



tourette syndrome association, inc.

April 2009

Dear TSA Friend,

WHY THE TSA GOVERNMENT AFFAIRS OFFICE IS YOUR AFFAIR

**Our nation is the world's melting pot.
We are a people of every race, religion and ethnic group.**

These inspiring words eloquently summarize the diversity of the American population, and our own Tourette Syndrome population as well. Indeed, our nation harbors the most diverse mix of people anywhere and not a single race or ethnic group is immune from this tormenting disorder.

These are trying times. Now, in government, America is entering a new era and embarking on a new and uncharted voyage as it deals with an economic crisis of massive proportions. But ahead of us there is hope for progress in dealing with this worldwide situation and hope of a better life for all who live here — including people coping with Tourette Syndrome.

In the far-flung struggle against the burden of this disorder, a central factor will be the actions of a new Executive Branch and Congress. They will assume major authority in the allocation of funds — weighing the competing needs of the various segments of the U.S. population.

In view of the dire factors confronting the national economy, Congress and the administration are under severe pressure. Each day the media report growing demands for government intervention in another area of that economy. At the same time, there is equal pressure to reduce or even eliminate many worthy programs including support for TS-related issues.

It is abundantly clear, in light of the above, that a formidable task awaits our Government Affairs Office in Washington — a limited staff facing vast problems.

Despite all obstacles, however, we can point with satisfaction to what can be described as remarkable accomplishments such as these:

- 1) Vigorous advocacy that led to the inclusion of Tourette Syndrome in the 2006 re-authorization of Individuals with Disabilities Education Act (IDEA). This positioned TS as a true neurological disorder, not just a behavioral issue. Schools are now required by law to provide appropriate education and accommodations for all students with TS.
- 2) An ongoing Congressional Appropriation for the Tourette Syndrome Public Health Education and Research Program, now in its fifth year, of a critical TSA/Centers for Disease Control and Prevention (CDC) partnership program. To date, over 20,000 medical and educational professionals have been trained in diagnosing and treating people with TS, as well as in educating our nation's children touched by the disorder.

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- 3) Passage of Mental Health Parity in 2008. Now insurance and medical benefits for people seeking medical treatments by Mental Illness Professionals, are on the same scale as those with any mainstream disease or disorder.
- 4) Passage of the Genetic Information Nondiscrimination Act in 2008. Anyone with a genetic predisposition to TS cannot be denied employment, insurance or other benefits on that ground.

While the entire TS community can take great satisfaction in this record, we must now face a new reality: the current roster of House and Senate committee members acutely aware of and dealing with a faltering economy.

To adapt to this new reality, the basic day-in, day-out operations of our Government Affairs Office must be reinforced and new techniques adopted to reeducate a changed government. It is also clear that such a renewed offensive must be adequately financed to accomplish a difficult but an essential mission.

At this critical stage, our Government Affairs Office staff must turn to you as an essential ally in the campaign to retain vital gains we have achieved for the men, women and children by the hundreds of thousands who battle with TS every day of their lives and to forge ahead with essential new initiatives.

While you cannot work alongside our hard-pressed Washington staff in their daily activities on Capitol Hill, your donation can. We ask that you make the size of that donation an adequate one in the light of the size of the task that confronts them. And in the light of this urgency, we ask that you act now.

Gratefully,

Judit Ungar
President