

# NAVIGATING TOURETTE SYNDROME

## An Educator's Guide to Planning and Support





# Brief Overview of Tourette Syndrome



## BRIEF OVERVIEW OF TOURETTE SYNDROME

- Tourette Syndrome (TS) is a neurodevelopmental disorder which becomes evident in early childhood or adolescence. TS is part of the spectrum of similar conditions known as Tic Disorders. Motor and vocal tics are the main characteristics described in a TS diagnosis.
- Motor tics are uncontrolled movements, such as eye blinking, shoulder shrugging and jumping. Vocal tics are repetitive, involuntary sounds, words or phrases, including sniffing, grunting and repeating others' words.
- TS and other Tic Disorders are not rare. The current estimates are that 1 out of every 160 children between the ages of 5-17 in the United States has TS and that 1 out of every 100 children has TS or another Tic Disorder. However, it is important to note that TS often is not recognized, and therefore not diagnosed.
- Some Tic Disorders may be transient, while others may persist into adolescence and adulthood.
- It is common for people with TS to have other co-occurring conditions. The most common co-occurring conditions are attention-deficit/hyperactivity disorder (ADHD), dysgraphia and obsessive-compulsive disorder (OCD).
- There is no cure for TS, but thanks to years of dedicated research, there are various treatment options.
- Frequently, in unstructured settings and at the end of the day, symptoms and tics will increase.

**TIP FOR ALL EDUCATORS:** Avoid writing annual goals or benchmarks for tic reduction. While tics, at times, can be disruptive both to the student experiencing them and the other students in the classroom, it is not appropriate to write annual goals or benchmarks around tic reduction, just as these aren't written for people with other medical conditions.

## TYPES OF TICS

CLASSIFICATION	SIMPLE	COMPLEX
<b>Motor Tics</b> Some Examples:	<b>SUDDEN, BRIEF MOVEMENTS:</b> Eye blinking, head shaking, face grimacing, shoulder shrugging, abdominal tensing, arm jerking	<b>MOVEMENTS ARE OFTEN SLOWER AND MAY SEEM PURPOSEFUL IN APPEARANCE:</b> Touching, tapping, hopping, squatting, skipping, jumping, <i>copropraxia</i> (obscene gestures)
<b>Vocal Tics</b> Some Examples:	<b>SUDDEN SOUNDS OR NOISES:</b> Sniffing, coughing, spitting, grunting, throat clearing, snorting, squeaking, shouting, animal noises	<b>WORDS OR PHRASES THAT OFTEN OCCUR OUT OF CONTEXT:</b> Syllables, words or phrases ("shut up", "stop that"), <i>coprolalia</i> (uttering of obscenities), <i>palilalia</i> (repeating own words), <i>echolalia</i> (repeating others' words)





# Supporting Students with Tourette Syndrome and Tic Disorders



This toolkit is designed to assist educators and support staff in recognizing complex symptoms and serve as a guide towards developing effective support plans to allow children with Tourette Syndrome (TS) and Tic Disorders to thrive both socially and academically. The toolkit provides resources to teachers, administrators, counselors, school psychologists, speech and occupational therapists, consultant and resource teachers, school nurses, college professors and other support personnel to help understand and support children with TS and Tic Disorders.

TS and Tic Disorders affect one in 100 students. More than half of school-aged children with TS may have a co-occurring condition such as ADHD, OCD, anxiety, depression or dysgraphia. These conditions, along with other learning disabilities, can negatively influence learning, making it extremely difficult for students to concentrate in the classroom.

The Tourette Association of America (TAA) provides educators with information to recognize the symptoms of TS and common related disorders. It is critical for educators, parents and students to work together in developing effective accommodations to optimize teaching and learning for all students. If symptoms of TS and common related disorders are appropriately addressed, children with TS can have positive, enriching and successful school experiences.

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100

**At least 1 in 100 children have Tourette Syndrome or tics.**



Awareness. Research. Support.

## HOW TO REACT TO TOURETTE SYNDROME AND TICS IN A CLASSROOM

The rule of thumb for the majority of tics is to ignore them as much as you can. The benefits of ignoring the tics are as follows:

- Reduces stress and anxiety for the student, who may be embarrassed or afraid of consequences.
- Reduces stress and anxiety for the student, which can lead to a reduction in symptoms.
- Reduces bullying.
- Demonstrates acceptance and normalization of symptoms.
- Models appropriate behavior and reactions for classmates.

## IDENTIFYING COMMON EDUCATION DIFFICULTIES WITH TOURETTE SYNDROME



Educators and families should be aware of common challenges that affect school performance among children with TS. Sometimes these challenges are misunderstood or thought of as "purposeful behaviors" instead of complications due to a complex neurodevelopmental disorder.

Education difficulties often become a larger issue in middle and high school.

The following is a list of common education-related difficulties that students with TS and related conditions may exhibit:

- **Challenges with transitioning:** Problems with transitioning between tasks and classes; resistance to changes in schedule and/or routine.
- **Difficulty completing homework:** Failure to understand the assignment; inconsistency in copying down assignments; not completing assignments on time; refusal to begin assignments.
- **Difficulty following directions:** Slow to respond; inability to complete tasks which have complex or multiple directions; repeated requests for directions.
- **Discrepancy between verbal and performance scores:** Difference between scores on psycho-educational evaluations (e.g.- high average range for reading comprehension, with low average range for written language skills; high scores in verbal and low scores on performance).
- **Disorganization and executive function deficits:** Problems managing time, tasks and belongings; difficulty beginning and/or following through on tasks, which may result in failure to produce a product.
- **Dysgraphia (handwriting issues):** Sloppiness; frequent erasing; consumed with writing neatly; reduced output; slowness of handwriting; difficulty with punctuation, spelling, and capitalization; refusal to write.
- **Dysinhibition:** Behaviors that the student recognizes as inappropriate or prohibited, but has difficulty inhibiting. Some examples include touching certain objects, making inappropriate yet contextual statements or reactions and shouting out answers.
- **Explosive behaviors in school or at home:** Significant and disruptive behaviors, which appear to be overly reactive to a situation, may be the result of symptom suppression. Other behaviors include being overwhelmed due to anxiety, feelings of failure, sensory issues, interfering symptoms, or skills deficits.
- **Impulsivity:** Exhibiting impulsive behaviors, such as yelling, shouting or screaming at others.
- **Oppositional behaviors:** Inconsistent refusal to follow directions or engage in a task or instruction. It is important to consider oppositional behavior as an attempt to communicate a skills deficit, or an obsessive-compulsive, anxiety or sensory need. This viewpoint will encourage a positive, proactive plan teaching strategies instead of ineffective punishment.

