

# LIVING WITH TOURETTE & TIC DISORDERS

## A Guide for Patients and Families





# Getting Diagnosed and Receiving Treatment



## TICS, TOURETTE SYNDROME, AND TIC DISORDERS

Tics are involuntary, repetitive movements and vocalizations. They are the primary symptoms of a group of childhood-onset neurological conditions known collectively as Tic Disorders and individually as *Tourette Syndrome (TS)*, *Persistent (Chronic) Motor or Vocal Tic Disorder*, and *Provisional Tic Disorder*.

These three Tic Disorders are named based on the types of tics present (motor, vocal/phonic, or both) and by the length of time that the tics have been present. Below are the criteria that a doctor or other health care professional will use to diagnose TS or other Tic Disorders.<sup>1</sup> There is no test to confirm the diagnosis of Tic Disorders, but in some cases, tests may be necessary to rule out other conditions.

### **Tourette Syndrome (TS), also known as Tourette's Disorder**

- 1) At least 2 motor tics and at least 1 vocal (phonic) tic have been present, not necessarily at the same time.
- 2) Tics may wax and wane in frequency but have occurred for more than 1 year.
- 3) Tics started to appear before the age of **18**.
- 4) Tics are not caused by the use of a substance or other medical condition.

### **Persistent (Chronic) Motor or Vocal Tic Disorder**

Either motor tics OR vocal tics have been present for more than 1 year; cannot be both motor and vocal tics.

### **Provisional Tic Disorder**

Motor and/or vocal tics have been present for less than 1 year, and have not met the criteria for TS or persistent (chronic) motor or vocal tic disorder.

<sup>1</sup> Criteria are modified from the American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, 5th edition. Arlington, VA., American Psychiatric Association, 2013.

## TYPES OF TICS

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

## OTHER IMPORTANT THINGS TO KNOW ABOUT TICS

- They can change in type, intensity, or location.
- They often increase with stress, excitement, anxiety, and fatigue.
- Some may be suppressed, but only temporarily.
- They may be reduced during focused activities.
- They can be preceded by a **premonitory urge**, described as a *sensory or mental sensation that occurs before a tic*.

**\*Only 1 in 10 people with tics have coprolalia. The presence of coprolalia is not necessary for a diagnosis of Tourette or other Tic Disorders**

## ONSET OF TICS AND DURATION

Tics typically emerge between the ages of 5 and 7 years, usually with a motor tic in the head or neck region. They tend to increase in frequency and severity between the ages of 8 and 12 years and can range from mild to severe. Most people with TS see improvements by late adolescence, with some becoming tic-free. A minority of people with TS continue to have persistent, severe tics into adulthood.

**1 OF EVERY 100** Children between the ages of 5 and 17 have Tourette or another Tic Disorder

## TS AND TIC DISORDERS ARE COMMON

- Tics occur in as many as **1 in 5** school-aged children at some time, but may not persist.
- **TS and other Tic Disorders combined** are estimated to occur in **more than 1 in 100 (1%)** school-aged children in the United States.
- **TS** occurs in **1 in 160 (0.6%)** school-aged children. The reported prevalence for those who have been diagnosed with Tourette is lower than the true number, most likely because tics often go unrecognized. TS affects all races, ethnic groups and ages, but is **3-4 times more common in boys** than in girls.
- There are no reliable prevalence estimates of TS and other Tic Disorders in adults. However, they are expected to be much lower than in children as tics tend to decline into late adolescence.

## CAUSES OF TS

The causes of TS and other Tic Disorders remain unknown. These conditions tend to occur in families, and numerous studies have confirmed that genetics are involved. Environmental, developmental, or other factors may also contribute to these disorders but, at present, no specific agent or event has been identified. Researchers are continuing to search for the genes and other factors underlying the development of Tic Disorders.

## FINDING A MEDICAL PROFESSIONAL WHO KNOWS ABOUT TOURETTE AND TIC DISORDERS

The Tourette Association of America (TAA) maintains a state-based referral listing of medical and allied professionals who have experience addressing and treating Tic Disorders. Additionally, the Tourette Association Centers of Excellence (CofE) program includes premier medical institutions around the country that offer expert and coordinated care. Please refer to the *Support* section for more information about the Centers of Excellence. You can contact the Tourette Association at **tourette.org** or by calling **888-4TOURET**.



## PREPARING FOR YOUR DOCTOR'S VISIT

Prior to the doctor's visit, assemble information about any past history, including evaluations, records, and test results. It may also be helpful to bring a journal or video of you or your child's tics to show the doctor in case tics are not evident during the appointment. It is important to talk with your doctor about your child and your full medical history, including other health conditions, and any current and past medications or treatments.

## COMMON CO-OCCURRING CONDITIONS

People with TS often have other mental, behavioral, or developmental conditions that may be present prior to the onset of tics. While tics are the primary symptoms, these co-occurring conditions may cause more problems and can be more bothersome than the tics themselves.

