

Tourette Syndrome is a complex and often misunderstood neurobiological disorder. This presentation will provide you with an introduction to Tourette Syndrome.

In addition to the 30 minute presentation, shorter modules are also available to provide more in depth information about issues and disorders which often accompany Tourette Syndrome.



A Teacher's Perspective

I've come to the conclusion that I am the decisive element in the classroom. It's my personal approach that creates the climate. It's my daily mood that makes the weather.

As a teacher, I possess a tremendous power to make a child's life miserable or joyous. I can be a tool of torture or an instrument of inspiration. I can humiliate or honor, hurt or heal.


In all situations, it is my response that decides whether a crisis will be escalated or de-escalated and a child humanized or de-humanized.

– Haim Ginott

This slide is included just as a reminder of how critically important teachers responses are to children regardless of whether they have a disability or not. We all have days that are more difficult to get through than others, but it is so important to always recognize the power teachers have regarding a student's academic education, as well as his social abilities and self-worth.

(((X))) **About TSA**
www.tsa-usa.org

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Our Mission Is To Identify The Cause Of, Find The Cure For And Control The Effects Of Tourette Syndrome

(((X))) tourette syndrome association, inc. *Education, Research and Support* 3

The national office of the Tourette Syndrome Association (TSA) is located in Bayside, New York. It was founded in 1972 and is the only national, voluntary, non-profit membership organization dedicated to identifying the cause, finding the cure and controlling the effects of TS.



Tourette Syndrome (TS)



- **Neuro-biological disorder**
- **Genetic**
- **Involuntary**
- **More common than once thought**
- **Symptoms involve both motor and vocal tics**
- **Due to the nature of TS, symptoms will vary from person to person**

Tourette Syndrome is a hereditary, neurobiological disorder that begins in childhood usually between the ages of 6 and 10. One in every 1000 persons manifests some degree of TS. It is not as rare as once thought. Tourette Syndrome occurs about 3 times more frequently in boys than in girls.

This highly misunderstood disorder varies in severity from person to person, even within families who share the same genetic background.

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This video was a combined effort of national TSA and HBO. This Emmy- award winning documentary shows, through the eyes of children, what it is really like living with TS. Anyone working with children should have this valuable tool. This DVD is available on the TSA website.



Motor Tics

- **Simple Motor Tics**
 - Eye blinking, grimacing, nose twitching, leg movements, shoulder shrugs, arm and head jerks, etc.
- **Complex Motor Tics**
 - Hopping, clapping, throwing, touching (self, others, objects)
 - Holding funny expressions, sticking out the tongue, kissing, pinching, tearing paper or books, etc.



Tics are involuntary movements and sounds that can occur and impact any part of the body.

Simple motor tics can take many forms including, but not limited to the following: shoulder, head and neck shrugging; leg jerking; hand and foot movements; facial grimaces; eye blinking, etc...

Complex motor tics are just that, more complex than simple tics. These can include hopping, skipping, jumping, deep knee bends, spinning or wind-milling of the arms, touching people, objects or themselves, etc.

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Vocal Tics

- **Simple Vocal Tics**
 - Whistling, coughing, sniffing, screeching, animal noises, grunting, throat clearing, etc.
- **Complex Vocal Tics**
 - Linguistically meaningful utterances
 - Coprolalia (racial slurs, inappropriate language), repeating words/phrases
- **Speech Atypicalities**
 - Unusual rhythms, tone accents, intensity of speech, stutter-like, immature voice