Education difficulties often become more apparent in middle and high school. A common, yet highly unrecognized reason is that students' intellectual abilities can disguise symptoms in elementary school; in higher grades, symptoms begin to interfere with being able to demonstrate true intellectual abilities. Additionally, older students often put more energy into suppressing or masking symptoms for social acceptance.

- **Paying attention:** Tics or obsessions can interfere with concentration, although the student appears to be focused. However, the opposite may also be true. Some students are able to attend to activities while experiencing tics, even if it may appear otherwise.
- **Perfectionism:** Erasing; must have things "just right"; hyper-vigilant regarding rules; insistent on performing rituals.
- **Sensory issues:** Sensitivity to light, sound, touch, smells or tastes; need for additional sensory input, sometimes resulting in a need to physically harm oneself; the need to relieve a certain sensory urge, through excessively chewing on objects, hitting self, running into objects, excessive hugging, etc.
- **Social communication deficits:** Immature behaviors; rigid responses; socially inappropriate behaviors; inability to get along with peers.
- **Stress and anxiety:** Including, but not limited to, school or academic avoidance; shutting down when overwhelmed; excessive trips to the nurse, bathroom or counselor; emotional outbursts.

## 504 PLANS AND INDIVIDUAL EDUCATION PROGRAMS (IEPS)

504 Plans, as described in Section 504 of the Americans with Disabilities Act (ADA), ensure that students with TS have equal access to academics, social and emotional support,

extra-curricular activity involvement, and protection from bullying. Students with TS are often eligible for 504 Plans because they are intellectually capable, but have misunderstood symptoms which prevent them from achieving their true potential. Common 504 Plans include the use of a computer, scribe, smart pen, or permission to leave class if necessary to reduce anxiety or tics. Other accommodations include separate testing locations, specific seating, being in the halls when not crowded and reduced assignments when appropriate.

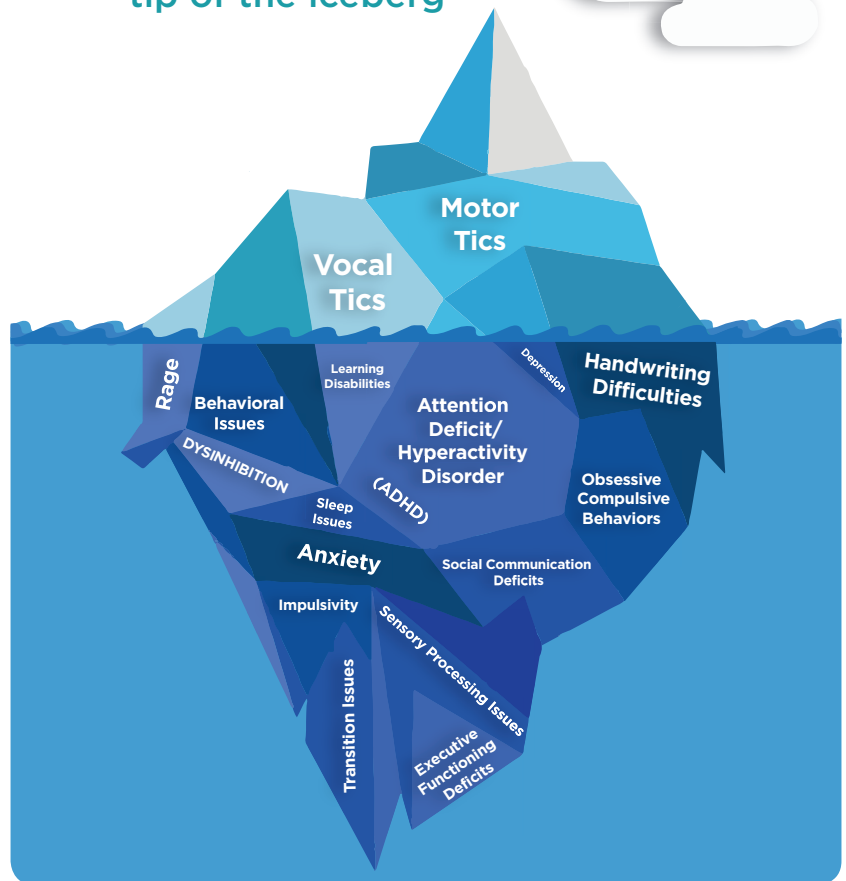
When 504 Plans are not adequate in meeting the unique needs of students with TS, an IEP becomes necessary. Too often, IEPs are denied to students with TS due to high grades and above average scores on educational assessments. While IEPs provide the same protections and modifications/accommodations as 504 Plans, IEPs also provide services from support personnel when social communication deficits, processing delays, sensory integration, anxiety and/or executive function deficits interfere with a student's academic or social achievement. Additionally, a student with TS may require the support of a paraprofessional for assistance in developing specific skills. They may also assist in developing and implementing a complex, positive proactive behavior plan. TS is included in "Other Health Impairment" and is generally the definition under which students with TS are classified for an IEP. The following is a quote from the U.S. Department of Education regarding common misperceptions of Tourette Syndrome and the reason for including TS in IDEA:

***"..., we do believe that Tourette syndrome is commonly misunderstood to be a behavioral or emotional condition, rather than a neurological condition. Therefore, including Tourette Syndrome in the definition of other health impairment may help correct the misperception of Tourette syndrome as a behavioral or conduct disorder and prevent the misdiagnosis of their needs."***

***Changes:*** We have added Tourette syndrome as an example of an acute or chronic health problem in §300.8(c)(9)(i).

## TOURETTE SYNDROME

Tics are just the tip of the iceberg





Appropriate education assessments, evaluations and consideration of the student's unique needs and strengths are the foundations for both an IEP and a 504 Plan. **Neither an IEP nor a 504 Plan should include goals regarding tic reduction.** These plans may, however, include supports from school staff and accommodations and modifications aimed at providing an environment that reduces anxiety and overall symptoms. The TAA website provides educators with critical information and resources for the appropriate support of students with TS.

