

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 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 Syndrome Association of Texas 281-238-8096 <http://TouretteTexas.org> [TouretteTexas@aol.com](mailto:TouretteTexas@aol.com)**

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# tSample 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 “Whoo” 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 5<sup>th</sup> 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.