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Thank you for your inquiry to Tourette Texas. You are not alone. Current conservative statistics show that 1 out of every 160 children between the ages of 5-17 years in the United States has TS and that 1 out of every 50 children has TS or another persistent Tic Disorder. All ethnic groups are similarly affected.

Enclosed please find:

- *Facts About Tourette Syndrome* with general information about T.S.
- Tourette Texas Chapter Programs and Services information
- Specific information regarding tics and other issues
- A teacher packet including:
 - Teacher letter
 - General educational recommendations
 - Sample child letters/Fast Facts for teacher (to be replaced with specific information about your child)

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

Please check our website for information about Support Group meetings, signing up for our e-newsletter, other documents, events around the state.
www.TouretteTexas.org

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

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

Sheryl Kadmon, R.N.
Executive Director / Educational Specialist

FACTS ABOUT TOURETTE SYNDROME

Answers to Most Commonly Asked Questions

What is Tourette Syndrome (TS)?

TS is a child-onset complex neurological disorder characterized by tics – involuntary, rapid, sudden movements and/or vocal outbursts that occur repeatedly. TS is often accompanied by obsessive-compulsive disorder (OCD); attention-deficit/hyperactivity disorder (ADHD); poor impulse control; and other behavioral issues. Although TS typically improves after adolescence, it may persist into adulthood and be a life-long condition. The severity of tics and co-morbid behavioral problems typically wax and wane over a period of time and can vary widely between individuals, with symptoms ranging from mild to disabling. Tics can sometimes be temporarily suppressed, but this requires mental effort and may be followed by a rebound worsening.

What are the most common symptoms?

Commonly, motor tics consist of eye blinking, head jerking, shoulder shrugging, facial grimacing, and other jerk-like limb and body movements. Phonic (or vocal) tics are typically manifested by throat clearing, humming, barking noises, sniffing, and tongue clicking. Some patients make a variety of sounds and shout out utterances, including obscenities, called coprolalia (see below). Most patients describe sensation before each tic, referred to as a premonitory urge.

What is ADHD?

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

What is OCD?

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

OCD symptoms include repetitive touching, tapping, a need for symmetry/evening up, and checking and re-checking. The obsessions (recurrent thoughts) and compulsions (repetitive behaviors) may lead to marked distress and dysfunction.

What is the cause of the syndrome?

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

Is it inherited?

While the exact cause is unknown, TS appears to be genetically inherited in the majority of individuals. Genetic studies indicate that TS is not due to a single gene mutation but results from complex interaction of many genes. Sons are three to four times more likely than daughters to exhibit clinical symptoms of TS.

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

Although often overemphasized in lay and social media, the fact is that cursing, uttering obscenities, ethnic slurs, and obscene gestures are not manifested by all people with TS. These forbidden and socially unacceptable behaviors are often embarrassing and potentially expose the people with TS to bullying or other aggressions. New studies are being conducted on coprophobia, and the TAA MAB is in the process of publishing a white paper on this topic. For now, it is estimated that around 20% of children with TS have coprolalia.

How is TS diagnosed?

Diagnosis is made by observing symptoms and evaluating the history of their onset. No blood analysis, X-ray, or other type of medical test can identify this condition.

How is it treated?

Currently, there is no known cure for TS, but many safe and effective treatments are available to alleviate the symptoms. It is essential that the selection of the therapy is individualized and targeted to the most troublesome symptom. Therefore, a comprehensive evaluation by a Tourette expert is important, as symptoms associated with ADHD, OCD, or other behavioral difficulties may be more problematic than the tics. Tics usually improve with drugs that block or deplete dopamine or in some cases with injections of botulinum toxin into the abnormally contracting muscles causing focal tics. Tics can sometimes be managed with Comprehensive Behavioral Intervention for Tics (CBIT), a non-pharmaceutical recommended treatment. Central stimulants and drugs that act on the adrenaline system are useful in the treatment of ADHD, and Cognitive Behavioral Therapy (CBT) may also be helpful. Serotonin receptor blocking drugs and other medications are often effective in treating symptoms of OCD as well as anxiety and mood abnormalities. Individuals react differently to the various medications, and frequently it takes some time until the right substance and dosage for each person are achieved. In addition, appropriate accommodations at school, tutoring, counseling, and other interventions may be helpful in addressing academic, emotional, social, and behavioral problems that arise as a result of the impact of TS, OCD, and ADHD on their daily lives.

