

Teachers Who “Get It”

by Candida B. Korman

To a child with Tourette Syndrome a teacher who “Gets It” — one who really understands the impact of TS on a child’s life — is a hero. A school full of teachers who get it is like having a dream team on your side every day of the school year. TSA has always made educating the educators a top priority and in recent years the ranks of ‘teachers who get it’ have grown with the TSA/CDC partnership.

The following is dedicated to those special individual teachers who have taken the time to learn about TS and put into practice strategies that enable students with TS to thrive. Many have contacted TSA for resources and information. We’ve asked a few teachers to share their perspectives and hope that their ideas will be useful to students, parents, school administrators and — most of all — encouraging other teachers on the road to understanding Tourette Syndrome.

How the Teachers Who “Get It” First Learned About TS

One thing that teachers who ‘get it’ have in common is the willingness to listen to students, parents and other TS experts — even when the information about TS seems to contradict long-held ideas about education and classroom discipline. Being open to new perspectives enables teachers to adapt to the presence of a student with TS in their classroom. Although general awareness of TS has grown in recent years, it’s one thing to have seen a child with TS on TV and another to have the responsibility of teaching a child with TS.

Teachers need to have a deeper understanding of the syndrome and related disorders (ADD, ADHD, OCD) and, most of all, be prepared to acknowledge the variability of TS symptoms. TS manifests itself in many ways, it waxes and wanes and children with TS experience many changes in symptoms. Teachers who hold rigid ideas about the learning process will find themselves mystified by their students with TS. There

will be good days and bad days, noisy days, days with extraordinary nervous energy and days when the side effects of medication make a normally energetic child lethargic.

For many teachers, the journey toward understanding TS begins with a child taking a seat in class or, if things are going well, a pre-first day of school meeting. Kathy Dunaway was fortunate because a parent arranged for a conference before school began. The parent came with information from the TSA including a DVD. She was well on her way to ‘getting it’ when the student entered her classroom. Of course, TS is too complicated to be understood in one meeting or one video orientation. Ms. Dunaway’s TS education continued with a teacher training led by one of TSA’s Education Specialists, Sue Conners, plus some additional information from the TSA education team.

Sue Conners had a chance to observe my students and “She was very helpful,” Ms. Dunaway recalled.

Ms. Dunaway observed that her student’s coprolalia-induced rude comments were uttered in a higher pitch than his normal speaking voice. This made it much easier for her to distinguish tics from emotional outbursts and defiant behavior. But some of her fellow teachers persist in their belief that his coprolalia is really intentional speech. Even after attending a seminar with Sue Conners and viewing the TSA/HBO documentary “*I Have Tourette’s But Tourette’s Doesn’t Have Me*,” a few continue to cling to their ideas about the student’s behavior. The solution for Ms. Dunaway’s student’s dilemma was to keep him out of the classes of the skeptical teachers.

It’s sometimes almost impossible to change fundamental ideas about behavior, intention and responsibility, making the ‘teachers who get it’ all that much more important in the lives of their students with TS.

What Teachers Who “Get It” Think All Teachers Should Know About TS

Educator Michele Kloth thinks all teachers should be given some general information about TS, but points out that, “. . . hearing about it and living within the classroom are two different things. The best education is when the teachers who need the information use it immediately.”

This is the kind of direct education that is at the heart of the TSA education programs, but Ms. Dunaway’s student is not the only child to have had negative experiences in the school hallways when teachers, without direct responsibility for his education, were alarmed by his coprolalia. The level of general knowledge is critical in creating a positive atmosphere in the entire school — from the cafeteria and the playground to the hallways and the gym.

Teacher and author Brad Cohen experienced life as a student with TS before he grew up to become one himself. He thinks that teachers, “. . . need to know as much as possible, just in case they encounter some of the characteristics related to TS. Often times the hardest thing for teachers to understand are the things they can’t see. They can understand ignoring a vocal tic, but teachers have a hard time understanding a child’s OCD or his or her sensory issues. Teachers must remember that there is a lot more happening with that child than the naked eye can see.”