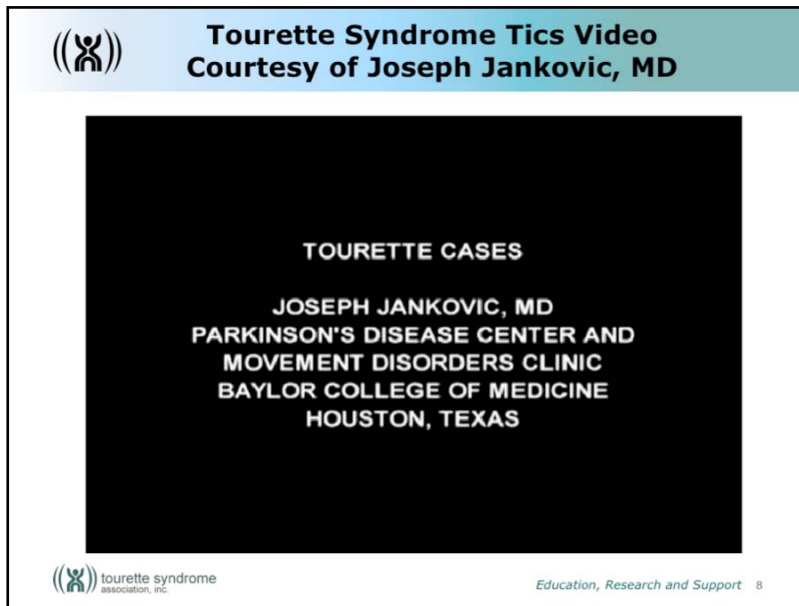


Vocal tics are any sound, word or group of words an individual makes that may be meaningless and or out of context. Vocal tics may appear to be purposeful because symptoms often increase during times of stress and anxiety.

Simple vocal tics may be a whistle, a shout or whooping noise, sniffing, coughing, throat clearing, grunting. Complex vocal tics are groups of sounds or words, sentences or sayings.

There are some more complicated vocal tics: echolalia where the individual echoes what someone else has said; palilalia, the involuntary repetition of their own words and coprolalia which is most often heard of through the media. This is the most infamous and often the most problematic of all vocal tics. It involves the utterance of curse words, racial or sexual slurs and other inappropriate comments. Additionally, it is important to keep in mind that coprolalia is not necessary for a diagnosis of TS.

Although coprolalia may be the most often talked about component of TS, less than 10% of all people with TS have this symptom.



As you can see these children are just like you and me when they are not ticcing. Their tics are very obvious and not everyone with TS has tics that are so pronounced.

The video shows multiple examples of what tics might look like. Many people with TS learn to compensate for and mask many of their tics. For instance, they can take a head tic and try to make it look like they are just shaking their hair out of their eyes. But please remember that tics are involuntary and not controllable.



The Nature of Tics

- **Naturally wax and wane**
- **Change in appearance and frequency**
- **Change in severity and intensity**
 - **May worsen during adolescence**
- **Can sometimes be suppressed for short periods of time**



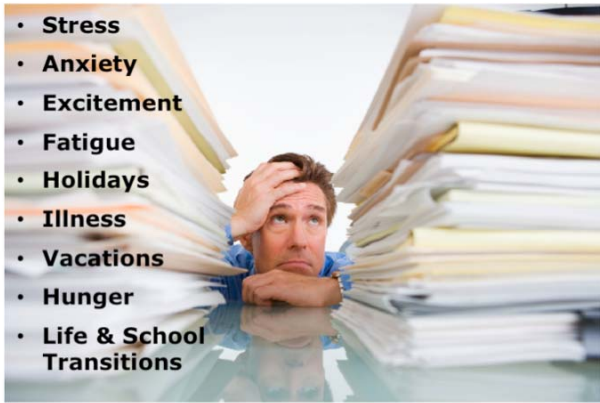
Both motor and vocal tics tend to wax and wane over time, even hourly or daily. The symptoms of TS may worsen during puberty and ease up as the individual matures. TS is a chronic and lifelong disorder.


Some tics can be suppressed for short periods of time. When seeing this, sometimes educators assume and expect that students are able to control their tics when they want to. This is the wrong expectation. Suppressing tics is difficult, exhausting and often results in an explosion of tics later in the day.

There are often periods of time where the symptoms of TS are absent because the person is absorbed in an activity that is extremely compelling for them. For example, a surgeon with TS can perform operations “tic free” without having to consciously try to suppress them.

