



## tourette syndrome association, inc.

1301 k street n.w. 600 east tower washington, dc 20005

### HOW TO ADVOCATE

#### PREPARATION

- Read and review the “TSA Legislative Issues.” Decide which issue you want to relate a personal story with but be sure to thank Congress for authorizing the CDC to administer a Public Health Education and Research Program on Tourette Syndrome in partnership with the TSA.
- Prepare to give a personal story on how TS affects you. Lawmakers are very interested in hearing about real life consequences of their legislative actions so we suggest that you bring in pictures of you and family, current chapter newsletter, or souvenirs to leave behind (nothing of monetary value).
- To familiarize yourself with how your legislator voted in the past with our legislative issues and other issues. Visit the following sites:

Senate <http://www.senate.gov/>

House of Representatives <http://www.house.gov/>

Vote Smart <http://www.vote-smart.org/index.phtml>

#### MEETING GUIDELINES

- Be Yourself
- Share your TS Stories
- Thank the Legislators for their Congressional support on our issues.
- Identify yourself as a constituent and represent your community as an Ambassador
- Express your concerns for TS Awareness, school and education services, and health care, disability benefits or medical insurance coverage issues  
TS Public Health, Education and Research Program at the CDC

#### DAY OF THE MEETING

- Dress professionally.
- Be on time for your appointment.
- Speak politely and concisely.
- For your Senatorial meetings, some or most of you will go as a delegation, comprised of many individuals. Please take turns on speaking and refer to specific issues. Make sure that each Youth Ambassador is acknowledged and speaks followed with Parents.
- Obtain the business cards of any aides who attend the meetings so you can properly address your thank you letters and to provide contact to the TSA.

- If a lawmaker or staff is opposed to your issue, do not get frustrated. Remain polite and continue with your visit. Leave the appropriate material. Remember, you are on a mission to educate.
- If you cannot answer a legislator's or aide's question, let them know that you will find out the information and get back to them as soon as possible and then refer them to TSA's Government Relations Office. (My card will be included in the folders provided for you to leave behind).
- Volunteer to act as a resource for the legislator on TS related issues.
- Remember to leave behind the Congressional Folders provided by TSA.
- At the conclusion of the meeting, be sure to thank the legislator or aide for their time.

### **Follow-up**

- **Meeting Notes:** Immediately following the meeting, jot down notes about who you saw, what they learned or knew about TS, what their views were on the issues you discussed, whether or not they plan to support our request of support, and any additional information that you feel was important during the meeting.
- **Thank You Letters:** Send a thank you/follow up letter after your meeting to each legislative office. If you email the letters, please copy me at [elridge.proctor@tsa-usa.org](mailto:elridge.proctor@tsa-usa.org) or fax me a copy at 202-408-3260.
- Provide TSA's Government Relations Office with copies of all your letters and email correspondence to help with following up on your behalf.