Professor Peter Hollenbeck, who did not receive his own TS diagnosis until he was teaching medical school, wants teachers to put a student’s TS into perspective. “Young teachers need to understand that kids do not have these problems to make the teacher’s life more difficult! It is part of the teacher’s job to figure out how to make his classroom work for everyone, not just the brilliant and docile. Teachers often complain privately that, once this kid gets out into the real world, no one is going to be giving him the breaks that we do. My response is that, ‘when this kid is out in that real world, will he have a better chance of coping with or without a first-rate education?’ Obviously it is the former — so let’s do what we need to make that possible.”

What Teachers Who “Get It” Think About the Role of Parents and Siblings

Connie Newman sums up the positive role that parents can play in facilitating the awareness of TS in teachers. “Parents are important in sharing the impact of TS and how it manifests in their child. The more open and sharing parents and students are in discussions regarding their life with TS, the better their peers and their teachers can accommodate their child’s needs and enhance the school experience. The more we know the better we can be.”

Parents who share their knowledge and experiences with TS are an invaluable resource to teachers. Parents who go the extra mile and bring educational materials to school, arrange for in-service trainings, screen videos and meet with teachers can make the difference between a difficult school year and one that works for the student.

Ms. Kloth emphasizes the importance of open communications. “The parents need to work with the school — allowing information about TS to be shared. They need to share information about any medications their child may need to take and the possible side effects. They need to keep in contact with the teachers, school nurse, psychologist, principal or any other staff member who works with their child so that there is communication on a daily basis about the type of day, the academics, any areas of difficulty, and any good news to share.”

Parents may see changes in their child’s symptoms before they are noticed during the school day and may be more aware of situations that cause stress and exacerbate tics. Keeping teachers informed about these changes may help a child adjust to them.

Professor Hollenbeck agrees that parents can be effective resources, but cautions parents against the temptation to “. . . smooth out every bump” as it’s important for children, as they grow older, to learn to be their own advocates.

Ms. Dunaway has found that some parent advocates have difficulty letting go as their child grows up. The very qualities that were effective in advocating on behalf of a young child can become “. . . controlling and overprotective . . .” when the child reaches high school and he has to learn to advocate for himself.

Teachers Who “Get It”

Mr. Cohen thinks it’s never too early to involve the child as a member of the educational advocacy team. “Parents, teachers, support staff and the child should all be aiming for the same goal — to inform others about Tourette’s. The child **MUST** have a part in this process. People often ask me, “How young is too young to educate others in my child’s school?” The answer is simple: it is never too early. I first came out and educated the other students in my school when I was in 8th grade. I only wish I could have done it sooner, it would have made my life so much easier. Education is powerful no matter if you are educating a kindergarten child or a senior in high school.”

The parent turned advocate is a familiar image, but parents are not the only family members involved in the process of educating a school about TS. Siblings often play a pivotal role in a school’s level of TS awareness, a role they are not always happy to fill.

Ms. Kloth explains the juggling of needs and priorities when more than one sibling attends the same school. “The siblings are often asked about why their brother or sister act the way they do. It is important the siblings have the information that the family wants them to share. It is important that all families get the information about TS so the sibling isn’t pressured for information. They need to understand TS themselves because the child with TS will be getting more attention from the parents and there could be jealousy, which could create problems in the home.”

School can be difficult for a brother or sister who is uncomfortable talking about TS, who doesn’t understand TS or who is dealing with conflicting agendas in the family, concerning the amount of information that it’s appropriate to share. Siblings must also cope with other children who may confuse the genetic aspects of TS with something that is contagious. The sibling of a child with TS may find themselves growing up quickly shouldering the burden of protecting a brother or sister.

Jessica Druliner is sensitive to the needs of siblings. “I think it is good to allow them to be as normal as possible at school. With our student’s sibling, we try to make sure that she is able to just have regular days, not surrounded by tics. For a while, she didn’t want to walk down the hallway that had her sister’s class in it because she didn’t want to hear the tics or have her sister see her. So her teacher accommodated that and took the class on a different route when needed.”