Environmental Factors May Impact TS Symptoms

- Stress
- Anxiety
- Excitement
- Fatigue
- Holidays
- Illness
- Vacations
- Hunger
- Life & School Transitions

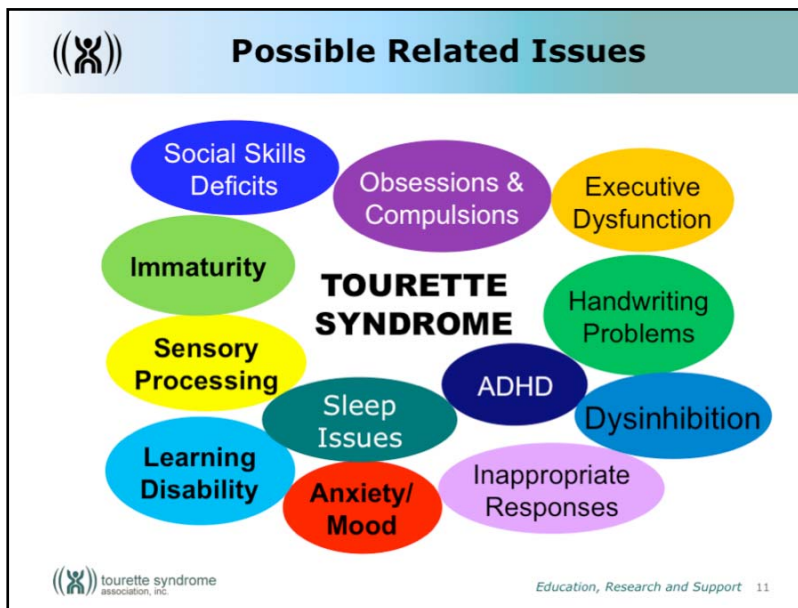
A photograph of a man in a blue shirt looking stressed, with his hand on his forehead, surrounded by large stacks of papers on either side of him. The background is a light blue gradient.

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Education, Research and Support 10

The symptoms of Tourette may wax and wane in response to environmental factors. The following factors may heavily influence a person with TS: stress, fatigue, illness, excitement and transitions within the family or school environment.

In knowing and understanding this, educators and families of individuals living with TS can plan ahead and compensate in different areas where possible. Examples of preventing increased symptoms might be encouraging some quiet time during holidays, transitions or times of extra excitement. Something we adults need to remember is to ask the student with TS what affects his or her tics and what might help them.



As you can see, many conditions and difficulties co-occur with TS. This slide illustrates that TS and related difficulties can be extremely complex and difficult to understand which in turn makes it challenging to develop appropriate supports.

Most children have a combination of related issues as well as the tics. For many, the accompanying neurological disorders cause more difficulty than do the tics.

While all support personnel do not have to be experts in every related disorder, it is important that someone on the team be aware of the possibility of related difficulties and their symptoms. School staff should be aware of effective accommodations, modifications and supports to assist the student not only with tics, but with the effects of related conditions as well.

If the student with TS struggles with sleep issues and OCD, the school needs to be prepared to be flexible in the student's output of school work. If the child is not getting sleep at night and the OCD or tics are exacerbated, the child may not be capable of much work. At other times, the child may have an increase in abilities when his or her symptoms are less severe. Punishing the student for not completing the work will only exacerbate symptoms not increase the amount of work completed.

Without this information, "behavior" may be misinterpreted as intentional, resulting in inappropriate interventions, failure for the student and aggravation of TS symptoms.



Dysgraphia

- **Characteristics include**
 - Slow and laborious writing
 - Hand and finger cramping
 - Sloppy handwriting, e.g., uneven spacing, irregular margins, and inconsistent lettering
 - Inability to copy correctly from book to paper or board to paper
 - Inability to transfer thoughts onto paper
- **Can be addressed with the use of computer technologies**





Dysgraphia affects a high number of children with TS. This can cause many problems within the educational setting if not diagnosed and attended to early. It may appear that the student does not want to write, or is unmotivated or “shutting down” when a writing exercise is given. Children with dysgraphia may know what they want to write, but the mere act of writing is extremely laborious and often physically painful. This is not a muscular issue, but a neurological one. This problem needs to be evaluated by an Occupational Therapist (OT), and sometimes a follow up by an Assistive Technologist (AT).

An assistive technologist can be helpful if the child struggles with reading due to eye tics, as they may assist with software that can read material to the student when symptoms interfere.