Among people diagnosed with TS, it is estimated that 86% have been diagnosed with at least one of these additional conditions. The most common co-occurring conditions include the following:

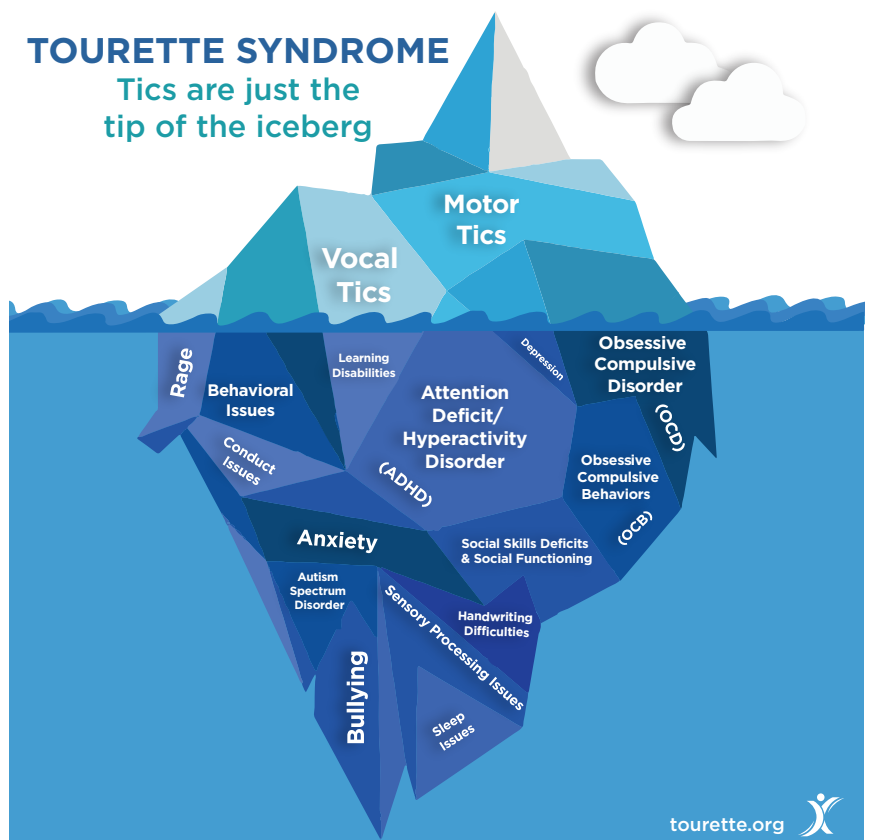
- **Attention Deficit/Hyperactivity Disorder (ADHD):** Problems with concentration, hyperactivity, and impulse control.
- **Obsessive Compulsive Disorder or Behaviors (OCD/OCB):** Repetitive, unwanted intrusive thoughts and/or repetitive behaviors. These thoughts lead to compulsions, which are unwanted behaviors that the individual feels he/she must perform over and over or in a certain way.
- **Behavioral or Conduct Issues:** Aggression, rage, oppositional defiance or socially inappropriate behaviors.
- **Anxiety:** Excessive worries or fearfulness, including excessive shyness and separation anxiety.
- **Learning Disability:** Reading, writing, mathematics, and/or information processing difficulties that are not related to intelligence.
- **Social Skills Deficits and Social Functioning:** Trouble developing social skills; maintaining social relationships with peers, family members, and other individuals; and acting in an age-appropriate manner.
- **Sensory Processing Issues:** Strong sensory preference and sensitivities related to sense of touch, sound, taste, smells, and movement that interfere throughout the day.
- **Sleep Disorders:** Trouble falling or staying asleep.

## TREATING TS AND OTHER TIC DISORDERS

Most often, tics are mild and treatment is not required. However, if tics are moderate to severe, they may need direct treatment. If co-occurring conditions are present, it may be necessary for your child or you to be evaluated and treated for the other conditions first or simultaneously, as they can be more impairing than tics. In every case, it is essential to be educated as a parent of a child or an individual with Tourette, as well as to educate people around your child or you (with his or her permission).

## A PERSONAL STORY

Sam, a boy of 7 years, had been making noises and movements for over 3 years that were affecting his family and school life. His teachers thought these were purposeful misbehaviors. His pediatrician, on the other hand, suggested it might be neurological and referred Sam to a doctor at a Tourette Center of Excellence. Sam was diagnosed with Tourette Syndrome and other conditions (difficulties with attention, obsessive-compulsive behavior and sensory sensitivities) that often occur with TS. With this information, a treatment plan, and resources found on the Tourette Association's website, his family has a better understanding of how to help Sam, and his school is providing him with the supports that are reducing his anxiety and symptoms. Sam and his parents know that they will need to educate people and continue to advocate for him, but they no longer feel they are alone in living with TS.



## BULLYING PREVENTION

The nature of TS symptoms and the lack of understanding that they are involuntary behaviors make children with TS particularly vulnerable to being bullied, which can contribute to loneliness and anxiety.

- It is important to educate all family members, teachers, friends, and peers about TS. Be sure to involve your child in the discussions. It can be helpful to emphasize that TS is a medical condition and that telling your child to “stop ticcing” is not a strategy (similar to telling someone, “You have blue eyes. Stop having blue eyes.”) and is likely to cause significant frustration.
- Consider what situations make tics better and worse. There are strategies your child can utilize to help manage tics in various situations. More information can be found in the *Education* section of this tool kit.
- In school settings, it can be very helpful to educate teachers and peers by presenting to the class, or showing the HBO documentary, *I Have Tourette's But Tourette's Doesn't Have Me* and sharing other resources on TS. You can request a free copy of this video by contacting the Tourette Association.



