Tourette Syndrome is a neurodevelopmental disorder that is complex and often misunderstood. This presentation will provide you with an introduction to Tourette Syndrome (TS) and to conditions that frequently occur with TS, such as Obsessive-Compulsive Disorder, Attention Deficit Hyperactivity Disorder, Executive Dysfunction, and other learning disabilities.

This presentation is intended for school-based professionals who may be working with students who have TS. The Association recommends that school psychologists, nurses, special education directors, and other training staff use this as a tool to educate their faculty and staff.
This slide is included as a reminder of how critically important teachers’ responses are to all children. We all have days that are more difficult to get through than others, but it is so important to always recognize the power teachers hold regarding a student’s academic education, as well as his or her social abilities and self-worth. The teacher is a role model for the entire class. His or her actions will often have a bigger impact than words. Demonstrating a positive attitude verbally as well as non-verbally is critically important.

We are hopeful that providing information regarding this complex and highly misunderstood disorder will assist you in recognizing symptoms and providing positive supports for children with TS.
The office of the Tourette Association of America is located in Bayside, New York. The Association was founded in 1972 and it 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 is a hereditary, neurodevelopmental disorder that is often first recognized in childhood, usually between the ages of 6 and 10. TS is not a rare disorder.

To have a diagnosis of Tourette Syndrome, individuals must display more than one motor tic and at least one vocal tic over the course of a year. However, tics may wax and wane, and individuals may experience tic-free periods. Individuals with tics may not necessarily meet the diagnostic criteria for TS or other tic disorders. All tics should be examined by a physician or other medical professional.

This highly misunderstood disorder presents differently and varies in severity from person to person, even within families who share the same genetic background. All instances of TS are not alike. Therefore, it is important to determine management strategies on an individual basis.
The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) lists three types of tic disorders: Tourette Syndrome, Persistent Motor or Vocal Tic Disorder, and Provisional Tic Disorder. To learn more about the criteria for these diagnoses, visit http://www.cdc.gov/ncbddd/tourette/diagnosis.html

TS can affect children of all races and both sexes. While study results can vary, it is estimated that 1 in 160 (or 0.6%) children, ages 5-17, living in the United States has TS. When considering TS and tic disorders, the combined prevalence is estimated to be approximately 1 in every 100 (or 1%) children.

Tic disorders occur more frequently in boys than in girls.

For many, tic severity will decrease with age. However, the course of every child’s TS will be different.
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 tics that involve multiple muscle movements. These can include hopping, clapping, throwing, touching (self, others, objects) holding funny expressions, sticking out the tongue, kissing, pinching, tearing paper or books, etc. Other complex tics can include copropraxia (inappropriate or obscene gestures) or echopraxia (imitating others’ gestures).
Vocal tics may or may not appear to be purposeful or meaningful and can seem out of context.

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

Vocal tics can vary and may include: echolalia, when the individual echoes what someone else has said; palilalia, the involuntary repetition of their own words; and coprolalia. Coprolalia involves the utterance of inappropriate comments (such as curse words, racial or sexual remarks). Coprolalia is most often mocked in the media; in movies, TV, online and by comedians. You can see how this symptom can be the most problematic of all vocal tics. It is important to emphasize that people with coprolalia do not intend to say these inappropriate things, and also that coprolalia is not necessary for a diagnosis of TS. While coprolalia may be the most often talked about component of TS, only 10-15% of all individuals with TS have this symptom. Awareness of the facts about coprolalia will help promote better understanding of this symptom and of the disorder itself.
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 an individual matures. However, this does not always occur for everyone.

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, athletes or musicians with TS often report being tic-free while performing. Again, this varies from individual to individual.

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. However, suppressing tics is difficult, distracting, and requires a great deal of physical and mental energy. Therefore, this is not an effective management strategy for TS or tic disorders.
This Emmy-award winning documentary, produced by the Tourette Association and HBO, 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 in the Publications section of the Tourette Association website www.Tourette.org
The severity or frequency of TS symptoms may be influenced by environmental factors such as stress, fatigue, illness, excitement and transitions within the family or school environment, among others.

In knowing and understanding this, educators and families of individuals living with TS can plan ahead and accommodate in different areas where possible. An example might be encouraging additional quiet time during holidays, transitions or times of extra excitement. Remember to ask the student with TS what affects his or her tics and what might help them.
The Tourette Association has worked very hard for years to have the facts about TS clarified in education law. We are very pleased that children with TS are now classified under the federal definition of "Other Health Impairment" (OHI) in the Individuals With Disabilities Education Act (IDEA). 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 identified as a neurological condition. Additionally, it clearly states that this change has been done to correct the misperception of TS as a behavioral or a conduct disorder. Most importantly, this new definition will “prevent the misdiagnosis of [students’] needs.”

