

UPDATE: TSA GOVERNMENT RELATIONS

What's New in Washington

The Tourette Syndrome Association in Washington, D.C.

People often think that lobbyists are “fat cats” with big expense accounts and industry clients in search of tax breaks or a big federal contract. That may be true of some of the people who lobby legislators in Washington, but there is another kind of lobbyist — the advocates for important causes. TSA is one of many organizations with a presence in the Capitol.

After decades of pressing for a change in the Individuals with Disabilities Education Act (IDEA), Tourette Syndrome was finally added to the category of Other Health Impaired (OHI) on August 4, 2006. This critical change in the language of the legislation will enable students with TS to receive the accommodations that they may need in school.

The long road to the IDEA triumph is a lesson in how people can make a difference. The change in the IDEA was achieved in great part through the efforts of individuals who made certain that their representatives understood the nature of TS and how the IDEA could become a helpful tool for students. In face-to-face meetings on Capitol Hill and home offices; at the annual Congressional Reception; in testimony before the Department of Education and Congressional committee hearings; and through e-mails, letters and phone calls, constituents educated the lawmakers about

TS. By putting a face on the disorder — the face of a voter or a voter's child — members of the TSA family made TS a real issue for legislators.



Allocating Funds and Focusing on Critical Issues

Right now there are several things keeping TSA's professional and amateur advocates busy. For the past three years, TSA, in partnership with the Centers for Disease Control and Prevention (CDC) has successfully received funding for the Tourette Syndrome Public Health, Education and Research Program. The CDC-funded program has achieved a great deal in its three years — reaching out to educators and healthcare providers with the essential information about TS; adding physicians to the roster of those prepared to care for patients with TS; helping TSA to offer Continuing Medical Education credits; updating the TSA website with important information for medical professionals, and more.

The TSA/CDC Partnership, like any other federally-financed program, is periodically reviewed before funding is renewed. TSA keeps tabs on the level of support in congress as interest in the continued funding of the partnership, and a general understanding of TS, is key to keeping the program on the track for renewals.

“The Program was originally authorized by Title 23 of the Children's Health Act of 2000, but each year, TSA must go back to ask Congress to fund it. This year, The House Appropriation's Committee implemented some very strict rules with limits on appropriation's request. As a result we launched a grassroots advocacy campaign to take action in securing the funds for fiscal year 2008,” Elridge Proctor, Director of TSA Public Policy, explained.

Through grassroots e-mail alerts, TSA members are directed to the TSA website's Legislative Action Center where they will find instructions that make the process relatively simple. The site includes a draft of a letter that members are encouraged to personalize and a function for quickly identifying the correct representative by zip code.

“Each time TSA members take action in support of TS we are a day closer to reaching our goals and mission. It took the constant persistence of TSA members — calling, e-mailing, faxing and meeting

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Prominent Law Makers at TSA's Third Annual Reception



Jamie-Grace with
Senator Hillary Rodham Clinton

On February 28 Senators and Congressional Representatives and Staffers and members of TSA met at TSA's Third Annual Congressional Reception. The honorary co-chairs were Senators Hillary Rodham Clinton and Gordon Smith and Representatives Chet Edwards and C.W. Bill Young. Prominent lawmakers and important legislative aides also attended, including; Senate Majority Leader Harry Reid (D-NV), House Majority Leader Steny Hoyer (D-MD), Congressman Chet Edwards (D-TX), Senator Gordon Smith (R-OR), Senator Ted Kennedy (D-MA) and Senator Ben Cardin (D-MD).

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