

## WHAT EVERY TEACHER SHOULD KNOW ABOUT TOURETTE SYNDROME

Our annual back-to-school issue is always well-read and well-received. This year, we've moved it to the summer so that teachers, parents and children with TS can use it to get ready for the first day of school. Educators, parents, children and adults with TS were consulted on their ideas of what every teacher should know about TS—before a child with TS enters a classroom.

### Top Down Organization

Classrooms and schools are top down organizations. The teacher sets the tone in the individual classroom and principals and administrators set the overall tone in the school. If the principal of a middle school is certain that he or she “understands” TS, but that limited understanding is based on one child with one kind of symptoms, the variety of tics another child presents may be misconstrued as intentional misbehavior.

An otherwise well informed principal recently told educator and TS Education Specialist Sue Conners, M.A., “Don’t tell me that burping is a tic!” But of course it can be—as can a myriad of other behaviors that are easily confused with the attention-getting schemes of the class clown. When administrators choose to define TS within narrow confines, teachers don’t get the support they need to distinguish “bad behavior” from tics. It’s a frustrating situation that can baffle even the best teachers.

Tracey Louis-Charles, mother of eight-year-old Jordan, has a simple piece of advice for teachers—ask the child how he is doing that day. “Children with TS have good days and bad days. It doesn’t help to say—he didn’t act like that yesterday—because every day is different. My deepest heart’s desire is that teachers go that extra mile and take time to pick up on the cues that mean a child is having a rocky day.”

Professor Peter Hollenbeck didn’t receive a diagnosis until he was an adult, but his experiences in the classroom were very similar to those of children today. “The approval of teachers can be more important than that of classmates, and I

think that the grief and rolled eyes that I got from teachers bothered me even more than what I took from classmates.”

The top down organization of the classroom gives the teacher the opportunity to set a tone of tolerance and acceptance—or impatience and disapproval.

Every child in the room follows the lead of a teacher who rolls his or her eyes in disbelief or chastises a child with uncontrollable tics. They also follow the lead of teachers who are flexible and take into account the impact of stress on children with TS.

continued on page 6

## HOLLYWOOD and WASHINGTON MEET AT TSA BRIEFING

Actress Polly Draper, James Baker IV and other notable figures from both Hollywood and Washington’s elite met at TSA’s Congressional Luncheon hosted by Margaret Bush, sister-in-law to the President in March. The topic for the day was Tourette Syndrome. Members of Congress and their aides learned

about TS first hand and why continued funding of the partnership between TSA and the Centers for Disease Control and Prevention is so critical.

For Ms. Draper, TS is a very personal mission. She described the impact of TS on both her husband, jazz musician Michael Wolff, and their nine-year-old son Nat. Ms. Draper’s father William H. Draper III, a venture capitalist and civic leader, was joined by another grandfather, George Loder. Both shared their unique perspective on family life with TS.



William H. Draper III at the podium



Polly Draper’s turn

continued on page 10