## ACADEMIC CONCERNS AND BEHAVIORS IN SCHOOL

- Request direct input from your child's teachers about his/her academic performance and behavior in the classroom.
- Consider educational testing to assess co-occurring learning and attention difficulties.
- Talk with your child's school about 504 Plans or Individualized Education Programs (IEPs), which can greatly improve the academic performance of students with tics.

## WHEN TO SEEK TREATMENT FOR TICS

When tics become problematic or interfere with daily life, behavior therapy and/or medication may be considered. Since every person is different, you will need to work with a trained clinician who is familiar with TS and Tic Disorders to find the best treatment. It may take some time and patience to determine the most effective approach.

## COMPREHENSIVE BEHAVIORAL INTERVENTION FOR TICS (CBIT)

Comprehensive Behavioral Intervention for Tics (CBIT, pronounced “see-bit”) is a behavioral, non-medicated treatment that has been shown in clinical studies to reduce tics in children and adults. Studies have also indicated CBIT to be as effective as medication in many cases, and is often recommended as the first treatment approach.

There are 3 main components to CBIT:

1. Becoming more aware of tics.
2. Developing competing responses that are incompatible with the tics and less noticeable.
3. Making changes in daily activities that can be helpful in reducing tics.

Additional screening may be needed for co-occurring disorders that would get in the way of CBIT, such as untreated ADHD or significant Oppositional Defiant Disorder (ODD). Determine whether certain therapies are feasible from a logistical perspective. Is there a trained CBIT provider available locally? Is there transportation? Does your insurance cover these services? Only therapists who have received specific training in CBIT should provide this treatment. The Tourette Association maintains a list of healthcare professionals who have completed a formal CBIT treatment program. Visit [tourette.org/find-a-doctor/](http://tourette.org/find-a-doctor/).



## MEDICATIONS FOR TICS AND CO-OCCURRING CONDITIONS

If you or your child have multiple or severe tics, or tics that cause self-harm, your doctor may recommend medication. Although medication may help, it does not cure tics. Tics can still wax and wane in frequency and severity, and fluctuations can continue to occur.

Haloperidol (Haldol), pimozide (Orap), and aripiprazole (Abilify) are the only medications currently approved by the U.S. Food and Drug Administration (FDA) to treat tics. Doctors often start with “off-label” medications (not FDA approved specifically for treating tics) that tend to be moderately effective in reducing tics and may have fewer problems related to side effects compared to other drugs.

Treating co-occurring conditions, such as ADHD and OCD, often requires use of medication, which can improve quality of life in patients with TS and may help to reduce tics. Behavioral approaches are also available to treat these conditions. Stimulant medications and/or behavioral therapy can be effective in children who have TS and ADHD. Non-stimulant medications may also be beneficial. Selective serotonin reuptake inhibitors (SSRIs), cognitive behavioral therapy, including exposure and response prevention, are effective in youth and adults with anxiety/OCD and generally tolerable. Be sure to ask your doctor about the benefits and risks for any use of medications.



|                            | OT | PT | SLP |
|----------------------------|----|----|-----|
| Executive Functioning      | ●  |    | ●   |
| Sensory Integration        | ●  |    |     |
| Attention Training         | ●  |    |     |
| Pain Management            |    | ●  |     |
| Social Skills & Pragmatic  | ●  |    | ●   |
| Activities of Daily Living | ●  |    |     |
| Handwriting                | ●  |    |     |
| Sleep Hygiene              | ●  |    |     |
| Assistive Devices          | ●  |    |     |
| Stuttering                 |    |    | ●   |
| Pelvic Health Issues       |    | ●  |     |
| Incoordination             | ●  | ●  |     |
| Fine Motor                 | ●  |    |     |
| Gross Motor                |    | ●  |     |
| Reading Comprehension      |    |    | ●   |
| Dyslexia                   |    |    | ●   |
| Vocational Skills          | ●  |    | ●   |
| Oculomotor or Vision       | ●  |    |     |
| Feeding Aversion           | ●  |    |     |
| Driving Readiness          | ●  |    |     |
| Arousal & Impulse Control  | ●  |    | ●   |

## REHABILITATION AND ANCILLARY SERVICES

**Occupational Therapy (OT), Physical Therapy (PT), and Speech-Language Pathology (SLP)** services are often used to treat co-occurring conditions and are often readily available even in rural areas.

- **Occupational Therapy (OT):** Therapy to enable participation in roles, habits, and routines in home, school, workplace, community, and other settings.
- **Physical Therapy (PT):** Therapy to restore, maintain, and promote physical function.
- **Speech-Language Pathology (SLP):** Treatment of speech, language, social communication, cognitive-communication, and swallowing disorders.

If your child or you struggle with tics in any of the above areas, seeking rehabilitation services may help. **Consider the following questions to ask a rehabilitation facility when looking for a clinic to receive services:**

- Does your clinic offer interdisciplinary care with OT, PT and SLP?
- Do you have specialty training or certification in the above areas?
- Do you have any training specifically tailored to treat patients with Tourette Syndrome (or any of the co-occurring conditions that you are addressing)?





