Senior Director of Public Policy

The EveryLife Foundation for Rare Diseases (ELF) is seeking a Senior Director of Public Policy to lead our federal and state advocacy programs, focused on closing the innovation gap for rare diseases and ensuring patients have access to treatment and diagnosis opportunities.

The EveryLife Foundation is a science based advocacy organization dedicated to bringing treatments to the 30 million Americans with rare diseases. Currently, there are fewer than 400 approved treatments for 7000 rare diseases. The science exists for many of these diseases to be treated; however, treatments may never be developed because of roadblocks in the development process, such as a lack of investment and a challenging regulatory environment. The Foundation works with patient organizations, industry, academic scientists, the Food and Drug Administration (FDA), and National Institutes of Health (NIH) to improve the clinical development process.

Responsibilities

Reporting to the Executive Director, the Senior Director of Public Policy is a member of ELF’s senior staff and takes the lead in developing and implementing the organization’s policy agenda at both the federal and state level.

Responsibilities include, but are not limited to:

- Monitoring and analyzing relevant activity on Capitol Hill, in the executive branch, the Food and Drug Administration, National Institutes of Health as well as other US and International Health Agencies and relevant legislation at the state level;
- Providing strategic analysis and background for the development of ELF’s annual policy agenda on both a federal and state level, alongside any potential international policy issues related to drug development;
- Developing and implementing strategy for advancing policy goals with key decision-makers in the legislative and executive branches;
- Organizing the Advocacy efforts of ELF’s policy team and other staff who monitor and act on the national and state level policy agenda;
- Preparing and managing the budget for the Public Policy team;
- Leading the Foundation’s Newborn Screening, Community Congress, and Scientific Workshop programs and events;
- Working with the Board to write and publish white papers on policy related issues.

Qualifications

The Senior Director of Public Policy will have:

- A minimum of five years of related experience, preferably in health policy;
- Familiarity with the drug development process and strong scientific knowledge in this area;
- Demonstrated ability to analyze public policy proposals, including the drafting of legislative language;
- Experience in and comfort communicating with high level Congressional and executive branch policy-makers and staff;
• Ability to use data in shaping policy messages;
• Experience in coalition-building and working collaboratively in a team environment;
• Ability to communicate complex information clearly in writing and in oral presentations to a range of audiences;
• Previously published papers in academic journals;
• Strong organizational and interpersonal skills;
• Ability to think strategically;
• Experience in managing support staff;
• Master’s or higher degree in a related field preferred.

Compensation

This is a full-time, direct-hire position. Compensation is commensurate with experience and includes a competitive benefits package. This position can be based in Washington, D.C., or Novato, CA and will require some travel.

To apply, please send an up-to-date resume and cover letter with salary requirements to jlally@everylifefoundation.org