

# Inside TSA

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## “I Have Tourette’s But Tourette’s Doesn’t Have Me”: Five Years Later

### The “I Have Tourette’s” Phenomenon

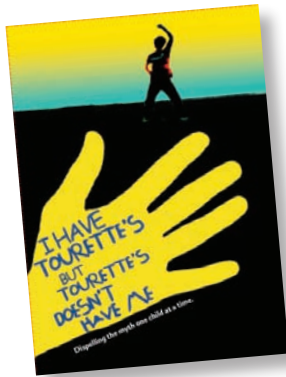
The TSA-HBO documentary “I Have Tourette’s But Tourette’s Doesn’t Have Me” premiered on HBO on November 12, 2005. One million viewers — an extraordinary number, higher than any other children’s program on HBO — saw it that first night and countless others have seen it since. The documentary went on to win the prestigious 2006 Primetime Emmy Award for an Outstanding Children’s Program, a Media Access Award, a Parent’s Choice Award, the Voice Award and a nomination from the Directors Guild.

Chapters hosted dozens of screenings in homes, schools, churches and community centers across the country in conjunction with the debut. Since producing DVDs of the documentary in 2006, TSA has sold over 12,000 copies and given away another 20,000 DVDs to schools, libraries, at CDC program events and family meetings, at medical and education seminars, and at TSA conferences.

The accompanying Teacher’s Guide with complete lesson plans and the half hour of DVD extras have made the DVD a particularly successful tool for increasing awareness among school aged children and educators. Both the Teacher’s Guide and DVD are available exclusively from TSA.

### The Making of a Masterpiece

The development of the project began in the late 1990s when Sheila Nevins, President of Documentary and Family Programming for HBO, brought representatives of TSA together with HBO executives. From the very start, the project was close to Ms. Nevins’ heart and is in many ways a tribute to her son who has TS. (See page 14 for Ms. Nevins reflections on the documentary.)



In January of 2004, the project started becoming a reality when national TSA reached out to chapters across the country seeking children who would be comfortable discussing their lives on camera. HBO had a long list of volunteers to sort through before they chose the 26 children for the film.

Hundreds of hours of tape were shot, both in an interview setting and out in the world with the children. Ellen Goosenberg Kent, the director and producer, recalls working with the children as a special experience.

“My memory of working on this documentary is one of extreme pleasure. When I told people I’d be looking for children to interview about

living with Tourette’s, every one of them said ‘Good luck!’ I was told that the children would be ashamed and self-conscious. They would be uncomfortable in the studio with all the lights and strangers. They wouldn’t be able to focus. How wrong those people turned out to be! The children who came to be interviewed were smart and self aware, spunky and sensitive, open hearted and open minded, honest and kind. And they genuinely wanted to help other kids like them. They focused beautifully and shared their feelings generously and it was an incomparable experience for me. I salute TSA for being a strong support to children and their families, and I’m grateful to have had the chance to know and work with so many of them,” Ellen said.

Beth Aala, the co-producer, felt privileged to have been a member of the creative team. “I thought every single child who participated in the documentary was so brave for sharing their stories. And though very young, they were incredibly mature. They offered big life lessons that applied to everyone—not just those with TS or kids their age, but adults as well. I certainly walked away learning a lot from all of them. I found that they had the most amazing honesty about them,” she said.

Millions of viewers were introduced to “I Have

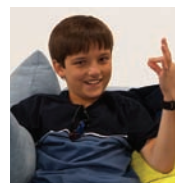
Tourette’s” four days before the HBO premiere when three of the children, Colin, Amanda and Jasper, traveled to Chicago to appear on *Oprah*. With ratings estimated at 21 million in the U.S. and more around the world; clips of the documentary were previewed by a huge audience. “I Have Tourette’s” attracted even more national media attention when William and his mom, Kelly, Aungeni and Dr. John Walkup were featured on *The CBS Early Show*; Colin and William were interviewed on *CNN with Paula Zahn*; and seven of the young stars sat down with Lara Spencer for a segment on *The Insider*. Some of the children were also featured in their local hometown media, increasing the impact of the show in their communities.

### More Than 15 Minutes of Fame

Five years later, it’s hard to see the cover of the DVD without thinking about Riley’s karate skills, Amanda’s emotional home videos, and William’s “Tree of Telling” theory. Participating in “I Have Tourette’s” was an important experience which enabled them to make a genuine difference in the lives of every child, and adult, with TS.

**Colin**, best remembered for his pointed quip, “I hate substitutes. Tourette’s and substitutes ... don’t mix!” has since become an outspoken advocate as well an active member in the TSA Ohio Chapter.

Currently a junior in high school, Colin is completing an internship as a music therapist at an elementary school for children with disabilities. An aspiring musician, he composes his own songs, plays guitar and drums and is known for his infectious and relentlessly upbeat attitude onstage and off, performing in local clubs in Ohio.



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