## DEVELOPING A SUPPORT PLAN

Before developing an effective support plan, there are important factors to keep in mind.

**Be prepared:** Prior to developing a plan, the Tourette Association suggests that the education team read *Understanding Behavioral Symptoms in Tourette Syndrome: TS is More than Tics*. This article provides a brief overview of many of the related difficulties that are common for students with TS. The TAA article, *Educator's Guide for Developing Plans for Students with Tourette Syndrome*, is also an important resource for use prior to and during a planning meeting. Both articles are available on the TAA website.

**Include the student:** The student should be included in as much of the planning process as possible. If the student does not consider the supports to be helpful, then he or she probably will not use them, making the plan ineffective. Students are more likely to respect and engage in a plan that they helped to develop.

## IMPORTANCE OF COMMUNICATION

Communication is key for many reasons. Communication and trust will facilitate effective strategies and techniques, as well as play a positive role in the student's learning environment. Communication with family members is important for developing collaborative relationships that are essential to the success of students with TS.

Communication among team members about the effectiveness of the support plan is also critical. Any factors that might affect the student should be shared amongst team members and modifications to the plan should be made when necessary. Examples of factors that might affect the student include increased symptoms, stress, change in routine or providers, and medication changes. It is helpful for the team to be informed of these particular changes, as well as all positive and negative changes in general. The team should be sure to identify creative strategies that might be most helpful to the student, as each student is unique and may benefit from new and innovative strategies. Team members should also monitor and share strategies that are both helpful and counterproductive to ensure that strategies do not increase anxiety or other symptoms.

Additionally, team members should communicate with the student regarding what he or she believes might be helpful. Pay close attention to his or her thoughts because the student's insights can be instrumental when developing or modifying strategies.

## ROLE OF TEACHERS

Teachers play a pivotal role in their students' lives. They set the tone of the classroom, encourage and support strengths and creative talents, and are overall role models for the students. Teachers make the difference between a student with TS experiencing a safe and supportive environment or a stressful and negative one. A positive relationship between the teacher and student contributes to a child's success or failure. Although every student and case of TS is unique, the following general suggestions may assist teachers in supporting students to attain academic and social success:

- Recognize tics as involuntary movements and sounds due to neurological factors. Tics can wax and wane in severity and evolve unpredictably. In many cases, students with TS will attempt to suppress tics to avoid negative attention from others. Although tics may appear to be intentional and within the student's control, this is not true.
- Reduce stress and anxiety. Stress typically exacerbates symptoms. An effective strategy to reduce symptoms is to note which scenarios or factors increase stress and implement appropriate accommodations, modifications or special education services.
- Identify skills deficits which may contribute to increased stress or symptoms, and create strategies and supports to address these deficits.
- Ignore symptoms. This demonstrates acceptance and normalizes TS. Modeling acceptance can reduce both bullying and stress and allows students with TS to focus their energy on academics rather than tic suppression.
- Know that handwriting issues are among the most common school difficulties for children with TS. Accommodations can include the use of a computer, tablet, smart pen or a scribe.

- Be aware of co-occurring conditions, such as OCD or ADHD, which are especially common in students with TS. The characteristics of these conditions often are more problematic and more difficult to manage than the tics themselves.
- Be creative with interventions. Teaching lifelong strategies and providing support, accommodations and modifications are more effective than relying on punishment.
- Involve the student with TS in developing plans and strategies for managing symptoms that are difficult or impossible to ignore.
- Promote communication with parents or caregivers. Be sure to share the student's achievements and strengths, not just the weaknesses.
- Ensure that substitute teachers are aware of the student's symptoms and supports.
- Use the TAA's resources, such as the *Educator's Guide for Developing Plans for Students with Tourette*, to assist with developing supports and strategies.

## EDUCATIONAL SUPPORT STAFF

Educational support staff are critical members of the school community and are vital to student success. They perform a variety of jobs which affect students' lives, foster positive learning environments and support quality education. Educational support staff are in a unique position to understand and aid children with TS and Tic Disorders. As a member of the student's team, they can assist in ensuring proper accommodations and modifications through specially designed instruction and assistance. Below are recommendations for the types of support that can be provided based on each designated role.

## ROLE OF THE SCHOOL PRINCIPAL OR ADMINISTRATOR

School principals and administrators are frequently involved when there is an unresolved disciplinary situation. It is critical that administrators understand TS to ensure that students do not receive negative consequences for TS symptoms. The school principal or administrator can help students with TS in the following ways:

- Ensure that all stakeholders involved with the academic and social development of students have proper in-service training regarding TS and associated disorders.
- Support staff in recognizing that no two cases of TS are alike. TS will manifest itself differently with each individual and therefore creative, positive and proactive interventions are necessary.
- Be supportive of students with TS and ensure staff is keeping parents or guardians informed of how TS is affecting the student's work or ability at school.
- Recognize that TS is commonly associated with many conditions such as: OCD, ADHD, sensory-processing disorder, social communication deficits, intrusive or obsessive thoughts, depression, oppositional defiance disorder, dysgraphia, anxiety disorders, rage attacks, migraines, panic attacks, autism spectrum disorder and more. A basic knowledge and understanding of these issues will help administrators relate to and work with students with TS.

## ROLE OF THE SPECIAL EDUCATOR

Special educators are in an exceptional position to address the individual abilities and needs of students with TS. The special education teacher can serve as both an educator and an advocate by giving students the tools and guidance needed to be successful. These educators assess students, plan and apply lessons and manage IEPs that are appropriate and specific to each student's needs. Below are suggestions for special education teachers when working with students who have TS:

- Be prepared to explain to the student's team how the symptoms of this complex neurodevelopmental disorder often impede with a student's ability to reach his or her full academic potential. Additionally, know that symptoms can be misinterpreted as purposeful behaviors and interfere with appropriate social communication skills.
- Provide resources to help others understand that symptoms and behaviors of this complex disorder are involuntary.
- Assist others in developing and ensuring specially designed instruction, modifications and accommodations.
- Determine the need for assistive technology, as tics and common related disorders often interfere with writing and reading.

