RARE DISEASE LEGISLATIVE ASSOCIATES (RDLA) PROGRAM MANAGER

DESCRIPTION

Rare Disease Legislative Advocates (RDLA) is a core program of the EveryLife Foundation for Rare Diseases. RDLA is designed to be a clearinghouse for stakeholders in the rare disease community to raise awareness about state and federal policy issues. The Program Manager will play a vital role in coordinating various events, activities, and initiatives that are part of RDLA, which will entail working closely with staff at the EveryLife Foundation as well as rare disease patients, researchers, industry professionals, Congressional staff, and Members of Congress. This is a full-time position (~40 hours/week) based in Washington, DC. Attending evening or weekend events may also be required. Periodic travel (10%) may be required for legislative or event activities.

- 3-5 years of experience in health advocacy or direct legislative experience at the state and/or federal levels
- 1-3 years of program management experience, ideally in areas related to health policy, advocacy or community organizing
- Familiarity with the legislative process at the state and/or federal levels
- Minimum of bachelor’s degree; master’s degree preferred; educational background in the health sciences and/or public policy preferred
- Superb communication skills – must be a capable presenter and experienced writer
- Ability to prioritize, take initiative, think strategically and execute projects with limited supervision
- Commitment, passion and drive for advancing science-based policy and ensuring patients have a voice on Capitol Hill and in state capitols

Duties and Responsibilities:

- Plan, convene and run monthly webinars and lunches to inform and educate rare disease stakeholders about public policy issues
- Plan, convene and run quarterly Congressional briefings on Capitol Hill in coordination with the bicameral Rare Disease Congressional Caucus
- Provide content updates and manage the RDLA website (www.rareadvocates.org), community calendar and social media accounts
- Track state and federal rare disease policy issues
- Publish the monthly RDLA newsletter containing policy analysis, action alerts and community events
- Recruit and manage interns
- Manage voting records for RDLA’s Congressional Scorecards
- Assist in the coordination of RDLA’s Fly-In Rare Disease Week on Capitol Hill
- Assist in the coordination of In-District Lobby Days during the summer Congressional district work period
- Assist in the planning and management of the RareVoice Awards
- Act as a pro-bono consultant to patients in the rare disease community seeking advice on initiating legislative initiatives at the state and/or federal level
- Assist with creating action alerts for patient organizations
HOW TO APPLY

Submit a resume/CV, a policy-relevant writing sample and a concise cover letter indicating availability and salary requirement to jlally@everylifefoundation.org. Applications will be reviewed immediately.

MINIMUM EDUCATION REQUIRED:

4-year degree