## FREQUENTLY ASKED QUESTIONS

The following are some of the most frequently asked questions from people seeking treatment in Tourette clinics. Answers are provided from members of the Tourette Association Medical Advisory Board.

### **WILL MY CHILD OUTGROW HIS TICS?**

Many school-aged children have a tic at some point, with approximately 1 in 10 children having tics that last for more than a year. There is no way to predict when or whether tics will ultimately resolve. When tics persist for longer periods, they tend to follow a relatively predictable course. Children usually begin having tics between the ages of 5 and 7, the tics peak in frequency and severity between the ages of 8 and 12, and improve from the mid-teen years through the early 20s.

### **WILL MY CHILD DEVELOP COPROLALIA OR COPROPRAXIA? MY CHILD SOMETIMES SWEARS, BUT I AM NOT SURE WHETHER IT IS A TIC.**

While worrisome to patients and families, coprolalia (involuntary speech of obscene or socially inappropriate words) and copropraxia (involuntary act of obscene or inappropriate gestures) only occurs in a small number of people with TS. There is no way to predict whether a person will develop these particular tics. Those who do often find ways to mask them, e.g., mumbling the word under their breath or incorporating the obscene gesture into a different, more socially acceptable gesture. It is also important to differentiate voluntary swearing, which occurs in the context of how someone is feeling and what is happening, from an involuntary vocal tic. While involuntary, some tics may be interpreted as bad behavior or a symptom of poor parenting. Children who have tics should work with a healthcare professional and an education professional to determine positive, proactive approaches to managing these more complex tics.

### **LAST YEAR, MY CHILD STARTED BLINKING HIS EYES REPETITIVELY. NOW HE IS CLEARING HIS THROAT ALL THE TIME. SHOULD WE BE CONCERNED THAT HE IS GETTING WORSE?**

Although a given tic tends to look essentially the same every time that it occurs, an individual's repertoire of tics can—and generally does—change over time. Tics can also vary in frequency and intensity from day to day and week to week.

### **I'VE NOTICED THAT MY SON'S TICS INCREASE WHEN HE IS PLAYING HIS VIDEO GAMES. HE DOES NOT SEEM TO NOTICE THE TICS WHILE HE IS PLAYING, BUT SHOULD WE PROHIBIT HIM FROM PLAYING?**

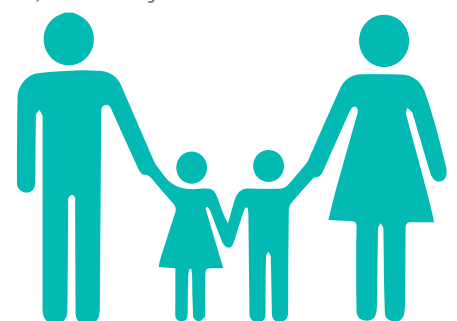
Tics tend to increase with stress—good stress (e.g., excitement, anticipation), bad stress (e.g., anxiety, worry), and physical stress (e.g., fatigue, illness). Since your child is not bothered by his tics while playing, there is no need to limit his video game time based on his tics; however, the American Academy of Pediatrics does recommend limiting screen time to 2 hours per day for children and teens as part of a healthy lifestyle.

### **MY CHILD ARRANGES ALL OF HIS TOYS IN A VERY PARTICULAR WAY, WASHES HIS HANDS EXCESSIVELY, AND HAS TO ERASE HIS LETTERS REPEATEDLY UNTIL THEY “LOOK RIGHT.” ARE THESE BEHAVIOR TICS?**

These behaviors are more consistent with obsessive-compulsive behavior than with tics, but many children have both types of behavior. Tic Disorders show a significant overlap with a number of other neurodevelopmental conditions, including ADHD, anxiety disorders, obsessive-compulsive disorder, dysgraphia/fine motor impairment, learning difficulties, and impulse control disorders.



**Chapters, Support Groups, and Family Workshops provide guidance, tools and resources for thousands of people nationwide.**



**MY CHILD HAS A VOCAL TIC THAT IS VERY DISRUPTIVE IN THE CLASSROOM SETTING DURING TESTS. THE SCHOOL IS SUGGESTING THAT OUR CHILD BE ON MEDICAL HOMEBOUND. WHAT SHOULD WE DO?**

According to the Individuals with Disabilities Education Act (IDEA), all children are entitled to a free and appropriate education in the least restrictive environment possible. If a child's tics are interfering in the classroom setting, then the most appropriate next step would be for the school to develop an educational plan (504 Plan or Individualized Education Program – IEP). In many cases, simple accommodations, such as allowing the child to take his/her tests in a separate location, are all that it takes for the child to be successful in the school environment.



**MY CHILD RECENTLY STARTED MEDICATION FOR HIS TICS. HIS TICS HAVE DECREASED IN FREQUENCY BUT HAVE NOT STOPPED. DO WE NEED TO TRY A DIFFERENT TREATMENT?**

Although there are a number of very effective treatments for tics including medication, the current treatments do not “cure” tics. The goal in treating tics should be to reduce the tics to the point that they are no longer painful and/or interfering with the child's quality of life.



