

Inside TSA

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Tourette Syndrome Around the World: Awareness, Education, Media and Medicine



In some parts of the world Tourette Syndrome is as familiar to the general public as it is here in the United States, but there are other countries where people with TS struggle every day to find well-informed physicians, battle rigid school policies about behavior in classrooms and where the general public has little or no awareness of TS. International medical conferences, outreach to educators and the concerted efforts of organizations very similar to our own TSA are working to increase awareness, improve educational opportunities and widen access to appropriate healthcare all over the world.

In addition, the distribution of American and British television shows and movies throughout the world and the increased use of the Internet, have begun to bridge the information gap. But, as we all know, not all of what appears on TV, in films and on the Internet is accurate. In countries where positive depictions of people with TS serve as a counter balance to the negative impressions and solid, up-to-date information is also available, the

impact of stereotypes and not very funny jokes is tempered. This isn't always the case, but life is improving for people with TS across the globe.

Tourette Syndrome, What's That?

In the United Kingdom, Canada and Australia, the general public is very aware of TS. So much so that Elizabeth Burns of the Australian counterpart of TSA said, "TS seems to be the disability of the year with references popping up in TV programs, in articles and radio interviews." Of course this awareness was the result of ten years of concentrated efforts on behalf of the Australian TSA, including an annual Awareness Week in May. "This year, our Association organized a national ad campaign and filmed television and prepared radio ads to circulate nationally. They have been very successful and can be viewed on our website and on YouTube!" Ms. Burns continued.

In Canada, the challenge is to move beyond a general awareness and toward a more accurate picture of TS. Rosie Wartecker, Executive Director of the Tourette Syndrome Foundation of Canada, described the situation. "The population is generally aware, however, the vast majority still have the Hollywood version of the 'swearing raving lunatic' firmly entrenched. There is something to be said about public awareness efforts and we think we here in Canada are beginning to

make progress in breaking down that stereotype and dispelling some of the myth."

"Myth" is also the word used by Pelle Sandstrak, author of the Swedish bestseller, *Mr. Tourette and I*, conceding that the public is more aware than they were in the past but, "... We are still fighting myths about Tourette and coprolalia."

Dr. Jeremy Stern, Honorary Medical Director of the UK TS organization recently renamed Tourettes Action, describes a similar situation in the Britain, stating the populous is "... almost universally aware of the existence of TS but fixated on coprolalia."

In other parts of the world, TS remains a mysterious and mystifying condition. The Polish TS Association was founded in 1997 and has only 160 members. The organization's board meets once a week for two hours. During that time they answer phone inquiries about TS in general, treatment options, doctors and more. Once a year they hold a General Meeting that brings the entire membership together with physicians, psychologists, therapists, policemen and other professionals with expert knowledge.

The current emphasis is on preempting dangerous situations caused by the general lack of awareness. "We made an identity card to certify that the given

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