



Rare Disease Legislative Advocates

POWERED BY THE EVERYLIFE FOUNDATION

# Foster a Relationship with Your Member of Congress

## TIP SHEET

**Building relationships with your Members of Congress is important to ensuring that rare disease patients are heard on Capitol Hill and policymakers are working to improve the lives of patients with rare diseases.**

Members of Congress are more responsive to their constituents and more likely to support a policy proposal when they hear directly from people who live in their district!

To build a relationship with your Member of Congress, you can:

- ★ **Schedule a meeting** with your Member in the District office or on Capitol Hill,
- ★ **Get to know** the key staff who handle health care policy in the district and in Washington, DC,
- ★ **Invite** your Member of Congress or their staff to events held in your community,
- ★ **Attend events** like townhalls that your Member of Congress holds in the district and state,
- ★ **Volunteer** for a candidate's campaign activities,
- ★ **Engage** with legislators on social media,
- ★ **Write letters** or emails to your legislators,
- ★ **Write op-eds** for your local newspapers, and
- ★ **Send "thank you" messages** (call, email, letter, social media) when your legislators support rare disease issues.

### When should I engage with my Representative and Senators?

Anytime and all the time! Start out slowly, with one or two different activities. As issues arise, engage with your legislators on those issues. Pay attention to the issues you care about most.

As a bill progresses through Congress (committee, House vote, Senate vote, conference committee, etc.), let your legislators know about your position on the issue. Don't wait until it's too late to voice your support or concerns on legislation you care about.

### How do I connect with my legislator?

- ★ Find personal connections you have in common! As a constituent, you are from the same state and area as your legislator. You may live in the same neighborhood, go to the same school, etc.
- ★ Research the issues that are important to your legislator (check out their website and press releases).
- ★ Research the legislation that the legislator has supported (check out their website and press releases).

**TIP** ▶ *Staff are an amazing resource and Members of Congress rely on them to advise them on issues that affect their district and constituents.*

**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](mailto:svonfelden@everylifefoundation.org).