra sticker".

These are just some examples of what I feel is part of the big picture. By the same token, to expect the unexpected in youngsters with Tourette's syndrome is also to be happily surprised that they can be so responsive. Just when it appears that there is no chance for them to talk about what really is on their minds, they will open up and spill the beans.

Often medication clearly helps with some of the symptomatic behavior. However, frequently I see a parent go from medication to medication in search of a solution only to find subsequently that a new search is needed because the symptoms have changed. This can be a never-ending process, especially when parents reject the necessary but tiring search for the correct medication to accentuate the positive without significant unmanageable side-effects.

While psychotherapy cannot cure a vocal tic or an involuntary motor movement caused by the neurological aspects of this disorder, psychotherapy has its place. Often youngsters, because of associated learning and social disabilities, have problems with self-esteem. They need to have a forum that will provide a chance for them to talk about how painful, psychologically, it is to have so little control over what others seem to come by so easily. Psychotherapy also provides support for the family to change the rules, to not expect what they expect from other youngsters, to capitalize on the unexpected, and, most of all, to not take some of the loud tirades and diatribes too personally. It is not that these youngsters fail to appreciate or care about their parents, rather that, at times, they are helpless victims of a disorder that leads them to tantrum at the drop of a hat. The family, as with any special needs child, needs to come to terms with the fact that their child is on a rollercoasterlike syndrome in which the symptoms will wax and wane and change over time. Although all symptoms will usually worsen during puberty, many will, after adolescence, significantly recover control over their motor and vocal functions. Most will go on to have at least a marked decrease in symptoms. Despite this fact, many of the young adults I have seen who have been down this road still show some problems in judgment and in a sense-of-self, due to an inability to find prospects for themselves supported by misunderstandings about what they and others think and say about the disorder or a tendency to react strongly to minor insults and disappointments. So the legacy of this syndrome may continue in some form or fashion, although more masked from the glaring eyes of the observer and critics in the outside world.

On the positive side, people working with Tourette patients will often be pleasantly surprised. What also is to be expected is a challenging and rewarding involvement with youngsters who show more courage and bravery than ever thought possible. Significant adults need to accept the fact that the behavioral symptoms, tantruming, and repeated instances are a part of the Tourette's syndrome. Take care, caretakers, for with a Tourette's syndrome youngster, only patience and skillful response can counter the behavior and, of course, it helps to expect the unexpected.

Carol Ann Brady, Ph.D. has been on the Tourette Syndrome Association of Texas Medical Advisory Board for over twenty years. She was named one of the "10 Best Child Psychologists in the Country" by *Town and Country Magazine* and is a staff writer for *ADDitute Magazine*.

General Educational Recommendations

- Classify Tourette student as Other Health Impaired (OHI) / Special Education or Section 504 / Regular Education
- Individual Education Plan (IEP):

Each Tourette child is unique because of diverse range of symptoms.

Assessed for associated learning disabilities (LD)

Use of ancillary professional services:

School counselor / psychologist, OT, PT, adaptive PE

Placed in regular classroom with modifications as necessary

- Common Adaptations:
 - Decrease all paper and pencil tasks
 - Preferential seating
 - Copy of notes provided by teacher / NCR paper
 - Shorten writing assignments or oral assignments
 - Use of scribe
 - Use of graph paper
 - Use tape recorders, calculators, and computers when necessary
 - Oral testing
 - No timed testing
 - Frequent breaks
 - Extend time to complete assignments
 - Safe place to discharge tics or emotions
 - Allow frequent movement in classroom
 - Special homework plan:

Bi-weekly communication via email generated by parent (Tu/Thur)
Trapper Keeper or special homework folder
Weekly assignment sheet of homework and test dates
Set of textbooks to keep at home

Education of peers and school staff

Sample Child Letter #1 – "All About Bobby"

General Notes

- Update the note as it pertains to the current status of child (as symptoms wax and wane over time with no measure of predictability)
- Use colorful paper to be easily distinguished from other papers teacher receives
- Place in a pocket folder so additional info can be added as needed
- Add M & Ms-- Chocolate is always helpful
- Include a "Have a Great School Year" card to the teacher
- Include pertinent information from TSA packet, e.g., TS Fact Sheet, Q&A and Teacher letter. Do not enclose too much information initially, as teacher may be overwhelmed and delay reading.

