The EveryLife Foundation for Rare Diseases (EveryLife) is seeking a Director of Public Policy to join its team in Washington, D.C.

The EveryLife Foundation is a science based nonprofit, nonpartisan 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.

The Director of Public Policy is responsible for implementing federal and state policy and advocacy priorities and programs, focused on closing the innovation gap for rare diseases and ensuring patients have access to treatment and diagnosis opportunities. This position reports to the Chief of Policy and Advocacy.

**RESPONSIBILITIES**

- Monitor and analyze relevant activity on Capitol Hill, 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;
- Track state and federal rare disease legislation;
- Provide strategic analysis and background for the development of EveryLife’s annual policy agenda on both a federal and state level, alongside any potential international policy issues related to therapeutic product development;
- Implement strategy for advancing policy goals with key decisionmakers in the legislative and executive branches;
- Engage directly with policymakers in Congress and the Administration;
- Provide policy updates to patient organization and industry partners;
- Oversee planning, convening and running the Foundation’s Newborn Screening, Community Congress, and Scientific Workshop programs and events;
- Organize the advocacy efforts of EveryLife’s policy team and other staff who monitor and act on the national and state level policy agenda;
- Provide relevant content updates for Foundation’s website;
- Manage fellows and support staff;
- Facilitate engagement with coalition and industry partners;
- Draft articles, action alerts, papers, one sheets and various outreach items specific to EveryLife’s federal and state policy agenda.

**QUALIFICATIONS**

- 4-6 years Capitol Hill or Federal Government experience with a background in health policy, grassroots advocacy and working with patients; Experience in regulatory or drug development policy is a bonus;
- Strong organization and interpersonal skills;
- Ability to think strategically;
- Excellent communication skills including the ability to draft papers, copy edit, and speak publicly;
- Management experience preferred.
**BENEFITS**

This is a full-time, direct-hire position. Compensation for this position is commensurate on experience and includes a competitive benefits package. This position is based in Washington, D.C. and may require occasional travel, weekend and evening work.

**HOW TO APPLY**

To apply, please send a current resume, cover letter, salary requirements and three references to Megan Pinegar at mpinegar@everylifefoundation.org.

**MINIMUM EDUCATION REQUIRED**

4-year degree