



## THIRTY YEARS OF TSA

### The History of TS, Part 2



... As we all know, it has become clear that the incidence of Tourette Syndrome, worldwide, is much greater than anyone had ever thought. Therefore, we find ourselves in a unique position of great moral responsibility. As of this moment in time WE are the major bearers of information, the sole repository of raw data, and most importantly WE are the only group concerned enough to care about ferreting out and helping the undetected thousands who, unknowingly, are suffering from Tourette Syndrome. . . — **Michelle Cooler**, TSA President

Saturday, May 26, 1979, Keynote Address at First TSA Conference

In the last issue of this newsletter we discussed the “bad old days” of misdiagnosis, misunderstanding and mistreatment. In this issue some of the many individuals

who took part in the birth and growth of TSA as an organization, reflect on its impact on the lives of people with Tourette Syndrome. The last thirty years have

seen changes on many fronts—from dramatic increases in general awareness and interest in the scientific community, to progress in treatment options and the speed of diagnosis. We’ve come a long way since Elly Pearl brought a group of worried parents together in the small office her husband Bill rented.

“Nobody knew what TS was,” Abbey Meyers of NORD recalled the early days of TSA. “When the office opened, we started getting phone calls from people about tours of Spain. They thought we were a tour agency.”

One of the huge hurdles TSA had to overcome was a lack of familiarity with TS, and TS symptoms, in both the general public and in the professional communities that serve people with Tourette Syndrome.

Eleanor Curry, who has been a volunteer since the early years, said that one of TSA’s first accomplishments was the referral list of doctors around the country. The doctors, recommended by people, were

then sent questionnaires by TSA’s Medical Advisory Board (MAB) regarding their knowledge and training.

“I’ve been practicing medicine for thirty years and have been interested in TS for twenty-five,” stated Dr. Gerald Erenberg, Immediate Past Chair of the MAB. “The changes are astounding. It was a mystery. Telling a teacher that a child had TS was met with a blank stare. The principal, the guidance counselor, no one in the school heard of it. Families were stymied, they had nowhere to go for information. Fast forward to today, and almost 95% of the referrals we get are based on a parent’s or teacher’s knowledge. At this point we rarely make a diagnosis, instead we confirm a diagnosis made by a lay person.”

Dr. Erenberg also credits TSA with informing doctors about TS and interesting the scientific community in TS as a subject for research. He singled out Sue Levi-Pearl, Vice President Medical and Scientific Programs, for her “. . . extraordinary ability to mobilize the medical and scientific communities to work on TS.”

Diane Mallah, who has been on the TSA board since 1983, remembered the challenges well. “One of the first projects I remember was our struggle to get into medical text books.”

TSA has continued to focus on educating professional communities. The Educator’s Curriculum is only one example of TSA’s systematic approach to “educating educators” as well as school counselors, social workers, nurses, etc. The curriculum will reach hundreds of teachers a year, many times the number that learned about TS when skilled TSA members, like Sue Conners, made “in-service” presentations at local schools.

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**“Life with TS has changed dramatically since the founding of TSA.”**

### NY Yankees Join TSA's Awareness Campaign

#### World Champions Bolster TS Awareness with Joe Torre Television Ads

The New York Yankees are doing their part when it comes to Tourette Syndrome awareness. As part of a major new initiative to assist TSA’s awareness efforts, Yankees’ Manager, Joe Torre, recently shot a TV Public Service Announcement (PSA) with 13-year-old TSA member and die-hard Yankee fan, Joriel Sharp.

Accompanied by TSA President, Judit Ungar, Joriel made the recent trek to Yankee Stadium to co-star with Manager Torre in TSA’s newest PSA. The spot, which was filmed by the Yankee’s own YES (Yankees Entertainment Sports) Network, will air soon on YES and WCBS-TV in New York City. In addition, the Yankees will provide support for a variety of other TSA-related special events and awareness efforts.