Bobby - Symptoms at a Glance

Tics: (Motor)

- Twirling around
- Jerking his arm, neck, fingers, stomach
- · Stretching his mouth
- Taking a skip backwards with his feet, while walking
- Hitting his hand, elbow, or head on desk

Tics: (Vocal)

- Making "Mmm" noises
- Saying "Excuse Me" or "Sorry" repeatedly, other words
- Loud sniffing
- Clearing throat
- Loud "Whoo" sound

OCD:

- Difficulty with changes in routine
- Difficulty transitioning, gets "stuck" on thought or task

ADHD:

- Easily overwhelmed and frustrated
- Impulsive or restless
- Trouble with social cues
- Disorganized, forgetful
- Trouble staying on task

Dysgraphia:

- Difficulty with paper and pencil tasks
- Writing very slow and laborious
- Trouble keeping up with taking notes

Other:

- Drowsiness from medicine
- Headache when frustrated, overwhelmed, tired
- Writing varies, sometimes not very legible

Ways to help him cope:

- Giving a brief time for Bobby to tell the class about his TS and allow for class questions
- Drink of water from a water fountain or water bottle in backpack
- Breath of fresh air, quick outside walk
- Quick walk in the hall or to the bathroom
- Deep breaths
- Rubbing neck or back
- Distraction of some sort
- Change in task for a brief time, then back to the task at hand
- If absolutely necessary, trip to the clinic
 - *Nurse might allow a 10-15 min. rest, and then return to class
- **Important to let him know what he may have missed while out of class. **

Sample Child Letter #1 - "All About Bobby" Continued

Dear Teacher:

This is a little information to help you get to know Bobby this year.

Bobby loves animals, riding horses, drawing, playing guitar, riding bikes, swimming, and video games. He is involved in our church youth group and mission teams, FFA, and the Tourette Syndrome Support Group. Since the age of six, Bobby has been diagnosed with Tourette's syndrome. Bobby also has an older brother with TS who graduated from XX High School in 200X.

What Tourette's syndrome is: Tourette's syndrome (TS) is a neurobehavioral (brain-based) movement disorder characterized by motor and vocal tics. Beginning in childhood, it causes those affected to make movements and noises they cannot control. Additionally, many are plagued by obsessive-compulsive disorder (OCD), attention-deficit-hyperactivity disorder (ADHD), oppositional behavior, and other disorders. Although medications may help control the symptoms, as of yet there is no cure.

Bobby takes a variety of medicines to help control the symptoms associated with his condition. Unfortunately, drowsiness, stomachaches, and headaches are common side effects of most of these medicines. Drowsiness will usually be noticed more in the morning classes or after lunch time. Bobby is currently under the care of a doctor and medicines are constantly observed and adjusted as needed. Tics do change often and can intensify during stressful times or when attention is drawn to them. Tics will usually increase when Bobby becomes upset, frustrated, tense or anxious. It is difficult to make it through a school day when teased, mocked, or even bullied. It proves very helpful for X Bobby to have the opportunity to explain his TS to the class and even to allow for questions. It is best to ignore the tics unless it becomes too great a distraction for the other students.

In many cases, students with Tourette's syndrome are immature for their age. As much as we have encouraged and worked with Bobby, he is still quite disorganized, forgetful, has trouble focusing, and has difficulty staying on task. He will forget to write his daily assignments, test dates, information from a board, etc. It would be a tremendous help for Bobby to be reminded and also checked to see if he has all of the needed information so that homework may be completed at home. Setting up an email system for communication so that we both can encourage him to keep up with his daily work and studies is great. You're always welcome to phone as well.

Bobby also has dysgraphia – a mechanical difficulty with paper and pencil tasks. This causes writing to be extremely slow at times and extremely laborious which causes him to have difficulty ore even makes it impossible to keep up the pace with note taking. While always encouraged to try to write his own notes, he should be provided with hard copies which will aid him in his daily homework, studying for quizzes, tests, etc.

You are a very important part of Bobby's life. We know that you are concerned with not only the academics but the self-esteem of each of your students. It is a great privilege and challenge to teach and reach every individual in your classroom and encourage them to reach for their full potential. We will support you fully and encourage Bobby to do his best in all things. Through the TSA of Texas, we have access to videos, DVDs, and more detailed information if you are interested in learning more about Tourette's syndrome.

If we can be of any assistance to you, please feel free to contact us at any time. We are looking forward to working together with you to make this a great year.

Parent's name Include all phone numbers and Email address

Sample Child Letter #2 – "All About Brian"

Brian has a neurological disorder called Tourette's syndrome. The most meaningful definition that I have found of TS is that it is a disorder of "faulty brakes." Students with TS have to constantly struggle to stop a behavior, thought, or action. At times, these brakes don't work at all and other time the brakes freeze and the children get mentally stuck. This makes it difficult for these kids to be flexible. TS is also characterized by involuntary motor and vocal tics. Brian has vocal tics (yelling out) and some facial movements. Tics change often and can intensify during stressful times or when attention is drawn to them. It is best to ignore the tics while teaching.