This is particularly relevant when determining the right intervention for the child. For example, reactive interventions, such as those based on consequences and rewards, are often implemented when managing behavioral and emotional conditions. However, this type of intervention may be inappropriate when addressing a neurodevelopmental condition like TS. Rather, more proactive and positive approaches may be best suited for children with TS.
There are many strategies that a school can implement to help students with TS learn the skills needed to be successful. Sometimes these strategies are fairly simple, but others may require more creativity. Additionally, keep in mind that every student is unique, and strategies that are successful for one student may be ineffective, or even counterproductive, for another student with TS.

A proactive approach to managing TS in the classroom can include environmental changes that support the students’ needs. For example, a student who experiences more frequent tics in the afternoon may want to schedule their challenging classes in the morning.

Students who are easily distracted may benefit from sitting in the front of the class, while students with more visible tics may feel more comfortable sitting towards the back of the class. Likewise, providing a designated testing location or spot in the room with minimal distractions to the student or to others may also be beneficial.

Students who may experience increased anxiety due to the stress of a crowded hallway may need to be let out of class early.

Changes to the school environment may enable a student to thrive academically without drawing negative attention to his/her tics.
Other accommodations can be made that may assist the student in staying on task and completing assignments and written work. Because learning is the ultimate goal, not standardization, it may be necessary to depart from usual teaching practices that work for the rest of the class in order to support a student with TS. It may be helpful to focus on the quality of work produced rather than the quantity.

Students with TS who may have difficulty with handwriting their own class notes or written assignments may want to consider using a computer to type up their notes or using prewritten notes by the teacher. For longer hand-written assignments, perhaps a student could explore other methods of demonstrating their knowledge, such as giving an oral presentation. Providing extended time for test taking or completing assignments may also be necessary for students if their tics or other conditions interfere with completing their work.

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 student what might help to create a better learning environment. Strategies are likely to be more effective when they are individualized to each student’s needs. Be creative and flexible!

Educating others is a key strategy. A school staff and student body that are educated about TS are more likely to create a positive environment in which a student with TS can be encouraged to grow to his/her potential. Whether done through a professional education in-service or through the Tourette Association’s Youth Ambassador Program, in which students who have TS are trained to speak to a student’s peers about TS, educating others and raising awareness of TS can have a positive and enduring impact. Contact the Tourette Association if you have questions about classroom strategies. Also visit the Education Strategies and Education Advocacy pages on the Tourette Association website for more information and valuable resources.
As you can see, many conditions and difficulties co-occur with TS. This slide illustrates that TS and related issues can be extremely complex and difficult to understand. These can make it challenging to develop appropriate supports.

Accompanying issues may be more impairing than the tics themselves, thus affecting learning and performance in school. School staff should be aware of effective accommodations, modifications and supports to assist the student in addressing these concerns and avoiding inappropriate interventions.
Dysgraphia is a learning disability involving difficulties with written expression of language. Dysgraphia affects a significant number of children with TS. Children with dysgraphia may know what they want to write, but the mere act of writing is extremely laborious and may be physically painful. Therefore, students with dysgraphia may seem unwilling to write or erase frequently, preventing them from finishing assignments appropriately or in a timely manner.

An assistive technologist (AT) can also be helpful if the child struggles with reading due to eye tics, head jerks, etc. by providing software that can read material to the student when symptoms interfere. Students may also benefit from the help of a note-taker or the option to type or receive class notes ahead of time.
Now we are going to pretend you are the students and I am the teacher. I am going to give you a chance to experience TS symptoms firsthand. 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/compulsion. Each time I clap my hands you must stop writing and hit the top of the paper with your pinky 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? Class, you may begin.

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?

In this exercise, you were given only one tic and one obsession and compulsion – however, individuals with TS have multiple tics and very often experience other issues that can interfere with everyday tasks. What you experienced for 90 seconds is only a snapshot of what most individuals with TS experience all day long.
Obsessive-Compulsive Disorder (OCD), a condition often associated with TS, is difficult to live with and often invisible to the teacher and other students. Obsessions are recurrent, unwanted, intrusive thoughts, images or impulses that get stuck in the child’s mind. These obsessions can be unpleasant and disruptive. Compulsions are repetitive actions that are done to relieve the obsessive thoughts, but the relief may only be temporary. Not performing the compulsion often increases the student’s anxiety. Depending on how mild or severe the condition, it may even go unrecognized by the parent. However, living with OCD can make the student feel stuck and make it extremely difficult to concentrate.