**MY CHILD HAS ADHD, AND HIS TICS STARTED SHORTLY AFTER HE STARTED TAKING A STIMULANT MEDICATION. WE TRIED STOPPING THE STIMULANT MEDICATION, BUT THE TICS HAVE CONTINUED. DID THE MEDICATION CAUSE HIS TICS?**

Many children with TS have ADHD, so this is a very common question. There is good evidence that stimulant medications are safe and effective treatments for ADHD in children with tics. Stimulants do not cause tics, nor do they cause the tic to become worse. Stopping or adjusting your child's stimulant medication is unlikely to result in long-term improvement in his tics.

**ARE THERE ANY DIETARY OR NATURAL TREATMENTS FOR TICS?**

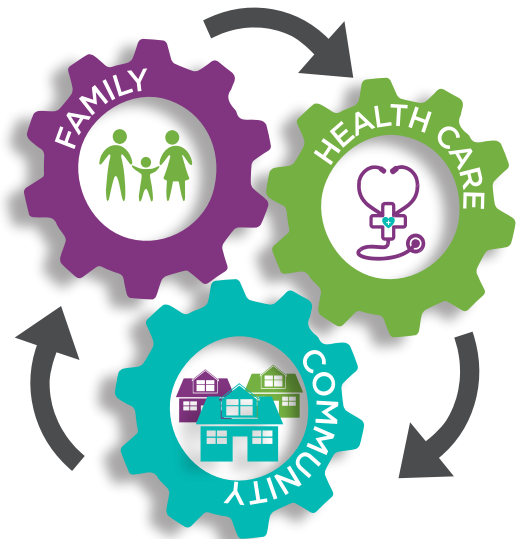
At this point, there is no scientific evidence to support the use of elimination diets, specialized diets, or dietary supplements to treat Tic Disorders.

**MY CHILD'S TICS ARE CAUSING HIM TO BE DISTRACTED IN SCHOOL**

More often than not, the distraction in school is due to ADHD symptoms rather than the tics themselves. Many individuals with TS also have ADHD that can interfere with learning and attending to or concentrating on the tasks at school. Get your child screened for ADHD and if present, consider treating the ADHD. You may also want to consider education testing for other learning difficulties. Classroom accommodations may help.

**HELPFUL TIP**

It can be helpful to make a list of your top 3-5 questions that you need to have answered by the end of the doctor's visit. This will help to focus the visit, especially when time is very limited.





## KEY ARTICLES REFLECTING THE CURRENT SCIENCE AND RESEARCH IN TOURETTE AND TIC DISORDERS

### General / Prevalence

Bitsko, R. H., Holbrook, J. R., Visser, S. N., Mink, J. W., Zinner, S. H., Ghandour, R. M., & Blumberg, S. J. (2014). A National Profile of Tourette Syndrome, 2011–2012. *Journal of Developmental & Behavioral Pediatrics*, 35(5), 317–322. Study key findings: <http://www.cdc.gov/ncbddd/tourette/features/keyfinding-nationalprofile.html>

Leckman, J. F., Zhang H., Vitale A., Lahnin F., Lynch K., Bondi C. Kim Y., & Peterson B. S (1998). Course of Tic Severity in Tourette Syndrome: The First Two Decades. *Pediatrics*, 102(1), 14–9.

Scharf, J. M., Miller, L. L., Gauvin, C. A., Alabiso, J., Mathews, C. A., & Ben-Shlomo, Y. (2014). Population prevalence of Tourette syndrome: A systematic review and meta-analysis. *Movement Disorders Mov Disord.*, 30(2), 221–228.

Thenganatt, M. A., & Jankovic, J. (2016). Recent Advances in Understanding and Managing Tourette Syndrome. *F1000Research F1000Res*.

American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, 5th edition. Arlington, VA., American Psychiatric Association, 2013.

### Genetics / Comorbidity

Hirschtritt, M. E., Lee, P. C., Pauls, D. L., Dion, Y., Grados, M. A., Illmann, C., . . . Mathews, C. A. (2015). Lifetime Prevalence, Age of Risk, and Genetic Relationships of Comorbid Psychiatric Disorders in Tourette Syndrome. *JAMA Psychiatry*, 72(4), 325.

### CBIT

Piacentini, J., Woods, D. W., Scahill, L., Wilhelm, S., Peterson, A. L., Chang, S., . . . Walkup, J. T. (2010). Behavior Therapy for Children With Tourette Disorder. *Jama*, 303(19), 1929.

Wilhelm, S., Peterson, A. L., Piacentini, J., Woods, D. W., Deckersbach, T., Sukhodolsky, D. G., . . . Scahill, L. (2012). Randomized Trial of Behavior Therapy for Adults With Tourette Syndrome. *Arch Gen Psychiatry Archives of General Psychiatry*, 69(8), 795.

### Pharmacotherapy

Scahill, L., Erenberg, G., Berlin, C. M., Budman, C., Coffey, B. J., Jankovic, J., . . . Walkup, J. (2006). Contemporary assessment and pharmacotherapy of Tourette syndrome. *Neurotherapeutics*, 3(2), 192–206.