Most TS kids, including Brian, also have Obsessive Compulsive Disorder (OCD). Most of Brian's OCD is intrusive thoughts so this is not something you will se, but it does cause him to be off task with his schoolwork. He may have a hard time completing tests. Brian can also get "stuck" on a thought and have a hard time transitioning.

Brian has had anger problems in the past, but he is trying very hard to control them. Every once in a while, he has a difficult time suppressing the anger. Mostly this happens when he feels threatened in some way. If another kid makes fun of him, he may lash out. Also in the past, if he was obsessed with a thought and couldn't get off of that thought, he would get angry. You will know when he gets angry, because you can see it in his face, and he may say inappropriate words. One way to handle the anger is to distract him. It is easy to distract Brian because he loves animals. He adores out golden retriever named Sammy, and he could talk about her forever. Another distraction that the teachers used last year was to send him to another class with a note. The note doesn't even have to have anything on it; it is just a way to remove him from the situation. Discipline does not work during anger episodes. Discipline comes later.

Brian can also be impulsive. His 5th grade teachers said he would act without thinking, especially yelling out answers in class. He may make inappropriate comments when called upon. The best way to handle this is to go to him and let him know he can talk to you after class. These kids have to be taught through practice and more practice the reasoning process that those of us without impulsivity take for granted.

Brian gets tired easily because he is constantly working at holding in the ties. When he does get overwhelmed, he lays his head on the desk and appears to be sleeping, but he hears everything the teachers say. As long as he's not disturbing anyone, let him be. There is something I read from the TSA National office, and it has stuck with me. It read, "We recognize how vastly important it is for the child growing up with TS to have an understanding and united support system with parents and teachers working together, so that these kids may have the best chance of emerging into adulthood with that all important sense of self-esteem."

If you have any questions or concerns, please call or email me.

Help TSA of Texas every time you shop for groceries!

Kroger. Ask the cashier or the courtesy desk staff to link your Remarkable card or your Kroger Plus card to TSA of Texas. The stores will donate a percentage of your eligible purchases to Print out any or all of the cards below and take them to your local Tom Thumb, Randalls or If you have trouble printing these cards, email Cindy at TouretteTexas(a aol. com. TSA of Texas. How easy is that?! Ask your friends & family to link their cards also.







Support Tourette Texas by shopping at Kroger with your Kroger Plus Card!

If you have already enrolled, please re-enroll each year starting in August- required by Kroger.

Link your Kroger Plus Card to **Tourette Association of Texas NPO #82092** starting August 1, 2015, and every time you purchase at Kroger, a percentage will go to the Kroger Community Rewards Fund, and a portion of the proceeds will be donated to Tourette Texas! All supporters must have a registered Kroger Plus Card account online to be able to link their card to an organization.

Do you use your phone number at the register? Call 800-576-4377 and select option 4 to get your Plus Card number.

Register online at www.KrogerCommunityRewards.com. If you are a new online customer, click on SIGN UP TODAY to register.

If you have problems signing in or creating an account please call Kroger Online Account Customer Service: 1-866-221-4141 or email TouretteTexas@aol.com for more information.

Help Tourette Texas While Shopping!



AmazonSmile is a simple and automatic way for you to support the Tourette Syndrome Association of Texas every time you shop, at no cost to you. When you shop at smile.amazon.com, Amazon will donate a portion (0.5%) of the purchase price to TSA! To shop at AmazonSmile simply click on your computer or mobile device. You may also want to add a bookmark to AmazonSmile to make it even easier to return and start your shopping at AmazonSmile.

http://smile.amazon.com/ch/74-2198940

or look for Tourette Association of Texas (Richmond address)



Join <u>iGive.com</u> -- which has links to hundreds of sites including Neiman Marcus, Gilt, Hilton Hotels and HUNDREDS more -- and link to Tourette's Association Texas - Gulf Coast. <u>www.iGive.com/TourettesAssociationTexas-GulfCoast</u>



Tourette Association of Texas

phone: 281-238-8096 fax: 281-238-0468 toll free: 1-866-896-8484

CASH DONATION

Please complete the necessary information below. You will receive a tax letter for your files. If being sent as a **tribute**, the honoree will receive a card acknowledging your donation (sans amount). Please print your information for clarity.