Obsessive-Compulsive Disorder (OCD) and TS

- **Obsessions**
 - Intrusive and recurring thoughts and images or impulses that your mind gets stuck on which are unpleasant and disrupt functioning
- **Compulsions**
 - Behaviors that are used to reduce the anxiety accompanying the obsessions
- **OCD and TS share chronic waxing and waning**
 - Exacerbated by stress, excitement and fatigue
- **OCD is often not apparent to the teacher or other students**
- **OCD makes children feel isolated**



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Obsessive-Compulsive Disorder (OCD) one of the associated neuro-behavioral disorders of TS, is difficult to live with because it is often invisible to the teacher and other students. Obsessions are unwanted, intrusive thoughts, images or impulses that get stuck in the child’s mind that can be unpleasant and disruptive. Depending on how mild or severe the condition, it may even go unrecognized by the parent. Living with OCD can make the student or child feel stuck, or driven to become a perfectionist.

Compulsions are the behaviors that are used to reduce the anxiety that accompany obsessions and help the child feel better.

Compulsions often need to be performed over and over again. Some children do not tell anyone about their obsessions or compulsions, because they know that the obsessions and compulsions are irrational and, therefore, make them feel “crazy.” This leads to a feeling of isolation. These children need to be reassured that they are living with a recognized, known neurobiological disorder, one that may affect much of their life.



Attention Deficit Hyperactive Disorder

- A very large number of students with TS also have ADHD
- They will sometimes, but not always
 - Be hyperactive
 - Be easily distracted
 - Be socially immature
 - Have impulse control problems
 - Exhibit short-term memory difficulties
 - Have problems with executive function



ADHD is another neuro-behavioral disorder that is associated with TS. Children with ADHD may need a great deal of time from their teachers. These are the children that lose their homework, come to class without a pencil, bring the wrong materials to class and often blurt out answers without being called on. They have trouble focusing and staying on task.

Problems **may** occur when the student :

- Is transitioning from one task to another
- Has a sudden schedule change
- Has unstructured time in the classroom or on the playground
- Is given several instructions at one time
- Is given a long assignment
- Is looking for someone to sit with at lunchtime
- Has to sit still for any length of time

An example:

Kevin was always being bullied by a classmate, Kate. One day while in line for lunch, she pushed her way in line ahead of Kevin. Even though he had rarely, if ever, had confrontations with other kids, he punched her. Being punished for that was not going to teach him anything. Aware of Kevin's condition, the principal helped him develop a way to avoid this impulsive act and to improve his impulse control. She suggested, while standing in line, keep your hands in your pockets.



Examples Of Executive Dysfunction

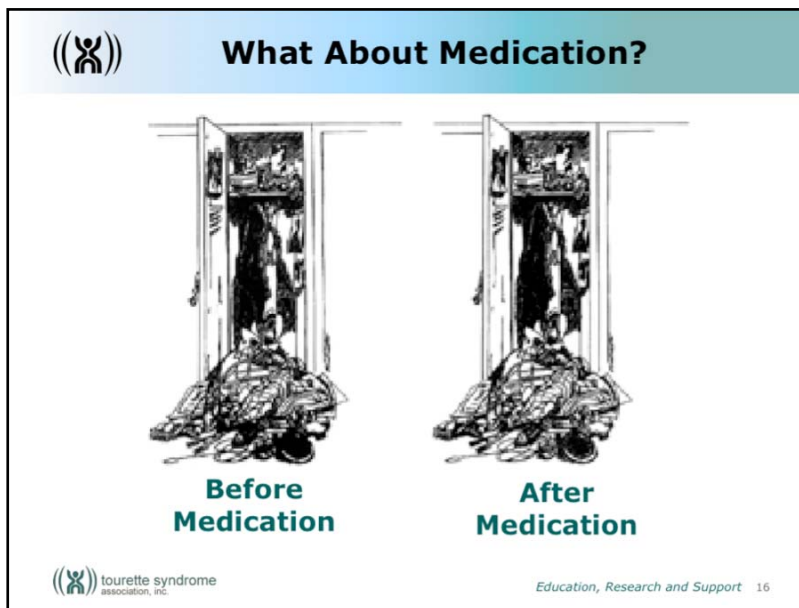
- **Executive Dysfunction is often associated with ADHD**
- **Difficulties include**
 - **Managing time**
 - **Forming goals**
 - **Organizing materials and activities**
 - **Starting/completing tasks**
 - **Breaking down long assignments and projects**
 - **Sequencing information**
 - **Dealing with the unexpected**



Executive Function involves the frontal lobe of the brain which is responsible for organization of time, materials, belongings, and thoughts. Students may be seen as lazy, purposefully forgetful, deliberately late and unmotivated. The frontal lobe is responsible for the executive functioning which results in “output,” similar to the activities of a conductor for an orchestra. The orchestra may have accomplished musicians, but without a conductor, the orchestra will fail.