Weisman, H., Qureshi, I. A., Leckman, J. F., Scahill, L., & Bloch, M. H. (2013). Systematic review: Pharmacological treatment of tic disorders – Efficacy of antipsychotic and alpha-2 adrenergic agonist agents. *Neuroscience & Biobehavioral Reviews*, 37(6), 1162–1171.

“The Spectrum of Tourette Syndrome and Tic Disorders: A Consensus by Scientific Advisors of the Tourette Association of America. This 2015 position paper is available on request from the Tourette Association of America.”

### Quality of Life

Cavanna, A. E., David, K., Bandera, V., Termine, C., Balottin, U., Schrag, A., & Selai, C. (2013). Health-Related Quality of Life in Gilles de la Tourette Syndrome: A Decade of Research. *Behavioural Neurology*, 27(1), 83–93.





## TS in the Classroom

### 10 THINGS PARENTS SHOULD KNOW ABOUT TS AND THE IMPACT ON STUDENT LEARNING

1. Informing the school that your child has Tourette can be important in receiving a **FREE AND APPROPRIATE PUBLIC EDUCATION (FAPE)**, which is mandated for students who have disabilities.
2. Schools can provide accommodations and modifications with a **504 PLAN. AN INDIVIDUALIZED EDUCATION PROGRAM (IEP)** can provide more intensive supports and services. Both 504 Plans and IEPs can be provided in the general education setting and do not necessarily require that the student be placed in a special education classroom/setting. Having an IEP or 504 Plan in school does not limit a child's career or college choices.
3. **REQUESTING A SMALLER SETTING MAY NOT BE THE BEST APPROACH FOR A STUDENT WITH TS.** Smaller settings tend to include students who have lower academic abilities and/or significant emotional or behavioral issues. Such a setting may not be a good fit for the student's learning potential.
4. The Federal law, **FAMILY EDUCATION RIGHTS AND PRIVACY ACT, (FERPA)** ensures that parents have access to their child's records and limit access to these records without parental consent.
5. **KEEPING A STUDENT HOME DUE TO TICS OFTEN DEVELOPS INTO CHRONIC SCHOOL AVOIDANCE** and should be a last resort.
6. Consequence-based programs (punishment and reward) are generally not a successful approach for students with Tourette. **TEACHING AND SUPPORTING STRATEGIES/TECHNIQUES TO HELP MANAGE SYMPTOMS TEACHES LIFE-LONG STRATEGIES.**
7. **IT'S IMPORTANT TO REMAIN KNOWLEDGEABLE** of possible co-occurring conditions, as they may be more likely to occur in adolescence and often interfere with a student demonstrating his or her true abilities.
8. **EVALUATIONS/ASSESSMENTS ARE PROVIDED FREE OF CHARGE BY THE SCHOOL** when requested by a parent in writing. These are critical in determining areas of strength and areas that may require additional support. If you are unsure about how to request an assessment, talk with your child's teacher, special education director, counselor, or principal.
9. **SUPPORTING A CHILD'S STRENGTHS AND INTERESTS** can make a major contribution in developing positive self-esteem.
10. **BEING FAMILIAR WITH THE "RESOURCES & SUPPORT" PAGE OF THE TOURETTE ASSOCIATION'S WEBSITE** as well as local TAA chapters are often helpful resources for you to use to help your child obtain an appropriate education.

## COMMUNICATING WITH SCHOOL PERSONNEL

Providing the appropriate support for students with Tourette Syndrome (TS) is a team effort that includes parents, teachers, and other school staff members. Fostering a positive relationship requires mutual respect and communication. While at times 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 approaches that will enable the student to achieve his/her fullest potential.

Developing a communication plan that works for everyone involved early in the school year can be a major component to the success of a student with a complex neurodevelopmental disorder such as TS.



## THE DOs & THE DON'Ts of talking with school staff and administration.

**Share accurate information with School Personnel about TS.**



**DO**

provide information from the Tourette Association of America (TAA).



**DON'T**

overwhelm them with too many resources at once.

**Educate the school staff or those working with the student about Tourette.**



**DO**

inform the school that the TAA provides free in-services for educators.



**DON'T**

assume teachers already know what tics are or that they are not willing to learn.

**Keep school personnel updated about your child's health and what can worsen or lessen tics.**



**DO**

have conversations informing teachers about current symptoms, medication changes, stressors & strategies.



**DON'T**

waste time talking about anger from past experiences or unimportant topics.

**Recognize that having a diagnosis of Tourette is often accompanied by other related conditions.**



**DO**

recognize that Tourette is a complex disorder that can manifest in many different ways and involve a wide variety of symptoms and co-occurring conditions.



**DON'T**

assume educators know this.

**Use strengths and interests of the child to your advantage.**



**DO**

encourage strengths and interest; these are important in developing positive self-esteem.



**DON'T**

punish students by taking away activities in which they excel or have an interest.

**Use terminology that school administrators know.**



**DO**

use the word 'appropriate' when discussing your child's education as this is what public schools are federally mandated to provide.



**DON'T**

use terms such as 'better or best education.'



Awareness. Research. Support.