What Teachers Who “Get It” Think Classmates Should Know About TS

Some kids are like young Brad Cohens — happy to stand in front of the class and talk about TS — but others are reluctant to take the lead. Ms. Druliner described a fourth-grader who wanted her classmates to understand TS but, “... she definitely didn’t want anyone to notice when she had tics.” The student’s desire to be seen as normal conflicted with her equally passionate need to participate in peer education.

Ms. Newman sees the positive aspects of peer education clearly — provided the student is “. . . open to a dialog about the condition and its impact on his or her personal life at school. When peers have information, they can make accommodations as a part of the everyday operation of the classroom. This contributes to a clearer understanding of the diagnosis and removes the fear of the unknown reason for tics.”

The biggest factors in peer education are the age of the students involved and the comfort level of the child with TS. Ms. Kloth describes a peer education success story. “Children can be very accepting. The children in the same grade level need to know what TS is. If they understand that it is not a choice, that TS can change, is not catching, etc., they will handle it well. They should be able to ask questions so they can feel more secure with the child, the teacher and the school. The child in my school went and talked to the grade level classes. It was her choice and it worked very well. Actually, the children in the class often handle this better than their parents. As far as the rest of the school, they were given general information about the disability and if they had more questions they could call the school psychologist or myself.”

Schools have found a variety of approaches to peer education — from assemblies with speakers and screenings of the TSA/HBO documentary and other videos, to quiet one classroom at a time discussions. The age of the students, the severity of the child’s symptoms and the personality mix all contribute to this decision-making process. Ms. Druliner’s school benefitted from the extroverted nature of their fifth grader with TS. Although she wished she did not have TS, she embraced the opportunity to educate other students. In this case the child’s flair and desire for communication worked to her advantage.

Teachers Who “Get It”

One issue persists: schools and teachers that follow rather fixed rules for behavior may encounter difficulties when trying to devise adaptations for a child with TS. Those who get it do understand that tic symptoms are *involuntary*. While some with the disorder are able to develop strategies to control their noticeable symptoms to a degree, this ability is short-lived and, in the end, the repressed symptoms must be expressed — and oftentimes they are expressed — with greater than usual frequency and intensity.

A child may need to take breaks from class to ‘let go’ of suppressed tics or use other coping strategies. Whether it’s extra time on a written test or chewing gum to lessen the impact of tics, classmates may view constructive accommodations as perks offered to the child with TS and denied to ‘normal’ students. If classmates have a clear understanding of the facts about TS, they are less likely to whine about unfair treatment.

The Strategies Teachers Who “Get It” Recommend to Other Teachers

Teachers who get it are known for both their creativity and flexibility in developing strategies for their students. Ms. Kloth’s attitude is clear. “The strategy is very simple, you differentiate academically for that student as you do for all students. You differentiate either in content, product or process. If the student has difficulty at home, the parent can let the school know and adjustments are made. If the student is having difficulty socially, we have buddy lunch, mediations and try to help the student resolve whatever the issues are.”

Ms. Druliner notes that the teacher must adjust to the symptoms. “The teacher who taught math for this student had an incredibly difficult time adjusting to and ignoring the tics. She would often react, unintentionally, to the tics. This made our student very upset and greatly hindered her progress in math to the point that she got behind and did math in the special ed resource room with a modified curriculum.”

To Mr. Cohen, it’s all about being a role model at the head of the class. “As a teacher you must lead by example. If other children see you doing something positive with the child with TS, then they will quickly follow behind. Give that child with TS experiences

that they never have had before. Let them show off their strengths so the other children see the positive aspects of the child rather than the negative.”

Ms. Kloth’s school had a student who experienced coprolalia for a period of time. She was allowed to leave the classroom — an often-used strategy in many schools which helps both the student experiencing symptoms and classmates who find the outbursts disturbing. “This allowed the other students to learn in a calmer atmosphere and made the student feel a bit better because she knew that swearing wasn’t a good thing to do.”