Your Name:		
Company (if applicable):		
Your Address:		
City:		Zip:
Phone:	Email:	
Amount of Enclosed Donation:	Check Encl	osed # (payable to Tourette Texas)
Credit Card:	Exp. Date	e:
Name on Card:	(AmE	x/Visa/MC/Discover accepted)
PLEASE FILL OUT THIS SECTIO		
Donated in name of:		
Their address:		
City:		
In Honor of (occasion):		
ORIn memory of:		
Other:		
Donor's Signature:	Dat	2:

Please mail your donation to:

Tourette Association of Texas 3919 River Forest Drive Richmond, TX 77406

Or fax form with credit card info to: 281-238-0468

WOULD YOU LIKE TO HELP SPONSOR A CHILD AT OUR WEEKEND TOURETTE CAMP?

Camp du Ballon Rouge



Tourette Texas Weekend Camping Program

Camp du Ballon Rouge, celebrting its 14th annual weekend in 2016, continues to be successful beyond all expectations. This is possible only through the incredible generosity and support of our donors.

Nestled in the Texas Hill Country, dBR is truly a magical place of hope where unprecedented acceptance and lasting friendships are the norm, and where differences usually so prevalent fade into a background of boisterous fun. Will you please assist us with this unique opportunity for our T,S, kids? You can truly make miracles happen.

Du Ballon Rouge is the only program of its kind in the country, where Texas children with Tourette's can attend <u>tuition-free</u>. The facilities, counselors, nursing staff, physicians, meals, activities and crafts are all provided by Tourette Texas – at a cost of around \$350 per child for the weekend – and made possible by donations.

Your tax deductible donation can help us send a happy child to camp.

Please purchase a "virtual red balloon" for only \$100.00 to help us continue the magic!

OTHER DONATION AMOUNTS ALSO WELCOMED AND APPRECIATED!

To purchase a virtual balloon and help send a child to camp, please fill in the credit card information below OR include a check, payable to Tourette Syndrome Association of Texas. You may also pay via PayPal. For more information, email TouretteTexas@aol.com or call the office at 281-238-8096.

Mail to: Tourette Texas, P.O. Box 147, Richmond, TX 77406

# of Balloons at \$100 each:	Type of Card:		
Card #		Expiration date:	-
Name as it appears on card:			
Mailing Address (with ZIP):			
		Phone/Email	



Volunteer Opportunities



Date Completed:

Would you be willing to help wi	th a TSA of Texas activity	?	
Publicity		Membership	
Fund raising		Golf Tournament	
Start a suppor	t group	Annual Gala	
Other talents/interests:			
Home Phone:	Cell Phone:	Email:	
Full Address:	Would you li	ve to he?	
Wember of National TSA? Note: Membership in the National TA. Cexas for information and assistance re How did you hear about Tourette	Would you li A automatically gives you mem garding Tourette's syndrome. Texas?		ourette
Member of National TSA? Note: Membership in the National TA. exas for information and assistance re How did you hear about Tourette What do you feel Tourette Texas	Would you li A automatically gives you mem garding Tourette's syndrome. Texas? can do for you? TOURETTE TEXAS QU	ce to be? Deership in Tourette Texas. There is no charge by To	ourette
To SIGN UP FOR email Tourette	Would you li A automatically gives you mem garding Tourette's syndrome. Texas? can do for you? TOURETTE TEXAS QU	ce to be? pership in Tourette Texas. There is no charge by To	ourette
Member of National TSA? Jote: Membership in the National TA. exas for information and assistance re Jow did you hear about Tourette What do you feel Tourette Texas TO SIGN UP FOR email Tourette OPTIONAL:	Would you li A automatically gives you mem garding Tourette's syndrome. Texas? can do for you? TOURETTE TEXAS QU Texas@aol.com or sign up	ARTERLY ON-LINE NEWSLETTER, on line at www.TouretteTexas.org	ourette
Member of National TSA? Note: Membership in the National TA. Yexas for information and assistance related by the Membership in the National TA. Yexas for information and assistance related by the Membership in the National TA. Yexas for information and assistance related by the Membership in the National TA. Yexas for information and assistance related by the National Tourette for Sign Up For email Tourette. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National TA. Yexas for information and assistance related by the National Ta. Yexas for information and assistance related by the National Ta. Yexas for information and assistance related by the National Ta. Yexas for information and assistance related by the National Ta. Yexas for information and	Would you li A automatically gives you mem garding Tourette's syndrome. Texas? can do for you? TOURETTE TEXAS QU Texas@aol.com or sign up	ARTERLY ON-LINE NEWSLETTER, on line at www.TouretteTexas.org	Durette

Email: TouretteTexas@aol.com www.TouretteTexas.org