The frontal lobe is responsible for the “executive” skills that allow students to organize all of the necessary skills needed to achieve what is expected for their age and intellectual abilities. They struggle with shifting gears; learning from past mistakes and being organized. Executive dysfunction is not a diagnosis like ADHD or OCD. Rather, it is a useful model to help people understand what might be occurring in brain interactions that could be a cause for disorganization, an inability to sequence a task; assess what needs to be done; change direction if necessary and independently complete tasks in a timely fashion.


Students require a non-judgmental atmosphere and a trusted teacher who can provide the necessary supports while teaching the strategies needed to accomplish tasks. This teacher must assist the student (and other teachers) to manage current workloads while teaching the skills, techniques and strategies required to independently manage their lives while in school and after leaving school. Some strategies used might be having the student use an agenda, sending emails to themselves regarding homework, using checklists so the child can check off necessary tasks on a daily basis.




Medication may or may not assist in addressing some of the problems associated with TS. Even with medication, a child with OCD, difficult tics, ADHD and Executive Dysfunction may still struggle. There is no one drug to help with the symptoms of TS, but various drugs may be used for different problem areas.

Many people with TS do not use any medication, and are able to manage very successfully. We always recommend that families consult their physician when it comes to treatment options.

 **Pledge Of Allegiance
Experiential Exercise**

 **How Does
Having TS
Really Impact
Classroom
Performance
And Learning?**

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Education, Research and Support 17

Now we are going to pretend you are the students and I am the teacher. (Pass out pencils and paper.) I am going to give you a chance to experience TS first hand. This will be a timed test and you will be graded on neatness and accuracy.


Your task will be to write “The Pledge of Allegiance.” I will give you 90 seconds to do this, but, I am going to give you one tic and one obsession and compulsion. Each time I clap my hands you must stop writing and hit the top of the paper with the little finger on the hand with which you write. Then you may continue. Then, every third word you write you must stop, erase or cross out and rewrite it. OK? Begin class.


(Clap your hands every 2-4 seconds and time the audience for 90 seconds.)

OK class, please set your pencils down and look up. How many of you finished writing the entire Pledge? How did you feel while taking this test? How many of you lost track of what you were writing? Was this an accurate reflection of your knowledge of “The Pledge of Allegiance?” How do you think you would feel about yourself if you were compared to students who had no tics or OCD?


What are some other ways we could test the knowledge of a student with TS?

Let’s remember now, you were given only one tic and one obsession and compulsion and that is not even enough to qualify as a full diagnosis of TS.

 **IDEA 2004 & Federal Regulations 300.8(c)(9)**

 "We 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."

Due to the intense advocacy efforts of the national Tourette Syndrome Association, TS is now included in the IDEA under the definition of Other Health Impaired

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TSA has worked very hard for years and we are very pleased that children with TS will now be classified under the federal definition of "Other Health Impaired." (OHI) Whenever a change such as this is made to the IDEA and Special Education Regulations, the authors of this federally mandated law clarify their reasons for this action in the "Comments" section of the federal regulations based on the IDEA.

As you can see, the IDEA states that TS is commonly misunderstood to be a behavioral or emotional condition rather than a neurological condition. Additionally, it states that this change has been done to correct the misperception of TS as a behavioral or a conduct disorder and most importantly, that this new definition will "prevent the misdiagnosis of their NEEDS."

TS symptoms are frequently seen as being behavioral or emotional difficulties for which the typical intervention is a reactive program based on rewards/ consequences. Instead, since this is a neurological problem, a proactive and positive approach is best suited to meet the needs of children with TS. One way to assist a child with difficult "TS symptoms might be to schedule his or her core subjects in the beginning of the day when they are most rested and ready to learn. For a child dealing with difficult and painful tics, hand them a laminated pass to take a break when the tics begin to overwhelm them. A student with dysgraphia can be handed a copy of notes instead of making them copy off the board. A separate test location can assist a child tremendously who deals with sensory issues and has trouble staying on task in a busy classroom.