Some of the most common issues as a result of OCD include: difficulty transitioning; touching things (especially those that may be off-limits); counting words or objects and/or lining things up in a particular order; inability to tolerate mistakes or not being able to start a task due to fear of imperfection; refusing to eat or participate due to obsession with germs or contamination; repeatedly checking to make sure an action was done correctly (i.e. locking the door); constant worrying or doubt; not completing work or appearing inattentive because of the time and focus on performing compulsions.

Some children might be afraid to tell others about their obsessions or compulsions to avoid feeling “crazy” or seeming different to others. This may result in a feeling of isolation. These children should be reassured that they are living with symptoms that are experienced by many people. Some students may exhibit obsessive-compulsive behaviors, even though they may not meet the clinical definition of OCD.
Several strategies can be implemented to help keep a child with TS and OCD on task. Symptoms may vary in different environments, so regular communication among the parents, teachers, and the student is key. If the student is working with a counselor or therapist, he or she might also be able to advise on classroom strategies. Collaboration will likely facilitate active participation from all parties in developing effective and appropriate strategies to help manage symptoms.

Assistive technologies can be extremely useful to support a student with OCD. The student who constantly erases, has to count words in each sentence, or write letters perfectly can be helped by various technologies. By using a computer, many students can write an assignment without the need to destroy the document if he/she makes an error. The delete button works easily and more effectively. Audio books/e-readers may be helpful for students who feel the need to count lines and letters in textbooks.

A separate location for quizzes and tests can be important for many reasons. This may minimize distractions and help the student to focus on the test. If the student has a symptom that is distracting to others, a separate location allows them to focus on their work instead of focusing on suppressing a tic, obsession and/or compulsion.

Many students with OCD will need extended time on tests and assignments to account for symptoms which interrupt their ability to complete their work.
ADHD is a neurobiological disorder that is often associated with TS. According to the DSM 5, there are three subtypes of ADHD:

- Predominately inattentive
- Predominately hyperactive-impulsive
- Combined

Children with ADHD may need extra attention from their teachers. These are likely the children that repeatedly lose their homework, come to class without a pencil, bring the wrong materials to class, or blurt out answers without being called on. They typically have trouble focusing and staying on task. These students may have difficulty with regulating their emotional responses and learning from consequences.

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 or on field trips
- Has to sit still for any length of time
- Is in an over-stimulating and/or distracting environment
Executive function skills guide thought and behavior and allow students to organize all of the necessary tasks needed to achieve what is expected for their age and intellectual abilities. There is no single behavior that indicates executive dysfunction. Executive function deficits (executive dysfunction) may result in disorganization, an inability to sequence a task, assess what needs to be done, change direction if necessary, and/or independently complete tasks in a timely fashion. To others, students may seem purposefully forgetful, deliberately late and unmotivated. However, students may just need more help staying organized while learning life-long organizational skills.

A useful analogy to think about executive function is to consider the role of a conductor in an orchestra: the conductor of an orchestra directs the musicians on rhythm and tempo so that they can perform together. Without a conductor, the individual musicians would not know when to start and stop or speed up, and their performances would not be in sync. Similarly, executive function skills allow for an individual to plan, organize and complete tasks effectively. Without these skills, students who have executive dysfunction will have difficulty in these areas.
A non-judgmental, trusted teacher, speech-language pathologist, and/or counselor can provide the necessary supports to help students learn how to accomplish tasks like time management, breaking assignments down into manageable segments, and developing organizational strategies.

It is important to identify a student’s strengths and interests in developing effective strategies. The student will then be more likely to use these strategies independently while in school and as an adult. Strategies could include the use of planners, checklists, or extra sets of textbooks at home, depending on the student’s needs.

Determining strategies for each individual student often requires brainstorming with the student and the use of creative approaches.

It may be helpful to meet with a designated person on a regular basis to reinforce the proposed strategies, ensuring sustained life-long management skills.
Difficulties with processing information frequently goes unrecognized. Instead, children are often perceived as defiant, uncooperative, lazy, intentionally unprepared, or generally less capable.

Signs of processing issues may include responding slowly to requests, questions, directions and comments, appearing forgetful, or struggling with peer relationships. Often students with processing delays will look around to see what other students are doing. It may appear as if he/she is cheating or attempting to be disruptive when, it may be an attempt know what directions were given.

Consulting a speech pathologist or educational diagnostician to develop environmental modifications can help students cope with these challenges.
An assessment by a speech pathologist or educational diagnostician can help determine the conditions under which the student experiences problems. Some questions to ask include:

- Is it during specific tasks, at specific times of day, or in certain subject areas?
- Is it caused by the need to complete tics and/or OCD symptoms?
- Is the speed at which verbal information is received a factor?