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

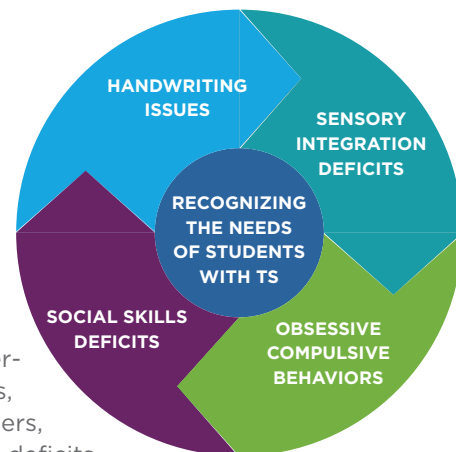




# Addressing Education Needs

## POTENTIAL IMPACT ON EDUCATION

Tourette Syndrome (TS) is difficult for some teachers to understand because every student has different symptoms, which can change, wax, and wane. Some teachers may not be well informed about strategies and techniques for recognizing the needs of students with TS, or the most effective teaching approach. Besides the tics, many common co-occurring conditions can be impairing, such as Attention Deficit/Hyperactivity Disorder (ADHD), handwriting difficulties, sensory integration or sensory processing disorders, obsessive-compulsive behaviors, and social skills deficits.



## RECOGNIZING THE SIGNS IN SCHOOL SETTINGS

Educators and families should be aware of signs that may point to underlying symptoms of the common conditions that co-occur with TS. It is important to recognize the signs so that the additional support in school can be provided for students with Tourette Syndrome or other Tic Disorders. The following are common indications that additional support may be necessary:

### Difficulty attending or staying at school

- A collaborative and positive working relationship with the school can assist in an honest discussion to determine why this may be occurring and then developing a proactive/positive plan to help.

### Behavior issues at home or school

- Focusing on when, where, and why behaviors are occurring will decrease the chance of making assumptions and punishing the child. The Tourette Association provides several resources geared toward addressing challenging behaviors at school and strategies for these difficulties.

### Significant reluctance to completing work in school and/or homework

- This could be a sign that the child has difficulties in the following areas: handwriting difficulties, problems with memory, processing delays, or difficulties with organization. It may also be due to fatigue, which can increase tics and symptoms of other disorders and make focusing more difficult. A meeting with appropriate school staff (such as the teacher, counselor, or others working with your child) to discuss why this is occurring can be helpful. An initial evaluation, or re-evaluation may be necessary to determine if specific skills deficits are the reason for this.

### Dropping grades

- It is common for students with tics and co-occurring conditions to receive good grades in elementary school and then experience a decline in the grades in middle and high school. An updated education evaluation/assessment will assist in determining if hidden symptoms may be responsible and assist in identifying appropriate supports.

### Increase in tics, anxiety, and obsessive compulsive behaviors

- This may be an indication that a meeting with school staff is needed to discuss any changes that may be increasing anxiety. Discussions should include difficulties with peers and specific teachers or support personnel.

### Difficulty socializing with peers

- Screen for social language deficits, as they are common difficulties for students with TS that can severely impact peer interactions and friendships. The use of social stories may not be effective because students with TS often know what to do and say, but are inconsistently able to perform as they know they should and are sometimes capable of doing.

### Loss of interest in preferred activities

- Consider the environment to determine if there is something or someone increasing anxiety. It may also be due to some obsessive-compulsive behaviors related to attempts to achieve perfection.

## KNOW YOUR CHILD'S EDUCATION RIGHTS

According to the U.S. Department of Education, every student with a disability in the U.S. has the right to a **Free and Appropriate Public Education (FAPE)**. Obtaining a parent handbook from your State Department of Education, or becoming familiar with your state website, is extremely helpful and important in recognizing laws specific to your state. For more information on each state, you can visit the U.S. Department of Education at [ed.gov/policy](http://ed.gov/policy).

The **Individuals with Disabilities Education Act (IDEA)** is a federal law that requires schools to provide special education services to meet the educational needs of eligible students with disabilities. **IDEA includes Tourette Syndrome under the definition of Other Health Impairment (OHI)**. Additionally, the Federal Department of Education states that Tourette Syndrome should not be confused with the needs of a student with behavioral or emotional disorders:

*... we do believe that Tourette Syndrome is commonly misunderstood to be a behavioral or emotional condition, rather than a neurological condition. Therefore, including Tourette Syndrome in the definition of other health impairment may help correct the misperception of Tourette Syndrome as a behavioral or conduct disorder and prevent the misdiagnosis of their needs.<sup>2</sup>*

## 504 PLANS & INDIVIDUALIZED EDUCATION PROGRAMS (IEPs)

Students with disabilities sometimes require services provided by either a **504 Plan or an Individualized Education Program (IEP)**.

**504 protections and supports** are part of the federal civil rights law. A 504 Plan typically provides modifications and accommodations for students who have symptoms that impede on that student's equal access to an education.

**IEPs** designate special education and related services to meet the unique needs of a student. They may include the same provisions of a 504 Plan.