Classroom Strategies

- Designate a safe place for the student to go to when tics are severe
- Positive and proactive supports involving TS symptoms
- Extended time for tests and assignments
- Reduce stressful situations
- Frequent breaks to provide opportunities for movement
- Preferential seating
- TS educational in-service for the entire school
 - TSA Youth Ambassador Program
- Find ways to make tics irrelevant



*"Every child is different, therefore every child will require different strategies, BUT there is a strategy for every child."
Judit Ungar, President, Tourette Syndrome Association*



Education, Research and Support 19

There are many strategies that a school can implement to assist a child with TS. Sometimes they are fairly obvious but others require more creativity. Note taking can be far too cumbersome for a child with TS, so handing the student a page of notes takes a huge burden off their shoulders. A child who is struggling in Middle School during lunch time with too much stimulation and too many social issues might do well if given the job of assisting someone in the office and eating lunch there with a buddy. A ready-made pass would be helpful so a student could get up and take it from the teacher if struggling with difficult tics. This would allow him/her to head off to a safe spot for a couple of minutes. This might just allow that child to remain in school successfully for the rest of the day.

The best strategy is education. A school that is educated about TS is more likely to create a positive environment in which a child with TS can be encouraged to grow to his/her potential.

Contact TSA if you have questions about classroom strategies. Also check out the Education Strategies and Education Advocacy pages on the website for more information and valuable resources.





Classroom Strategies (cont.)

- **Set up a signal for student to use when there is a need to leave the classroom**
- **Un-timed tests and exams for all subjects**
- **Allow student to leave class early to avoid crowded hallways**
- **Build schedule around student's most productive times of the day**
- **Consider accommodations for accomplishing work**
 - **Oral reports, use of a computer, shortened assignments, and/or a scribe**
- **Consider additional adult support during unstructured time**
- **Refer to TSA's "Catalog of Accommodations"**



Given that learning, not standardization is the goal, it may be necessary to depart from teaching practices that work for the rest of the class to reach the student with TS.

For example testing a child with TS verbally, even though the rest of the class may be tested in writing.

Oftentimes the child is your best resource. Since he or she has to figure out how to get through each day, don't hesitate to ask the child what might help create a better learning environment.



Parent-Teacher Relationship

- **Homework support**
- **Extra set of books for home use**
- **Frequent communication between school and family**
- **An informed, caring, and supportive environment makes all the difference**



Another very important strategy is to enhance home-school communication. There are many forms of communication available. We can email, fax, leave voice mails or send notes back and forth in an agenda. Talk with the family and decide what forms of communication will work best and set up a communication plan at the very beginning of the year.

If a parent feels comfortable sending you a short email letting you know her child had a rough night last night and didn't sleep at all, you, as an educator, may be able to better support that student in your class. Likewise, if a child has a rough day in school you can alert the parent. Whatever happens in school affects the family when that child walks through the front door at home.



Kids with TS Are Regular People Like You & Me

- All walks of life & all professions
- TS is an Equal Opportunity Disorder
- Kids with TS are kids first
- TS is life long and at this time, there is no cure
- Symptoms can look controllable
 - But they are not!!



Children with Tourette Syndrome are just like any other children with the added component of having to deal with TS. They can be anything they want to be. Sometimes the challenges of TS require creative thinking to get around the obstacles, but all career opportunities are available.

There are teachers, therapists, doctors, mechanics, surgeons, lawyers, pro basketball players and well known musicians who live successfully with Tourette Syndrome.



Additional Presentations

- **ADHD/Executive Functions**
- **Obsessive Compulsive Disorder (OCD)**
- **Factors That May Affect Learning**

There are a number of modules in our in-service that go more in-depth on various issues associated with TS. We would be happy to share these with you either now or in the future.



The Bottom Line

I *want* to learn and
do well in school!

Will you help me?



Thank you so much for having me here. TSA hopes the information presented will help you help others.



Contact TSA for More Information and Resources

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Education, Research and Support 25

TSA is open to assist all those living with or interested in Tourette Syndrome. Don't hesitate to call with questions or to become a member and to receive their informative quarterly newsletter. TSA can help keep you updated on the latest medical research, educational supports and resources available to those living with TS.