SENIOR DIRECTOR OF ADVOCACY

DESCRIPTION

The EveryLife Foundation for Rare Diseases (ELF) is seeking a Senior Director of Advocacy to join its leadership team in Washington, DC.

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 and the Board of Directors, the Senior Director of Advocacy is a key member of the Leadership team and will substitute for the Executive Director when the ED is unavailable.

Responsibilities include, but are not limited to:

- Responsible for all policy and patient engagement programs and initiatives.
- Three direct reports – Director of Policy; RDLA Program Manager; and Associate Director of Patient Engagement
- Provide support for all direct reports and be able to fill in for them when they are on vacation
- 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;
- Create & execute strategic plans for advancing policy at both the Federal and State Level
- Political advocacy campaign marketing – ensuring that policy objectives of the Foundation are presented in an honest and clear manner to the public to drive support for various forms of action.
- Oversee the Foundation’s RDLA, Newborn Screening, Community Congress, and Scientific Workshop programs and events
- Oversee all external communication from the Foundation and provide support in the crafting and editing of e-mails; newsletters; blog posts; action alerts etc
- Some weekend/evening work will be required

Qualifications

The Senior Director of Advocacy will have:

- Must have a background in health policy, grassroots advocacy and experience working with patients. Experience in regulatory or drug development policy is a bonus.
- Prior management experience;
- Experience crafting and managing a budget;
- Strong organizational and interpersonal skills;
- Ability to think strategically;
- Excellent communication skills including ability to write well, copy edit and speak publicly
• Master’s or higher degree in a related field preferred.

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

BENEFITS
This is a full-time, direct-hire position. Compensation is commensurate with experience and includes a competitive benefits package. This position is based in Washington, DC and will require some travel.

PROFESSIONAL LEVEL:
Senior Management

MINIMUM EDUCATION REQUIRED:
4-year degree