- Recognize that students may have a co-occurring learning disability and/or be in the gifted range intellectually. It is important to look beyond TS symptoms and perform a comprehensive evaluation to ensure that all of the student's needs are being addressed.
- Ensure appropriate environment and testing conditions. Regardless of the presence or absence of other learning issues, students with TS often will require more time on assessments. Testing in a separate area with planned extended time may be a necessary accommodation to include on an IEP or 504 Plan.
- Advocate for students with TS. They are entitled to the same environment protections as other students with disabilities. Too often, they are removed from the general education environment because their tics are bothersome to others. It is necessary to problem solve these situations and monitor the amount of time these students are spending outside of their general education classrooms.

## ROLE OF CONSULTANT AND RESOURCE TEACHERS

Consultant and resource teachers are often critical additions to the student's team, as they have access to resources to help teachers and students to understand TS. They can also be pivotal in aiding students with developing individualized strategies for managing difficult symptoms. Consultant and resource teachers can:

- Help students to manage current workload in order to prevent the feeling of being overwhelmed.
- Help students to develop lifelong strategies for executive function difficulties, such as organization and time management.
- Provide a smaller setting to take tests, quizzes and other assessments.
- Work with teachers to provide appropriate supports, modifications and accommodations.
- Assist the team in prioritizing time and length of assignments, which can help to reduce anxiety.
- Research strategies and visit the TAA website for information that will assist the overall team and student.

## ROLE OF THE SCHOOL PSYCHOLOGIST

To ensure student success, school psychologists evaluate the strengths and areas of weakness of a student so that individualized plans can be developed. School psychologists are often viewed by school staff and parents as being the professional who supplies overall guidance in providing appropriate support to students with TS. It is a major responsibility and therefore helpful for school psychologists to:

- Be the individual at key meetings who recognizes that students with high and low test scores need to be interpreted not as having "average" abilities, but as having an exceptional strength that is being impacted by a significant area of weakness for which supports need to be provided.
- Remind the student's team to avoid writing annual goals or benchmarks around tic reduction, as it is inappropriate.
- Have an understanding of the numerous common related disorders and how these disorders have an impact on academic and social growth.
- Provide teachers and support staff with information on the nature of tics and symptoms as neurological urges, which wax, wane and change.
- Explain the highly misunderstood yet critically important symptom of dysinhibition, which is sometimes mistaken as impulsivity or purposeful, "bad" behaviors.
- Recognize the similarities between autism spectrum disorder and TS in order to effectively assess the specific reason for challenges and to provide appropriate supports.
- Be able to explain to school staff and parents that symptoms are frequently increased at home, which is not necessarily a result of "bad parenting".
- Recognize the common misleading assumptions of TS (e.g.-student is attention seeking and purposefully disruptive), as these assumptions typically are not accurate or helpful.
- Be prepared to research the TAA website and contact the Information and Referral department and the Education Advisory Board for additional information. Refer to the TAA's *Workbook for Conducting a Functional Behavioral Assessment and Writing a Positive Behavior Intervention Plan for a Student With Tourette Syndrome*.



## ROLE OF THE SCHOOL COUNSELOR

School counselors are frequently the "safe" persons with whom a student feels comfortable discussing emotions and difficult situations. Counselors can provide support for students with TS in the following ways:

- Address anxiety and social skills issues through individual counseling and/or small group counseling.
- Provide relaxation or stress relief techniques.
- Advocate for the student if the student would benefit from a 504 Plan or an IEP.
- Discuss challenges such as bullying, specific teachers or classes, cafeteria, or assemblies.
- Designate a safe place to reduce anxiety and to release tics, if necessary.
- Assist staff and classmates in understanding complex symptoms.
- Be the person in whom parents can confide.
- Provide information and be familiar with TAA resources, which can be accessed by both parents and school personnel.

## ROLE OF THE OCCUPATIONAL THERAPIST

Occupational therapists are integral members of the team who can assist in addressing the needs of students with TS. Occupational therapists can help reduce the impact of TS and related disorders by addressing difficulties including executive functioning, sensory integration and handwriting. Within the school setting, occupational therapists can:

- Recognize that the majority of students with TS have written language deficits and will require computer access for written assignments, copies of notes or use of a smart pen for note taking.
- Evaluate sensory processing skills and develop a plan to enable students to understand, address and accommodate sensory issues throughout the day.
- Assist others in understanding that many students with TS have sensory issues, which can appear to be oppositional behaviors.
- Provide adaptive equipment, such as specialized seats or pencil grips, to assist with sensory input and/or optimum positioning for required tasks.
- Conduct assistive technology evaluations. Potential devices include text readers and voice to text dictation programs.
- Work with students to develop executive function skills needed to manage time, tasks and belongings, as this is a common yet typically unidentified challenge for students with TS.
- Recognize that students with TS frequently perform well on standardized evaluations since they are directed, closed ended tasks in a controlled environment.
- Interview parents regarding the student's ability to prepare for school, organize and complete assignments and determine the need to address social-emotional skills, activity levels and sleep issues.
- Perform clinical observation across all areas of the learning environment to determine the student's ability to participate, process sensory information and function at an age-appropriate level.
- Recognize that as students move into middle and high school, occupational therapy should focus on developing skills and techniques for life after school.



## ROLE OF THE SPEECH-LANGUAGE PATHOLOGIST

Speech-language pathologists (SLP) can assist students who have TS with much more than sound production or stuttering. It is imperative that the SLP understands how TS manifests and be aware of positive supports and strategies to minimize symptoms. This will ensure that testing is most reflective of the student's abilities, and results are not impacted because symptoms are misunderstood or mismanaged. A speech-language pathologist must:

- Be knowledgeable about TS and understand how it is different from other neurodevelopmental conditions (e.g.-autism) so that an appropriate evaluation and treatment plan can be implemented.
- Recognize that language based learning challenges are common, which can impact the ability to communicate clearly, understand what is heard, formulate messages, and/or other areas of communication.
- Be able to assess and treat Social Communication Disorder (SCD), a common challenge for students with TS.
- Understand that students often get in trouble for “behaviors” that they know are inappropriate but in the moment do not know how to correct.
- Assist in developing strategies for making and keeping friends, which is a common challenge for students with TS.
- Know that students with TS are frequently misdiagnosed as “autistic” and that SCD needs to be considered when the full criteria for autism is not met.
- Recognize that traditional social skills treatment approaches designed for autism often are not as effective for students with Tourette Syndrome/SCD. When determining appropriate strategies, it's important to work with other members of the team to prioritize the areas needing treatment and develop an effective interdisciplinary treatment plan.
- Understand how TS can influence voice and fluency to determine appropriate referrals and/or interventions.
- Be aware that cognitive-linguistic/executive function deficits are common in students with TS and are often not addressed, resulting in difficulty to learn and utilize necessary life-long skills.
- Assist others in recognizing that students with TS are too often identified as “lazy” or “disorganized” because he or she lacks the skills to manage the demands of changing classes, having supplies needed for each class, keeping up with assignments, or knowing where and how to begin an assignment.



