RDLA
Rare Disease Legislative Advocates
POWERED BY THE EVERYLIFE FOUNDATION

Lobbying for Rare Disease Nonprofit Organizations

TIP SHEET

Rare disease organizations can and should play a role in influencing policy! 501(c)(3) organizations can engage in lobbying at the federal level and have the right to express their views on policy and mobilize advocates.

There are two types of federal lobbying that nonprofit organizations can participate in:

- **Direct lobbying** involves communication with a legislator, employee of a legislator or legislative body, or any government employee who may participate in the formulation of legislation (Congress, the White House and federal agencies). The communication refers to a specific piece of legislation and expresses a view (support/opposition) on the legislation.

  Examples: Call, write, or meet a Member of Congress to ask them to support, cosponsor, or vote a certain way on a piece of legislation.

- **Grassroots lobbying** is an attempt to influence specific legislation by encouraging the public to contact legislators about the bill. A communication constitutes grassroots lobbying if it refers to specific legislation, supports a view on that specific legislation, and encourages the recipient of the communication to take a lobbying action.

  Examples: Send a letter or email to supporters encouraging them to contact their Members of Congress to cosponsor a bill, support funding for a program, or to vote a certain way on a piece of legislation.

The Lobbying Disclosure Act of 1995 is a federal lobbying statute administered by Congress that applies to legislative and executive branch contacts.

- LDA requires registration and disclosure of certain lobbying activities, including issues lobbied, individual lobbyists, and lobbying costs.
- Under LDA, a "lobbyist" is an individual who, for compensation, makes more than one "lobbying contact" and spends 20% or more of his or her time during a quarter on federal "lobbying activities."

The following activities are **not** lobbying, and nonprofits may have unlimited participation in:

- Nonpartisan analysis, study, or research (unless used for the purpose of lobbying).
- Meeting with your Member of Congress and/or Congressional staff to discuss rare disease issues and possible solutions (as long as a specific piece of legislation is not discussed).
- Asking for increased general funding for the Food and Drug Administration and National Institutes of Health.
- Educational briefing on rare diseases and related issues.

501(c)(3) organizations can engage in limited amounts of lobbying.

- Generally, if any 501(c)(3) organization spends less than 15% of their total annual budget on lobbying, they would not be in danger of violating lobbying limits.
- If an organization has a paid staff member who spends more than 20% of their time lobbying, that employee needs to file lobbying reports.
- An organization's volunteer or unpaid staff member time does not count toward the direct lobbying cap.
- For more information on the lobbying limits, refer to: irs.gov/charities-non-profits/lobbying.

501(c)(3) organizations must be non-partisan and cannot make campaign contributions or political endorsements of candidates. However, they can participate in non-partisan voter education on issues or non-partisan voter registration activities.

The information provided in this document is not intended as legal advice. If you have specific questions, please contact a lawyer.

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, please contact Shannon von Felden, RDLA Program Director, at svonfelden@everylifefoundation.org.