Is there a remission?

Many people with TS will improve, not worsen, as they mature, especially after adolescence. In a small minority of cases, symptoms will remit completely in adulthood, but others may recur later in life.

Do children with TS have special educational needs?

As a group, children with TS have a higher incidence of academic or artistic giftedness than the population at large. However, many also have difficulty demonstrating their abilities due to an increased incidence of learning issues, often associated with the level of severity of the symptoms and comorbidities of ADHD, OCD. Problems dealing with the tics, often combined with ADHD, OCD, and other learning issues, may necessitate special education (OHI) or 504 assistance.

How many people are affected?

Tourette Syndrome and other Tic Disorders are not rare. The current estimates are that 1 out of every 160 children between the ages of 5-17 years in the United States has TS and that 1 out of every 50 children has TS or another persistent Tic Disorder. All ethnic groups are similarly affected.

What is the prognosis?

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

What is the Tourette Association of America – Texas Chapter?

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

Tourette Association of America – Texas Chapter

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Tourette Texas Services:

**Advocacy * Counseling * Education * Referrals * Support Groups
Direct Client Services * Camp * Newsletters * Scholarships
Family Events and Activities * Youth Ambassador Program**



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SERVICES AND PROGRAMS

The Tourette Association of America – Texas Chapter strives to support the medical, educational, social, and economic needs of Texans with Tourette Syndrome and to improve their quality of life. Approximately 90% of our clients are children and their families. All Programs and Services are provided without cost to the recipients and no dues are assessed.

Tourette Texas’s vital and unduplicated work includes:

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

Education and In-Service: Accurate information about Tourette Syndrome is disseminated to physicians, educators, parents and families and at events and meetings throughout the state. In-Service presentations are made to school districts, and annual educational presentations are scheduled across the state at the start of school for college students, parents and young adults.

Medical Assistance Program: Financially distressed, under-insured and non-insured individuals are funded for visits to experienced physicians for diagnosis and management of their TS symptoms through the Andrei Jackson Memorial Medical Scholarship Fund.

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

Support Groups: Regular meetings at our many Support Groups around the state provide speakers, support, materials and social interaction for families, children, and adults dealing with

Tourette Syndrome. Currently, TS Support Groups are hosted in Austin, Bryan/College Station, DFW/Arlington, Golden Triangle, Katy/Sugar Land, New Braunfels, San Antonio, Victoria/Corpus Christi, and The Woodlands/North Houston.

Camp du Ballon Rouge: Hosting its 21st camp April 24-27, 2025, Camp dBR hosts children and teens with Tourette Syndrome to a **tuition-free** (the only tuition-free TS camp in the nation) four day camping weekend. For most, this camp is the only time they feel free of prejudice or embarrassment about their symptoms – and may even be the first time they meet another child with TS.

Family Events and Activities: Tourette Texas hosts across-the-state holiday parties, Summer/Back to School parties, pizza parties at support group meetings, or sports and cultural outings, all **free** of charge to our very often over-whelmed and under-funded families.

Youth Ambassador Program: In partnership with the Tourette Association of America, the Texas Chapter helps sponsor and train children and teens to talk about TS. These young people (ages 13-18) speak about TS before their peers at school, sports leagues, scout troops, camps and after school programs, helping to demystify TS and spread awareness and acceptance.

The Tourette Association of America – Texas Chapter strives to support the lives of those living with TS and their families. Until a cure for Tourette Syndrome is found, Tourette Texas will work diligently to provide medical assistance and scholarships; offer social activities and events for children, adults and siblings; educate the public and professionals; provide “whole person” consulting; and advocate for an improved quality of life for its clients. We receive no Federal or State assistance, raising funds through donations, events and select private grant opportunities.

***Tourette Syndrome** (TS) is a neurological movement disorder characterized by motor and vocal tics. Beginning in childhood, it causes those affected to make movements and noises they cannot control. Many with TS additionally have associated obsessive-compulsive disorder, attention-deficit-hyperactivity disorder and learning differences. Just as importantly, many experience serious self-esteem and social issues due to their often puzzling, misunderstood or disruptive symptoms. **The current estimates are that 1 out of every 160 children between the ages of 5-17 years in the United States has TS and that 1 out of every 50 children has TS or another persistent Tic Disorder.** Although symptoms usually diminish in adulthood, TS is considered a lifelong disorder.

