



Rare Disease Legislative Advocates

POWERED BY THE EVERYLIFE FOUNDATION

How to Attend a Congressional Townhall

TIP SHEET

Taking part in a public or townhall meeting is a great way to build a relationship with your Member of Congress and their staff as well as to raise the profile of the rare disease community to policymakers.

These events generally take place in your community or district throughout the year and provide an opportunity for Members of Congress to hear from constituents on a wide range of concerns. To find information on upcoming townhalls, visit your legislator's Congressional website or call the office to request information.

Tips for Preparing to Speak at a Townhall

- ★ **Determine the purpose and tone of the event.** Find out what the overall agenda of the meeting will focus on, who else is expected to participate or make a presentation, and the anticipated “tone” of the meeting. This will help you to prepare your remarks.
- ★ **Use your network.** Share information about the meeting with other advocates, partners, and coalitions.
- ★ **Encourage as many rare disease advocates to attend the town meeting as appropriate.** This will lend support to your efforts and demonstrate to your policy-maker the extent of the community support for people with rare diseases.
- ★ **Be prepared** with accurate, timely, and relevant information.

Tips for Presenting

- ★ **Work to present your position or statement as early in the meeting** as you are able, as press is more likely to attend and cover the first part of the event.
- ★ **Keep your presentation brief.** Limit your statement to three clear and concise points. Provide persuasive facts to assist participants to understand and remember your points.
- ★ **Practice your statement** to ensure you are comfortable and convincing when sharing your points with a larger audience.
- ★ **Provide written copies** of your statement to policymakers, their staff, and the press.
- ★ **Inform** your fellow advocates and RDLA on the outcome of the meeting.

TIP ► *Arrive 20 minutes early to the townhall. Congressional staff always arrive early to the events to set up. Introduce yourself to the staff and let them know why you are there. Be respectful and polite and give them your contact information.*

Rare Disease Legislative Advocates (RDLA) is a program of the EveryLife Foundation for Rare Diseases to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collaboratively, thereby amplifying the patient voice to be heard by local, state and federal policy makers. For additional assistance with creating a state rare disease caucus, contact Shannon von Felden, RDLA Program Director, at svonfelden@everylifefoundation.org.