

Communicating With Your Elected Officials

Establishing a relationship with your elected officials is an effective way of bringing the issues of HD to the attention of your legislators. Members of Congress are more than happy to meet with their constituents, who, after all, are the people they are elected to represent and serve. A home office visit with your legislator can give you valuable face-to-face time to let Congress know why HD matters to you.

Setting up a meeting

To find your Representative's home office address and phone number, visit Congress' the House of Representative's website at <http://www.house.gov/> or call the U.S. Capitol information switchboard at (202) 225-3121. If you go through the website you may need your 9-digit ZIP code, which you can find at <http://zip4.usps.com/zip4/welcome.jsp>.

- Contact your legislator's local district office and ask to speak with the scheduler to set up an appointment.
- Tell the scheduler you would like to discuss issues involving Huntington's Disease with the legislator.
- Make clear in which office you would like to meet, Senators have various local offices.
- Be prepared to send in a written request via e-mail or fax.
- If you can only get a meeting with an aide, take it. That aide can become an important ally and advocate on your behalf with the legislator.

Before the meeting

Once a meeting has been set, be prepared with concise and organized talking points to get the most out of your meeting.

- Pick a particular issue that will be the focus of your meeting, ideally some concrete action you would like your legislator to take such as to sponsor or co-sponsor a bill, to assign a staff person as a chapter liaison, or to speak at or attend a chapter meeting.
- Keep in mind what issues are dealt with at which level of government. Funding for the National Institute of Health, Medicare funding and regulation, Social Security disability rules, and certain health insurance issues involve federal law. Issues relating to day to day life are more affected by state laws.
- Know where your legislator stands on the issues you are advocating for, this way you demonstrate how knowledgeable you are about the issues that most concern you.
- Be prepared to show how HD issues affect you as a constituent, whether you are a patient, at-risk, a caregiver, etc.

The meeting

This is the opportunity to express to your legislator, or aide, exactly what HD is all about. If ever there is a time to tell someone about the devastation of HD, this is it.

- Be reasonable, polite, and factual at all times. Remember, you are trying to build a long-term relationship with that person, so do not be confrontational, accusatory, or demanding.
- Budget your time speaking during the meeting to allow for discussion afterward.
- If you are asked a question you cannot answer, do not guess. Tell the legislator or aide you and HDSA will look into the question and respond promptly.
- If your meeting is cut short, be flexible and offer to reschedule for another time.
- Have a written summary of the key points you discussed and your position on the issues ready to leave with your legislator.

Follow up

It is important to follow up any meeting with a legislator with a thank you letter and other correspondence to ensure a continued line of communication.

- In your thank you letter highlight the key issues that were discussed as well as what action you would like the legislator to take.
- Submit an article to your chapter newsletter about the visit, and forward the newsletter to your legislator.
- Be sure to include any information promised in your correspondence with your legislator.
- Keep HDSA informed of any new developments and information gathered from your meeting with your legislator.
- Maintain contact with the legislator's local and Washington offices, and offer to be an ongoing resource for more information.

Telephoning your elected officials

Legislators have limited time and may not be able to set up a personal meeting. You can still let your legislator know you care about these issues by phoning your legislator's Washington or local offices.

- Staff members answer constituent phone calls, so be sure to ask to speak with the aide who handles health issues.
- Identify yourself as a constituent of the legislator and an advocate for HD. Tell the aide you have a brief message for the legislator such as: "Please tell Senator/Representative (Name) that...."
- Have reasons to support the positions on the issues you put forth.
- Ask for your legislator's positions on the issues.
- Request a written response to your telephone call.