## ROLE OF THE BEHAVIOR SPECIALIST

Behavior specialists are often asked to develop plans to support students with TS and therefore, it is critically important to be familiar with the complex symptoms of TS and related disorders. Too often behaviors are viewed as purposeful or due to a similar, but incorrect, disorder. Behavior specialists are depended upon to provide accurate information regarding this highly misunderstood and complex disorder. This can best be accomplished by the following:

- Be familiar with the complexities of TS and the common related disorders by researching the TAA website.
- Contact the TAA Information and Referral department, who will refer you to the appropriate professional on the TAA Education Advisory Board.
- Make use of the *Workbook for Conducting a Functional Behavioral Assessment and Writing a Positive Behavior Intervention Plan for a Student with Tourette Syndrome*.

- Have a working knowledge of the similarities and the differences between autism spectrum disorder and TS.
- Recognize the effectiveness of positive and proactive interventions for TS symptoms, and the ineffectiveness of punishment and reward.
- Be prepared to explain the benefits of teaching life-long skills to assist in the management of difficult symptoms.
- Share knowledge with parents and educators regarding information and support available from the TAA.

## ROLE OF AIDES AND PARAPROFESSIONALS

Teacher aides and paraprofessionals often have the most one-on-one contact with the student and can play an important role in securing a student's sense of school safety. By being tuned in to the student's needs and providing positive supports, an aide or paraprofessional can assist in developing and implementing proactive and positive strategies as part of the student's behavior plan. The student must know that the paraprofessional is on his or her side as someone who provides appropriate supports and acts as a safety net or buffer, instead of an adult who is only there to "police" them. This may help to decrease the student's stress and reduce tic symptoms, therefore resulting in a more successful education environment. The following are important suggestions:

- Have an understanding of the strategies that have worked best for the student.
- Be aware of what increases the student's anxiety and therefore symptoms.
- Know when to allow privacy and when to offer support.
- Recognize and accept that the student must perceive you as being his or her safety net and a person who is on their side.
- Recognize the importance of working with the student.
- Feel comfortable having open discussions with the child's teacher regarding TS.
- Develop a system by which to communicate with the teacher regarding tasks and environments which increase and/or decrease symptoms.

## ROLE OF THE SCHOOL NURSE

The school nurse is the professional who can provide medical information. Because of this, students and parents will turn to the nurse for support in educating school staff regarding this complex neurodevelopmental disorder. To assist in this:

- Provide information regarding TS and co-occurring disorders to assist undiagnosed students or support those already diagnosed.
- Speak with parents who may be resistant to address a diagnosis.
- Provide a safe place for the student to rest and discharge tics, as needed.
- Be aware of medications and side effects.
- Provide a place for brief naps, which may be needed due to side effects of medications.
- Educate staff about tics and other related issues.
- Provide medical information during IEP or 504 Plan meetings.





## ROLE OF THE BUS DRIVER AND CAFETERIA PERSONNEL

Bus drivers and cafeteria personnel are the individuals working in surroundings with less structure and supervision, often the most difficult environment for students with TS. These staff members can play a valuable role by doing the following:

- Have an understanding of the significant challenges students with TS face on a daily basis.
- Recognize that many students with TS have sensory symptoms which increase in loud and unstructured environments, such as the cafeteria and bus.
- Know that while these may be difficult environments, these settings may represent the only opportunities for socializing and relaxing.
- Recognize that symptoms typically increase at the end of the day.
- Be aware of students being bullied, which can include imitation of a student's tics.
- Develop a relationship in which students feel safe discussing difficulties and strategies.
- Report difficulties to administration before they become significant.
- Be aware of any strategies and behavior plans and how they can support the student.

## ROLE OF THE COLLEGE PROFESSOR

College professors play a vital role in college success and influence student retention. Professors typically are in frequent contact with students and can counsel and mentor them on career opportunities and choices. They can also have a strong influence on a student's opportunity to be successful in his or her chosen field. Students may also be affected by faculty's judgments of their intellect due to misconceptions of TS, which may affect his or her self-esteem. It can be helpful to:

- Introduce yourself to the student, asking if there is anything you can do to be helpful.
- Educate yourself about TS. Having a basic understanding of TS and related disorders can prepare you for the presentation of both motor and vocal tics during class.
- Recognize that tics are involuntary movements and sounds which can change unpredictably. While tics may appear to be purposeful and within the person's control, this is not true. Students should not be expected to suppress their tics. If the tics are truly distracting, electronic options should be explored.
- Ignore the symptoms that can be ignored. This demonstrates acceptance and normalizes the tics. Modeling acceptance can reduce both bullying and stress and may help students with TS to focus their energy on academics rather than tic suppression.
- Understand that stress typically increases symptoms. Tests and presentations generally increase stress. Presentations may need modification and testing may need to be offered in a separate and private location.
- Set clear expectations and provide a detailed syllabus to minimize anxiety.
- Check with the designee at your institution to determine which accommodations and academic adjustments have been approved for the student. The ADA requires postsecondary institutions to make reasonable accommodations and modifications for students with disabilities. Accommodations for students with TS can help to reduce anxiety, address handwriting challenges and compensate for time spent either experiencing tics or focusing on the suppression of them.