Discerning the difference between willful behavior and an involuntary tic is not always easy. Ms. Kloth believes that the teacher’s acceptance of the child is key, “. . . and how they respond to the child and the tics influences how the classmates will respond. As a principal it is my job to educate the staff so they understand what is happening and to help develop strategies to ensure that all the children’s education can continue in a positive atmosphere.”

Sue Conners has presented at many schools in an effort to spread the word about TS as part of TSA’s teacher education programs. To her, one essential difference between teachers who get it and those who do not is the willingness to let go of some of the “. . . need to be vigilant and mistrustful. This is because since the beginning of time, students have been trying to get away with something.”

Teachers who get it realize that some of the bad behaviors usually associated with a child pushing the limits of classroom discipline are for a child with TS, simply symptoms of the disorder. Ms. Conners says that it is unfortunate that the, “. . . mistrust of students often becomes the foundation of the attitude of many teachers.” Letting go of this predisposition toward mistrust allows the teacher to develop individual educational strategies that are effective.

Professor Hollenbeck has yet to find a medical student with TS in his classroom, but he has encountered students with ADHD, OCD, LD, etc. He is concerned with minimizing the segregation of students who are receiving accommodations. “The major thing I do is to provide extra time on exams. I do this in a way that segregates them as little as possible from the rest of the class and stigmatizes them (I hope) not at all.”

Teachers Who “Get It”

TS symptoms may interfere with the process of learning. To Mr. Cohen, there is no question about who is responsible for developing effective strategies for educating individual students. “As teachers we must figure out ways to allow children to learn in the best possible situation.”

Developing an effective strategy takes work and can be frustrating; of course it’s important for teachers to keep in mind that the student’s experience is that much more difficult. Sue MacKenzie, the fourth grade teacher at Ms. Druliner’s school who worked closely with their student with TS, wants to make sure that teachers maintain a positive attitude and, “. . . have a sense of humor about things.” A teacher’s disdain will only heighten the student’s stress and create yet another barrier to an effective learning experience.

The Critical Role of Teacher Trainings and Continuing Education About TS

Sue Conners’ legions of fans include many teachers, principals and school administrators who have attended her presentations. She has helped many experienced teachers adjust to teaching a child with TS and has worked with new teachers who are surprised to encounter students with disorders that impact directly on the day-to-day learning process.

Ms. Conners offers teachers her insights on the TSA website and through TSA’s library of professional resources. “Teaching children with TS can be very challenging, but challenging doesn’t always have to have a negative connotation. It can be a good thing. The ‘easy’ students were great but it was the challenging ones who excited me. It became a challenge to me to try to put the pieces of the puzzle together to figure out why they were struggling with behaviors which appeared to be difficult. If I could reach that student, sort out and understand the behaviors, support him and help him to become a better person, then I felt that my teaching year had been successful.”

“I often feel that the lack of education about TS that most teachers have experienced creates much of the problem. The good news is that TSA has worked very hard to help ease that lack of knowledge. Below is a list of some of the most important brochures and videos that teachers can use to help further not only their understanding of this complex neurological disorder, but that will also help them tremendously to accommodate these children in their classrooms. Knowledge is power and we can never stop learning. When I go into a school to educate teachers about TS and I hear, ‘I taught a student with TS eight years ago so I know what I am doing,’ I know that just about anything I say will fall on deaf ears. It’s those teachers who are willing to admit that they don’t know it all who will approach what I have to teach them with an open mind and who will be the most successful with the student with TS.”

ADDITIONAL RESOURCES

For online ordering, please visit the TSA’s online store at tsa-usa.org

Brochures:

- + Introduction to Educational Advocacy: The Basic Tools
- + Catalog of Accommodations for Students with TS, ADHD, and OCD
- + Workbook for Conducting a Functional Behavioral Assessment and Writing a Positive Intervention Plan
- + The IEP for Students with TS: an Educator’s Handbook
- + TS and the School Psychologist
- + Learning Problems and the Student with TS
- + Understanding Coprolalia: A Misunderstood Symptom

Videos and DVDs:

- + *I Have Tourette’s but Tourette’s Doesn’t Have Me* (An HBO and TSA Presentation)
- + *A Teacher Looks at TS* by Susan Conners with Introduction by Polly Draper

About the Educators Featured

Peter J. Hollenbeck, Ph.D.