OCD can present itself as an auditory processing problem; for example, a student may need to repeat in his/her mind the last sentence said by someone or he/she may need to complete a thought or action before responding.

Because distractions (e.g. what a person is wearing, what is going on behind the person, a noise in the hallway, other activities in the classroom, etc.) can interfere with a child’s auditory processing, some children may require additional time for tasks, or may need to develop strategies for focusing attention on something else to reduce the amount of stimulation while processing information.

Asking the student to rephrase questions or directions can help to ensure that he or she has properly absorbed the information.
Sensory input for some children with TS may be perceived and/or interpreted incorrectly.

Some children are hypersensitive to touch, light, smell, taste and/or sounds. They may perceive simple touch as a much stronger sensation, such as hitting, or struggle in noisy environments. Children with sensory processing issues may also be extremely sensitive to shirt tags, sock seams, and other sensations that children typically can ignore. You may find that children with sensory processing issues avoid or struggle in situations that involve overstimulation, like the cafeteria, recess, gym, music or art.

These same children, at times, may be hyposensitive and require more sensory input. They may engage in painful behaviors such as skin picking, hitting themselves, purposely running into walls or lockers, chewing on items, self-injury, carrying heavy objects, or wearing heavy coats inside.
First, awareness that seemingly “bizarre” behaviors may actually be sensory-related symptoms is important.

Depending on the school system, there may be an occupational therapist (OT) available to work with the students. If this service is available, an OT trained in sensory integration can evaluate a student with TS. Following the evaluation, an OT can help develop a plan (also known as a “sensory diet”) consisting of strategies, accommodations and modifications specific to the child’s needs.

Sensory needs and symptoms may change over time. Re-evaluations and new plans may be periodically necessary. It is also important that the student be able to figure out new ideas and ways of coping with challenges over time. This will also increasingly allow a child to advocate for him or herself.

For example, some students may prefer listening to music while doing homework, while others will prefer silence. Eating crunchy food, hard candy or chewing gum while studying can assist some students with focusing on a task. Spinning in circles, jumping, or running might be helpful for some, while reduced lighting, soft material to touch, or specialized sensory pillows to sit on may help others. Strategies are only limited to the need and imagination of the trained specialists who develop the sensory diets.
Providing the appropriate supports for students with TS is a team effort on behalf of parents, teachers, and other school staff members. Fostering a positive relationship requires mutual respect and communication. While at times both parents and teachers can become frustrated and sensitive to each other’s suggestions or comments, sharing information about the child’s performance and productivity at home and at school may be beneficial in determining the best approach/es that will enable the student to achieve his/her fullest potential.

It is helpful in developing a collaborative relationship to occasionally inform a parent of a positive event without including anything negative. All too often, parents only receive a note, email or call from a teacher because of a problem.

Developing a communication plan that works for everyone involved early in the year can be a major component to a successful year for a student with a complex neurodevelopmental disorder such as Tourette Syndrome.
Children with Tourette Syndrome are just like any other children, with the added task of having to deal with the symptoms of TS, and often, related disorders. Just like all children, they can be successful with positive support from family and school. Sometimes the challenges of TS require creative thinking to determine the appropriate strategies, and to be supportive of natural abilities and interests. There are teachers, therapists, doctors, mechanics, surgeons, lawyers, professional athletes, and well-known musicians who live successfully with Tourette Syndrome. People who have TS are like everyone else; just with a few challenges to manage.
Today, we talked about:

- What is Tourette Syndrome?
- The co-occurring conditions and how they can impact learning.
- Potential strategies for managing symptoms of TS and related difficulties.

Review learning objectives from beginning.
This is a picture of a boy with TS who began every school year with a brief PowerPoint presentation for all of his teachers to explain how specifically TS impacts his educational experience. He ended his PowerPoint with this picture and has given us permission to use it for ours.
The office of the Tourette Association of America is located in Bayside, New York. The Association was founded in 1972 and it is the only national, voluntary, non-profit membership organization dedicated to identifying the cause, finding the cure and controlling the effects of TS.
The Tourette Association’s website has valuable information and strategies. There also are phone numbers and links if you have questions or would like to discuss specific issues with someone.

This resource was developed through a partnership with the U.S. Centers for Disease Control and Prevention. We appreciate any feedback you can provide via the Survey Monkey link above. Your responses will help us to evaluate and continue to develop new and authoritative resources on TS. Thank you for your time.