## COMMON TS RELATED CHALLENGES: EDUCATOR & SUPPORT STAFF ROLES

	OT	SLP	C	SP	PL	N	T	CT/ RT	SE	C&B	P/A	Behav
Activities of Daily Living	●	●	●	●	●	●	●	●	●			●
Anxiety	●	●	●	●	●	●	●	●	●	●	●	●
Assistive Devices	●	●		●			●	●	●			
Attention	●	●	●	●			●	●	●		●	●
Bullying Issues	●	●	●	●	●	●	●	●	●	●	●	●
Dysgraphia/Keyboarding	●			●			●	●	●		●	
Dysinhibition	●	●	●	●	●		●	●	●	●	●	●
Executive Functioning	●	●	●	●			●	●	●		●	●
Impulsivity	●	●	●	●	●		●	●	●	●	●	●
Language Based Disabilities	●	●	●	●			●	●	●		●	●
Obsessive Compulsive Behaviors	●	●	●	●	●	●	●	●	●	●	●	●
Organization	●	●	●	●			●	●	●		●	●
Reading Comprehension	●	●		●			●	●	●		●	●
Sensory Integration	●	●	●	●		●	●	●	●	●	●	●
Significant Symptoms	●	●	●	●	●		●	●	●	●	●	●
Sleep Hygiene	●					●					●	
Social Communication & Pragmatics	●	●	●	●	●	●	●	●	●	●	●	●
Stuttering		●					●				●	●
Vocational Skills	●	●	●	●	●		●	●	●		●	●

OT – Occupational Therapist

SLP – Speech Language Pathologist

C – Counselor

SP – School Psychologist

PL – Principal

N – Nurse

T – Teacher

CT/RT – Consultant Teacher/Resource Teacher

SE – Special Education Teacher

C & B – Cafeteria Support and Bus Drivers

P/A – Paraprofessional/Aide

Behav – Behavioral Specialist

## FREQUENTLY ASKED QUESTIONS FOR EDUCATORS

### 1. Will consequence-based programs help motivate a student to control tics in the classroom?

Punishment and rewards do not typically help students, since their symptoms are neurologically based urges and are not under their control. For some, engaging in or anticipating a favored activity reduces these neurological urges, which can be confused with an ability to control symptoms.

### 2. What is the best way to view symptoms of TS so that appropriate supports can be provided, rather than the use of punishment?

Symptoms of TS should be viewed as inconsistent neurological urges, similar to the urge to scratch a bug bite. By scratching the bite, an individual may experience momentary relief. However, the urge to scratch will often return after a short time. Additionally, a common TS symptom is dysinhibition, which involves significant difficulties inhibiting symptoms, physical or vocal behaviors, and reactions to the student's environment. Dysinhibition adds to the misperception that students are able to control symptoms. Supporting the student in developing strategies and techniques to manage challenges is more effective than punishment for these complex, highly misunderstood neurological symptoms.

### 3. Should a student be encouraged to suppress his or her tics?

No, **do not** encourage tic suppression. Suppressing tics and other symptoms requires a great deal of energy and attention. Tic suppression tends to diminish energy needed for paying attention and completing tasks. Since students suffer embarrassment from symptoms, they will usually attempt to suppress tics on their own when possible.

### 4. What are the most common related disorders that affect students?

Since every student is different, related disorders can vary. Common related disorders include obsessive-compulsive behaviors, dysgraphia, anxiety and ADHD. Executive function deficits, social communication deficits and sensory deficits are also common.

### 5. Are students being manipulative when they do their vocalization under their breath or try to use their tics as an excuse for not doing work?

Mumbling or vocalizing under one's breath most likely is a strategy for satisfying the urge in a way that will not be offensive or disruptive. Using tics as an excuse is not common; however, they generally will increase in stressful situations, leading to misinterpreting their use as an excuse. Therefore, it is wise to notice when this occurs to determine what skills deficit is interfering and to develop helpful supports so that increased symptoms or avoidance is not necessary.

### 6. Is it helpful to provide breaks whenever a student with TS is having tics?

Providing breaks can be helpful for some students but detrimental to others. It can be helpful for the student to know that he or she has the option of leaving the classroom for a brief time, as it reduces the anxiety of feeling "trapped". However, for others, being encouraged to leave due to tics may be sending a message that tics are something to be ashamed of instead of recognizing them as being "normal" for the student with TS.

### 7. Are tics always disruptive to other students?

It depends on how educators respond to tics and whether classmates have been educated about TS. In the majority of situations, if teachers accept and ignore tics, just as other sounds are ignored (e.g. lawn mower, airplane, hiccups, coughing, etc.), tics decrease and classmates typically learn to accept and ignore them. For more information and resources on educating classmates about TS, you can visit the TAA website or contact the TAA. There is an excellent article on the TAA website titled, Educating Classmates About Tourette Syndrome. Additionally, you can request a presentation through the Tourette Association Youth Ambassador program, which consists of teenagers trained to provide presentations on TS.

### 8. Why is it that some students have significantly more symptoms in certain classes and less in others?

Since anxiety increases symptoms, increased tics may indicate intensified anxiety in classes that are more challenging or in which there is additional stress. It may also be that a specific class has become a safe environment to have tics. Other reasons may be due to the time of day, as symptoms often increase with hunger, at the end of the day, or after or during stressful or heightened activities.

### 9. Why is it helpful to provide a separate location for a student with TS to take tests?

Since tic suppression requires energy and attention, students most often will attempt to suppress tics during testing in order to keep from distracting classmates. In a private location, the student can focus on the test instead of his or her tics.

### 10. Can having a short temper be associated with Tourette Syndrome?

Yes, for many reasons. Dealing with TS is embarrassing and exhausting. Students with dysinhibition issues may struggle with inhibiting his or her emotions. Additionally, many of the common related disorders such as sensory integration, processing delays, executive function, OCD and ADHD can increase frustration, resulting in anger.





# Awareness. Research. Support.

## TOURETTE ASSOCIATION OF AMERICA

Founded in 1972, the Tourette Association of America (TAA) is dedicated to making life better for all individuals affected by Tourette Syndrome (TS) and Tic Disorders. The TAA is the premier nationwide organization serving this community, working to raise awareness, advance research and scientific understanding, and provide on-going support. The Tourette Association directs a network of 32 Chapters and more than 80 Support Groups across the country. For more information on Tourette Syndrome and Tic Disorders, call **888-4TOURET**, visit **tourette.org**, and search "Tourette Association" on Facebook, Twitter, Instagram and YouTube.

## REQUEST RESOURCES AND INFORMATION ON TOURETTE SYNDROME

In addition to the information provided on the Tourette Association's website (**tourette.org**), the Tourette Association's Information and Referral (I&R) department offers accurate, evidence-based information on Tourette Syndrome, Tic Disorders, and related conditions to families, individuals, professionals, and the general public. You can request more information or speak with a TAA I&R staff member by calling **888-4TOURET** or by emailing **support@tourette.org**.