Professor Hollenbeck is a Full Professor and Associate Department Head of Biological Sciences at Purdue University. His field of study is cellular and molecular neurobiology. He received his Ph.D. from U.C. Berkeley and was a Postdoctoral Fellow at the Medical Research Council in London. Before moving to Purdue, Professor Hollenbeck was an Associate Professor of Neurobiology at Harvard Medical School. He joined the TSA Scientific Advisory Board (SAB) in 1997 and is currently the Co-Chair of the SAB.

Jessica Druliner

Ms. Druliner received her Bachelor’s in Psychology from the University of Wisconsin-La Crosse. She did her graduate studies at Michigan State University where she earned an Educational Specialist Degree in School Psychology. She is a school psychologist in the Greendale School District.

Kathy Dunaway

Ms. Dunaway received her Bachelor’s in Education with a specialization in Special Education from City University, Bellevue, Washington. She is currently working on her Masters with a specialization in Reading and Math K-5. She is the Resource Room Special Education Teacher at Castle Rock High School in Castle Rock, Washington.

Connie Newman

Ms. Newman is the Superintendent of the Lambert Public Schools in Lambert, Montana. Her long career includes 22 years as a classroom instructor, Federal Programs Director and Building and District Level Administrator positions. She completed her undergraduate work at Eastern Washington University and received her Master’s in Education from the University of Montana. She has done additional graduate level work at the University of Montana, Walden University and the University of Alaska.

Brad Cohen

Mr. Cohen was awarded his undergraduate degree from Bradley University and received his Master’s from Georgia State. He is an Area Lead Teacher in Cobb

County, Georgia. Mr. Cohen recounted his life as both a student and a teacher with Tourette Syndrome in his book, *Front of the Class: How Tourette Syndrome Made Me the Teacher I Never Had*.

Michele Kloth

Ms. Kloth received her BA in Education at the University of Northern Iowa, her MS in Educational Administration from the University of Wisconsin, Milwaukee and an MS of ED in Computers in Education from Lesley College. She has been with the Greendale, Wisconsin school district for 17 years and is currently the Principal of the Canterbury Elementary School which houses the district’s Early Childhood Program and the Cognitive Disabilities Program.

Susan Conners

Ms. Conners received her BA in French from Daemen College and her M.Ed. in Secondary French Education from the University of Buffalo, New York. She taught French for 33 years in the Williamsville, New York Central Schools; she served as Department Chair for 13 years; and for 25 years led students on summer travel programs to Europe — all while coping with the symptoms of her own Tourette Syndrome.

Founder of the Western New York Chapter of TSA in 1984, Ms. Conners still serves as its President. In addition, she has made presentations about TS at over 400 schools and service agencies in Western New York and acted as an educational advocate for children with TS, regularly meeting with teachers, school administrators, parents and students.

In recent years, Ms. Conners has served as an Education Specialist for TSA. In that capacity she is a popular and important speaker, making presentations at every national TSA conference since 1991 and around the country as part of the TSA/CDC Professional Education Program. Ms. Conners has also lent her considerable expertise to a variety of interested organizations including: The National Association of School Psychologists annual conventions and Regional Chapter events; a Pennsylvania Department of Education teleconference reaching 1,200 educators; and the U.S. Department of Education Office of Special Education.

This brochure has been created based on the advice of a group of experts. The recommendations made may or may not be relevant to a particular situation. Readers with questions should consult directly with a professional knowledgeable in TS for solutions that will meet their individual needs.

An up-to-date Catalog of Publications and Videos
can be downloaded from our website.



Tourette Syndrome Association, Inc.
42-40 Bell Boulevard • Suite 205
Bayside, New York 11361-2820
Tel 718-224-2999 • Fax 718-279-9596
ts@tsa-usa.org • www.tsa-usa.org

Copyright © 2007

Permission to reprint this publication in any form must be obtained from the national
TOURETTE SYNDROME ASSOCIATION, INC.