For more information, call or email or visit our website at www.TouretteTexas.org.

Your TAX-DEDUCTIBLE CONTRIBUTIONS are always welcome.

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



EXPECT THE UNEXPECTED

by

Carol Ann Brady, Ph. D.

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

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

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

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

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

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

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

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

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

Categories of Tics

Motor

Simple
Complex

Vocal (phonic)

Simple
Complex

Motor Tics

- **Simple:**

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

Examples:

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

- **Complex:**

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

Examples:

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

Vocal (phonic) Tics

- **Simple**

Single sounds or noises

Examples:

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

- **Complex:**

Verbalizations

Examples:

Coprolalia, echolalia, palilalia

Vocal Tics II

- **Linguistically meaningful utterances**

“Shut up”

“Oh, ok”

“Now you’ve done it”

- **Speech atypicalities**

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

Phenomenology of Tics

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

General Educational Recommendations

- Classify Tourette student as **Other Health Impaired (OHI)** / Special Education or **Section 504** / Regular Education

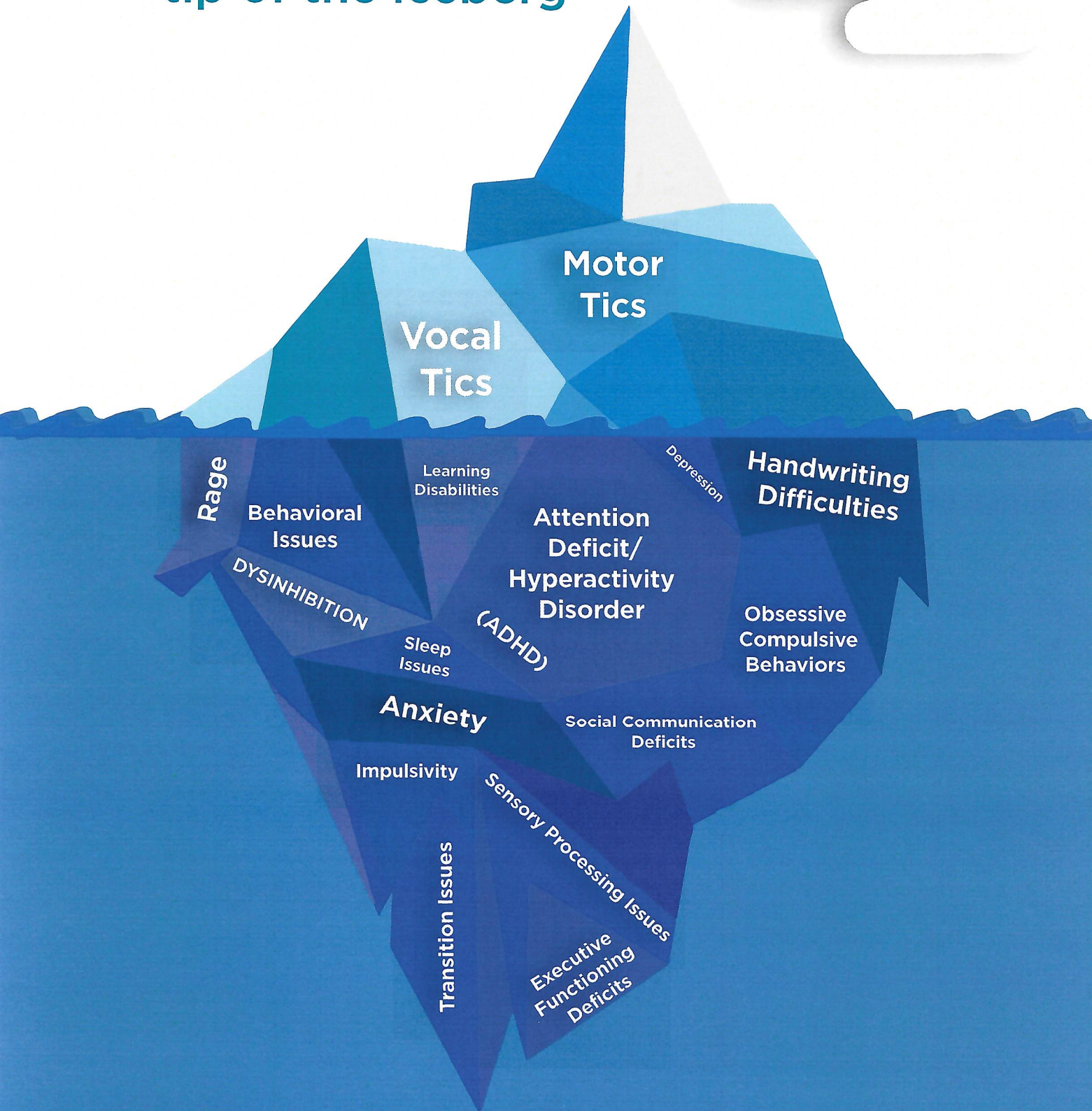
- Individual Education Plan (IEP):
 - Each Tourette child is unique because of diverse range of symptoms.
 - Assessed for associated learning disabilities (LD)
 - Use of ancillary professional services:
 - School counselor / psychologist, OT, PT, adaptive PE
 - Placed in regular classroom with modifications as necessary