### Some important things to note:

- **Both** 504 Plans and IEPs are legal documents detailing a student's specific needs, which must be implemented by school personnel. A team, which includes parents, determines if a student meets the specified requirements regarding eligibility for an IEP or a 504 Plan.
- Having a diagnosis of Tourette Syndrome does not automatically qualify a student for an IEP or a 504 Plan.
- Students receiving good grades may be eligible for an IEP or a 504 Plan.



**Manifestation Determination** is a federal law intended to ensure that students with 504 Plans or IEPs are not being punished for symptoms of their disabilities.

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<sup>2</sup> US Department of Education. Federal Regulations 300.8(c)(9), Comment Section.



Sample Letter Requesting Initial  
Evaluations/Assessments for IEP or 504 Plan



# Tourette Association of America

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*Sample Letter Requesting Initial Evaluations/Assessments for  
IEP or 504 Plan*

Date:

Special Education Director

Name of School

Street Address

City, State, Zip Code

Dear (Name of Special Education Director),

My/our child, (child's name) is in \_\_\_\_ grade at (school name). I/we believe that (s/he) might need special education services. The following difficulties support my/our concerns: (briefly list your concerns).

*(list specific examples of your child's problems at school. You do not have to use 'special education' terminology and they don't need to be limited to academics. Describe in your own words.)*

*Examples:*

- *Handwriting is messy, difficult to complete*
- *Lacks organization skills*
- *Difficulty making and keeping friends;*
- *Loud noises, bright lights are overwhelming*
- *Has anxiety*
- *Doesn't understand directions*
- *Other issues you believe are impacting your child's education*

Please consider this as our/my letter of referral to the IEP Committee, requesting an IEP meeting and our/my formal permission to provide evaluations in determining the special education services, accommodations and modifications necessary to meet (child's name) unique needs. If there is a form that I need to sign, please mail it to me as soon as possible.

Please send me/us information and results of all evaluations prior to the IEP meeting. I can be reached at (daytime telephone number). Thank you for your prompt attention to this request.

Sincerely,

Your name(s)

Street Address

City, State, Zip Code

cc: your child's principal (Send a copy to your child's principal and keep a copy for your records)



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# Awareness. Research. Support.

## TOURETTE ASSOCIATION OF AMERICA

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

## REQUEST RESOURCES AND INFORMATION ON TOURETTE

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

## LOCAL CHAPTERS OR SUPPORT GROUPS

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

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

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

You can view a complete list of and learn more about how to get involved with TAA's Chapter and support groups by visiting [tourette.org/resources/find-local-chapter/](http://tourette.org/resources/find-local-chapter/). You can also email **support@tourette.org**, or call **888-4TOURET**.

## TOURETTE ASSOCIATION YOUTH AMBASSADOR (YA) PROGRAM

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

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

## RESEARCH AND MEDICAL PROGRAMS

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

## GET INVOLVED IN THE TOURETTE COMMUNITY

### FOLLOW THE TOURETTE ASSOCIATION ON SOCIAL MEDIA

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

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

### PARTICIPATE IN A TOURETTE HEALTH AND EDUCATION WEBINAR, #TOURETTECHAT

The Tourette Health and Education Program, a TAA partnership with the US Centers for Disease Control and Prevention (CDC), offers regular webinars, Twitter chats, and live streaming presentations on various topics related to Tourette and Tic Disorders. Each workshop features designated Tourette Experts who are members of the TAA medical, science, and education advisory boards.

### UPCOMING EVENTS

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

### BECOME A MEMBER

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

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

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



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

# Where is Support Offered?



## COORDINATED CARE FOR TOURETTE & TIC DISORDERS

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

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

### EXPERT & COORDINATED CARE

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

### RESEARCH

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

### EDUCATION & TRAINING

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

### ADVOCACY & AWARENESS

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

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

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





## TOURETTE ASSOCIATION CENTERS OF EXCELLENCE CLINIC LOCATIONS

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

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

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

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

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

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

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

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

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

#### Weill Cornell Medical College

New York, NY  
Director: John Walkup, M.D.  
Co-Director: Shannon Bennett, Ph.D.  
(212) 821-0789

#### Northwell Health

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

#### University of Rochester Medical Center

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

#### Icahn School of Medicine at Mount Sinai

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

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

#### Emory University School of Medicine

Atlanta, GA  
Director: Jorge L. Juncos, M.D.  
(404) 778-3444

#### University of Alabama at Birmingham

Birmingham, AL  
Director: Leon Dure, M.D.  
Co-Director: Jan Rowe, OTR/L, FAOTA  
(205) 638-6820

#### University of Florida

Gainesville, FL  
Director: Michael Okun, M.D.  
Co-Director: Irene Malaty, M.D.  
(352) 294-5400

#### Palmetto Health

Columbia, SC  
Director: Rebecca Lehman, M.D.  
(803) 434-7961

#### University of South Florida

St. Petersburg, FL  
Director: Tanya Murphy, M.D.  
Co-Director: Adam Lewin, Ph.D.  
(727) 767-8230

Southeast CofE Coordinator  
Heather Simpson, MOT, OTR/L  
(352) 294-5385  
simph@shands.ufl.edu

Clinic website: [www.TouretteCareCenters.org](http://www.TouretteCareCenters.org)

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

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

### CENTER OF EXCELLENCE: UNIVERSITY OF UTAH

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

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

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



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