## LOCAL CHAPTERS AND SUPPORT GROUPS

Tourette Association of America Chapters and affiliated Support Groups are volunteers dedicated to supporting and promoting the mission of the Tourette Association of America in the community. Please visit **tourette.org** to find support in your area.

The following are some of the **services** that may be offered through the TAA Chapters and Support Groups:

- **CLIENT SERVICES:** Information and referrals; telephone help-line; support groups (may be done in person, by phone or electronically); website and/or electronic discussion groups.
- **PUBLIC SERVICE:** Awareness activities; information; publications; educational presentations and conferences.
- **PROFESSIONAL EDUCATION:** In-service presentations for educators and allied professionals; resource services; Medical and Allied Professional (MAP) referral lists; presentations provided by the Tourette Health & Education Program, a program of the TAA Partnership with the U.S. Centers for Disease Control and Prevention (CDC).
- **PUBLIC POLICY:** Partner with national organizations on public policy projects; meet with local representatives and government agencies to promote Tourette awareness and help lobby for legislation that helps the Tourette community.
- **PEER PROGRAMS:** Youth Ambassador Program; camps; socialization opportunities.

You can view a complete list and learn more about how to get involved with TAA's Chapters and Support Groups by visiting **tourette.org/resources/find-local-chapter/**. You can also email **support@tourette.org** or call **888-4TOURET**.

## TOURETTE ASSOCIATION YOUTH AMBASSADOR (YA) PROGRAM

The Tourette Association of America's Youth Ambassador Program trains teens to talk about Tourette Syndrome and Tic Disorders, to advocate for themselves and for others, and to provide their peers with accurate information. Youth Ambassadors teach understanding, sensitivity, and tolerance of TS and its symptoms, while dispelling the myths and stereotypes that are often attributed to and associated with TS and other Tic Disorders. Through this program, young people can speak to peers at schools, sports leagues, camps, after school programs, and similar venues, as well as in front of local and national politicians. Youth Ambassadors play an important role in increasing awareness and understanding of Tourette Syndrome and Tic Disorders in the community.

For more information about the Youth Ambassador Program, to apply to be a Youth Ambassador, or to request a Youth Ambassador presentation at your school or organization, please contact the TAA.

## RESEARCH AND MEDICAL PROGRAMS

The Tourette Association of America's Research and Medical Programs department has several established and developing initiatives that, together, seek to advance our understanding of Tourette Syndrome, facilitate the development of treatments, and improve care for individuals living with the disorder. These programs cover a wide range of treatment modalities and include the TAA Brain Tissue Program, which seeks to better understand TS brain changes; the TAA International Consortium for Genetics, which aims to identify chromosomes and genes that predispose people to TS; the TAA Neuroimaging Consortium, which aims to uncover the neural changes that underlie TS; and the TAA Behavioral Sciences Consortium, which is focused on disseminating and understanding the mechanisms of effective treatments like Comprehensive Behavioral Intervention for Tics (CBIT).

## GET INVOLVED IN THE TOURETTE COMMUNITY

### FOLLOW THE TOURETTE ASSOCIATION ON SOCIAL MEDIA

The Tourette Association of America is active on Facebook, Twitter, Instagram, YouTube and LinkedIn. Follow the Tourette Association for the latest news, stories, and updates.

**Facebook** @TouretteAssociation    **Twitter** @TouretteAssn  
**Instagram** @TouretteAssociation    **YouTube** @Tourette TV

### PARTICIPATE IN A TOURETTE HEALTH AND EDUCATION WEBINAR OR LIVE STREAMING PRESENTATION

The Tourette Health and Education Program, a TAA partnership with the CDC, offers regular webinars and live streaming presentations on various topics related to Tourette Syndrome and Tic Disorders. Each workshop features designated Tourette Experts who are members of the TAA medical, science, and education advisory boards.

### UPCOMING EVENTS

The TAA hosts events throughout the year that support its mission to make life better for all people affected by Tourette Syndrome and Tic Disorders. A full list of events can be found on the TAA website under the "Get Involved" section.

### BECOME A MEMBER

When you join the Tourette Association of America as a member, you play a critical role in making a difference and you join thousands of individuals, families, and professionals who are working to:

- Raise public awareness and foster social acceptance.
- Advance scientific understanding, treatment options, and care.
- Educate professionals to better serve the needs of children, adults, and families.
- Advocate for public policies and services that promote positive school, work, and social environments.
- Provide help, hope, and a supportive community across the nation.
- Empower our community to deal with the complexities of this spectrum of disorders.

Visit [tourette.org/membership](https://tourette.org/membership) for more information.



[tourette.org](https://tourette.org) 888-4TOURET

# Where is support offered?



## COORDINATED CARE FOR TOURETTE SYNDROME & TIC DISORDERS

The Tourette Association of America's Center of Excellence (CofE) program aims to improve the quality of life of people with Tourette Syndrome and other Tic Disorders by promoting the highest level of care, research, education and training, and advocacy and awareness. The program, which was developed in collaboration with leading medical and scientific experts in TS and related conditions, was launched in 2014 with the initial designation of nine CofEs located at premier medical and academic institutions across the United States.

The Centers are collaborating with the TAA and professional and lay communities to address many needs and concerns across the following key areas:

### EXPERT & COORDINATED CARE

The TAA CofEs provide timely and accurate evaluations of TS and related conditions. Thus, patients can receive coordinated care using evidence-based treatment and management approaches from multidisciplinary teams of care providers.

### RESEARCH

The TAA CofEs conduct or collaborate on scientific and clinical research studies within their own institutions or elsewhere. These investigations aim to provide a better understanding of TS/Tic Disorders, their impact, and to advance the development of more effective and safe treatments.

### EDUCATION & TRAINING

The TAA CofEs provide training and education to healthcare professionals and researchers on Tourette Syndrome and Tic Disorders. These centers also help to educate patients, families and the general public on these conditions.

### ADVOCACY & AWARENESS

The TAA CofEs work with the national Association and its local chapters and support groups to improve awareness and advocate for TS in their local communities and nationally.