- Common Adaptations:
 - Decrease all paper and pencil tasks
 - Preferential seating
 - Copy of notes provided by teacher / NCR paper
 - Shorten writing assignments or oral assignments
 - Use of scribe
 - Use of graph paper
 - Use tape recorders, calculators, and computers when necessary
 - Oral testing
 - No timed testing
 - Frequent breaks
 - Extend time to complete assignments
 - Safe place to discharge tics or emotions
 - Allow frequent movement in classroom
 - Special homework plan:
 - Bi-weekly communication via email generated by parent (Tu/Thur)
 - Trapper Keeper or special homework folder
 - Weekly assignment sheet of homework and test dates
 - Set of textbooks to keep at home

- Education of peers and school staff

TOURETTE SYNDROME

Tics are just the
tip of the iceberg



Dear Teacher:

If you have a student with Tourette's syndrome (TS) in your classroom, you are now and forever after one of the most influential people in that child's life. Think about this for a moment. This is true whether the child is a model student, or one who exhibits varying degrees of attention, learning, or behavioral problems. This is because a child with TS lives in constant fear of being betrayed by his own body. He feels only a limited sense of control. Quite naturally, his growing sense of self-esteem will be at risk, and he will rely more heavily than the average child on others in his environment for positive feedback and for reassurance and encouragement. As his teacher, you are that most influential person.

It is often reported to us by parents that the school environment is where their children experience the most anguish and frustration associated with TS. Problems arise and snowball when teachers do not understand and appropriately respond to the sometimes baffling behaviors accompanying TS. One major source of misunderstanding is not realizing that symptoms will increase and decrease in intensity over time in a cyclic manner. As a result, some days a student will be able to perform better academically and possibly, behaviorally, than on other days. This does not necessarily reflect a lack of motivation on the part of the child, or a wish to be defiant in his behavior. Remember that TS is a complex disorder of the nervous system. This may be the one child in a million who does have an answer to our rhetorical question, "You knew this last week; why can't you do this work as quickly or as well as you did then?" This will admittedly be a challenge to planning. Our best advice is to allow both you and the student all the flexibility you need on a daily basis.

Please keep in close contact with the child's parents. They are often the true "experts" in TS. They can supply you pertinent information about the child's medication and its effects, as well as little-known facts about that child's learning style, which pamphlets cannot adequately explain. The child will benefit to the maximum degree if you and his parents are allies, working together for his positive growth and development.

Although TS is a very complex disorder with varying types of disabling symptoms, often the most handicapping aspect is the lack of understanding and acceptance by society. Since school is the main occupation of children, this child's "society" may be only as large as your classroom. The single most effective effort that you can make is to create an atmosphere of acceptance in your classroom. Other children often mock TS symptoms and tease unmercifully. Please don't allow this in your school. It is our experience that once classmates are informed of the involuntary nature of TS, and are provided with an atmosphere accepting of all students as unique individuals, then everyone benefits. Teachers experience much less frustration and a peak satisfaction that comes with knowing they have taught their students much more than academics.

It would be almost impossible to over-emphasize your importance at this time in this child's long-term development. A bad year in school can do harm to his sense of self-confidence and self-esteem that can take literally years to overcome, if ever. We've seen it happen. Conversely, a successful school year can bring a child a new sense of worth and hopefulness for the future. Remember, dealing with TS symptoms can be a frustrating experience for you but not nearly as frustrating as it is for the child. It can also be an immensely rewarding experience when you realize one day that you and everyone else in your classroom has forgotten that one of the students has TS. Then you will know that you have addressed the challenges commendably and admirably. You can rest assured, then, that you have had an immeasurable positive impact on that child's course of future growth.

If at any time during the year you need support, advice, feedback, or resources, contact the Tourette Syndrome Association of Texas at 281-238-8096. Wishing you the very best in terms of a successful, productive and rewarding year!

**Tourette Association - Texas Chapter 281-238-8096 <http://TouretteTexas.org> TouretteTexas@aol.com
info@TouretteTexas.org**

Thanks to: Ramona Fisher, M.Ed., Tulakes Elementary School and Edward C. Collins, Ph.D., Central State University for this article.

Sample Child Letter #1 – “All About Bobby”

• General Notes

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

Bobby – Symptoms at a Glance

Tics: (Motor)

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

Tics: (Vocal)

- Making “Mmm” noises
- Saying “Excuse Me” or “Sorry” repeatedly, other words
- Loud sniffing
- Clearing throat
- Loud “Who” sound

OCD:

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

ADHD:

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

Dysgraphia:

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

Other:

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

Ways to help him cope:

- Giving a brief time for Bobby to tell the class about his TS and allow for class questions
- Drink of water from a water fountain or water bottle in backpack
- Breath of fresh air, quick outside walk
- Quick walk in the hall or to the bathroom
- Deep breaths
- Rubbing neck or back
- Distraction of some sort
- Change in task for a brief time, then back to the task at hand
- If absolutely necessary, trip to the clinic

*Nurse might allow a 10-15 min. rest, and then return to class

**Important to let him know what he may have missed while out of class. **

Sample Child Letter #1 – “All About Bobby” Continued

Dear Teacher:

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

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

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

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

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

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

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

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

Parent’s name

Include all phone numbers and Email address

Sample Child Letter #2 – “All About Brian”

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

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

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

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

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

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

FAST FACTS

Student's Name:

Birth Date:

School:

Grade:

Getting to know XXXX	Diagnosis and Health Issues
<ul style="list-style-type: none"> • XXXX is a bright child who likes sports, science, and spending time with friends and family. • She likes praise and is motivated by tangible reinforcers. • She is helpful, witty, and caring. • She likes leadership roles. • She's athletic and competitive. • She will only share her diagnosis with people she trusts. • Tic suppression makes it difficult for her to concentrate. • Tics worsen with stress, excitement, and anticipation (both positive and negative). • XXXX met the ELA and Math standard on the SBA 	<ul style="list-style-type: none"> • Diagnosed with Tourette Syndrome • She wears reading glasses • No medications at this time • Sensory issues-will only wear soft clothing • History of vocal tics (tics that produce a sound): sniffing, volume fluctuation while speaking, squealing, shouting random words, and grunting • History of motor tics (tics that cause movement): eye blinking, eye-rolling, head jerking, mouth opening, biting cheek and lip, hopping, squeezing/poking objects (especially paper). • Current tics-head jerk, jaw movement, and sniffing
Tourette Syndrome Information	Suggested Accommodations/Supports
<ul style="list-style-type: none"> • It is a neurodevelopmental condition (as the brain develops, the symptoms and disorder develop). • Tics are involuntary. • People can suppress tics for a short period of time. • Suppressing a tic is exhausting because you're using all your internal resources to suppress it. In addition, suppression makes it difficult to pay attention and concentrate. • Tics wax and wane (can be mild or nonexistent on one day, but very distracting on another day). • TS has been linked to a region of the brain called the basal ganglia. It regulates movement and emotions. • People with TS say they have to tic because of the premonitory urge. It gets the stress out of their bodies. • It's like having hiccups. Even though you don't want to hiccup, your body does it anyway. • Tics often reduce and get less severe as the child gets older. For some people, they go away completely. • TS is a very unique disorder. The only thing consistent about it is its inconsistency. 	<p>New suggestions for the 2021-2022 school year:</p> <ul style="list-style-type: none"> • Allow access to the nurse's office when the tics cause headaches (Tylenol in the office). • Ignore tics and ask peers to do the same. Try not to react to the tics. • Permission to leave class if necessary for tic reduction. • Sit her in a location that diminishes noticeability of the tics. • Communicate with XXXX's parents if she is not completing assignments or falling behind academically. • Allow for extended time to complete assignments. • All staff working with XXXX should be informed of her tics.