### CLINICAL SERVICES OFFERED AT CENTERS OF EXCELLENCE INCLUDE:

- Child and Adult Neurology and Psychiatry
- Allied Health Care Providers
- Evaluations, Diagnoses, and Advice
- Medical Treatments
- Behavioral Therapies (e.g. – CBIT/CBT)
- Counseling and Psychological Services
- Occupational Therapy
- Deep Brain Stimulation (DBS)
- Botulinum Toxin Therapy





## TOURETTE ASSOCIATION CENTERS OF EXCELLENCE CLINIC LOCATIONS

### **TOURETTE ASSOCIATION CENTER OF EXCELLENCE: BAYLOR COLLEGE OF MEDICINE**

Houston, TX  
Director: Joseph Jankovic, M.D.  
Co-Director: Suzanne Mouton-Odum, Ph.D.  
(713) 798-2273

### **TOURETTE ASSOCIATION CENTER OF EXCELLENCE: CHILDREN'S MERCY HOSPITAL**

Kansas City, MO  
Director: Keith Coffman, M.D.  
Co-Director: James Batterson, M.D.  
(816) 234-3674

### **TOURETTE ASSOCIATION CENTER OF EXCELLENCE: THE JOHNS HOPKINS HOSPITAL**

Baltimore, MD  
Director: Harvey Singer, M.D.  
Co-Director: Marcos Grados, M.D.  
(410) 955-4259

### **TOURETTE ASSOCIATION CENTER OF EXCELLENCE: MASSACHUSETTS GENERAL HOSPITAL**

Boston, MA  
Director: Jeremiah Scharf, M.D., Ph.D.  
Co-Director: Sabine Wilhelm, Ph.D.  
(617) 726-5532

### **TOURETTE ASSOCIATION CENTER OF EXCELLENCE: NEW YORK STATE CONSORTIUM**

**Weill Cornell Medical College**  
New York, NY  
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Co-Director: Shannon Bennett, Ph.D.  
(212) 821-0789

#### **Northwell Health**

Manhasset, NY  
Director: Cathy Budman, M.D.  
Co-Director: Jane Zwilling, Psy.D.  
(516) 562-3051

#### **University of Rochester Medical Center**

Rochester, NY  
Director: Jonathan Mink, M.D., Ph.D.  
Co-Director: Heather Adams, Ph.D.  
(585) 275-2808

#### **Icahn School of Medicine at Mount Sinai**

New York, NY  
Director: Barbara Coffey, M.D.  
Co-Director: Wayne Goodman, M.D.  
(212) 659-1660

### **TOURETTE ASSOCIATION CENTER OF EXCELLENCE: SOUTH EAST REGIONAL**

**Emory University School of Medicine**  
Atlanta, GA  
Director: Jorge L. Juncos, M.D.  
(404) 778-3444

#### **University of Alabama at Birmingham**

Birmingham, AL  
Director: Leon Dure, M.D.  
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#### **Palmetto Health**

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(803) 434-7961

#### **University of South Florida**

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(727) 767-8230

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(352) 294-5385  
simph@shands.ufl.edu  
Clinic website: [www.TouretteCareCenters.org](http://www.TouretteCareCenters.org)

### **TOURETTE ASSOCIATION CENTER OF EXCELLENCE: UNIVERSITY OF CALIFORNIA, LOS ANGELES**

Los Angeles, CA  
Director: John Piacentini, Ph.D.  
Co-Director: James McCracken, M.D.  
(310) 825-0122

### **TOURETTE ASSOCIATION CENTER OF EXCELLENCE: UNIVERSITY OF UTAH**

Salt Lake City, UT  
Director: Michael Himle, Ph.D.  
Co-Director: Francis Filloux, M.D.  
(801) 585-1086  
Clinic website: [www.TSUtah.info](http://www.TSUtah.info)

### **TOURETTE ASSOCIATION CENTER OF EXCELLENCE: YALE CHILD STUDY CENTER**

New Haven, CT  
Director: Robert King, M.D.  
Co-Director: Michael Bloch, M.D.  
(203) 785-5880



Sample Letter from School Informing Parents  
about Student in Class with TS Diagnosis/Symptoms



**Tourette Association of America**

Awareness. Research. Support.

*Sample Letter from School Informing Parents about  
Student in Class with TS Diagnosis/Symptoms*

Date

Dear Parents/Guardians,

We are sending this letter to inform you that a child with Tourette Syndrome (TS) will be in your child's class this year. We believe that classmates' awareness of symptoms can have a significant and positive impact on the classroom environment.

TS is a neurodevelopmental disorder that impacts 1 in 160 children and involves both motor and vocal tics. Tics are often perceived by others as being purposeful, attention seeking, and/or "bad" behavior. In reality, symptoms are the result of biological urges that need to be satisfied, or in other words, are involuntary. This is similar to the feeling of needing to scratch an itch, blink, or clear one's throat, which is difficult to ignore and not intended to offend anyone.

As you may know, a minority of individuals with TS have a symptom called coprolalia which involves verbalizing obscenities and/or socially inappropriate statements. As is true for all symptoms of TS, it is critical to understand that these words or phrases do not necessarily reflect the thoughts, beliefs or opinions of the child with TS. It is also important to recognize that awareness and acceptance of symptoms reduces the stress and embarrassment for the student with TS. Since stress typically increases tics and conversely, acceptance and understanding reduces this stress, we felt it was important for us to provide you with this information prior to the start of the school year. Knowing this can better help your child to be prepared and accepting of symptoms.

To ensure a learning environment which meets all of our students' needs, we are in contact with the Education Specialist for the Tourette Association of America to help the entire staff have a better understanding of this highly misunderstood neurological disorder.

An excellent video in which a teen with TS interviews other children with TS, titled "What I wish people knew about living with Tourette Syndrome", can be viewed at [https://www.youtube.com/watch?v=icp\\_alKTc94](https://www.youtube.com/watch?v=icp_alKTc94).

Sincerely,

Teacher/Staff Name(s)

Title

School Street Address

City, State, Zip Code



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[tourette.org](http://tourette.org) | 888-4TOURET



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### ABOUT THE TOURETTE ASSOCIATION OF AMERICA

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National Headquarters: 42-40 Bell Blvd., Suite 205, Bayside, NY 11361

[tourette.org](http://tourette.org) | 888-4TOURET | Facebook @TouretteAssociation | Twitter @TouretteAssn  
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