

Barth Syndrome Foundation

Health Policy and Patient Advocacy Manager

Location: Remote (Washington, DC Metro Area Highly Preferred)

Reports To: Chief Executive Officer

Employment Type: Contract

Travel: Approximately 10-15%

Salary: Commensurate with experience (\$95k-\$130k)

About the Barth Syndrome Foundation

The Barth Syndrome Foundation (BSF) is dedicated to improving the lives of individuals and families affected by Barth syndrome, an ultra-rare genetic disorder, through research, education, advocacy, and support. BSF works to accelerate scientific discovery, improve access to care and treatments, and ensure the patient's voice is represented in healthcare and policy decisions.

In 2025, our community's advocacy contributed to an astonishing milestone: FDA approval of the first treatment for Barth syndrome, making us one of just 5% of rare diseases with an FDA-approved treatment. Building on this success, we are committed to supporting bipartisan legislation and partnerships that will improve outcomes for our rare-disease community. In strategic plan's fourth pillar, "Advocating for the Community," we commit to:

- Keep current with key elected officials, federal agencies, and media contacts
- Develop the next generation of advocates
- Contribute to ultra-rare disease policy work, as appropriate
- Use targeted help to support families with reimbursement and access

We are looking for a Health Policy and Advocacy Manager with deep expertise in government advocacy and relations, the ability to build effective relationships across political groups, and a strong sense of community. This is a flexible, remote, contract position.

Position Summary

The Health Policy and Advocacy will build and expand a growing advocacy program that directly impacts people living with Barth syndrome. The manager will help shape policy, strengthen patient engagement, advance access to care and treatments, and ensure the Barth syndrome community has a strong voice in decisions that affect their lives. They will lead execution of "Advocating for the Community," one of the five pillars of BSF's 2026–2028 Strategic Plan.

This individual will leverage their knowledge of and existing relationships with congressional offices and federal health agencies to inform BSF's advocacy priorities, build and grow grassroots advocacy initiatives, train community members to become effective advocates, support regulatory and policy activities, and advance efforts to improve access to care, treatments, research, and support services for individuals living with Barth syndrome. They will have experience engaging with a variety of groups, including patients, families, caregivers, policymakers, and coalition partners.

Key Responsibilities

Legislative, Regulatory, & Policy Initiatives

- Serve as BSF's primary point of contact for congressional outreach, leveraging existing personal relationships with Hill staff to secure meetings, co-sponsorships, and support for BSF priorities.

- Plan and lead Hill visit logistics, including staffing meetings personally where existing relationships make that most effective.
- Track legislative developments (bill introductions, appropriations cycles) relevant to rare disease and translate them into actionable guidance for BSF leadership and our advocate network.
- Own and drive execution of federal advocacy campaigns tied to specific legislative or regulatory targets (e.g., NIH funding asks, orphan drug policy, rare disease coalition priorities).
- Represent BSF in rare disease coalitions (e.g., Mitochondrial Disease Advocacy Coalition, Rare Degenerative Disease Alliance, etc.) and identify opportunities to co-sponsor or co-lead initiatives with aligned organizations, bringing value to our partners' efforts and positioning reciprocal support for BSF strategic initiatives on the Hill and with the FDA.

Community Advocacy & Engagement

- Shape BSF's advocacy priorities, strategic milestones, and annual advocacy plan, in direct alignment with the "Advocating for the Community" pillar of BSF's 2026–2028 Strategic Plan.
- Lead Barth Syndrome Awareness Day bipartisan endorsement and community mobilization efforts for national and international awareness of the needs of our community
- Recruit, train, organize, and support a network of volunteer advocates capable of engaging their own members of Congress in a nationally coordinated advocacy effort.
- Maintain a working stakeholder map of key congressional health staff, committee contacts, and relevant agency officials, updating it as relationships evolve.
- Help prepare patient-focused testimonies, comment letters, and briefing materials for maximum impact with FDA and legislative audiences.
- Develop advocacy materials and toolkits, educational resources, and action alerts.

Communications & Reporting

- Collaborate with BSF team members on advocacy messaging, newsletters, social media, and outreach materials.
- Track advocacy activities, community engagement, and outcomes against established milestones.
- Maintain constituent records and prepare reports for Foundation leadership.

Qualifications

Education

- Bachelor's degree in Public Policy, Government Affairs, Political Science, or related field.

Experience

Required:

- 5+ years of experience in federal advocacy or government relations, with direct professional experience in a congressional personal office, committee staff position, or federal health agency (FDA, NIH, or HRSA).
- Demonstrated, current relationships with congressional health staff and/or federal agency officials that can be activated on BSF's behalf.
- Proven track record of engaging with the public and having constituents feel heard, respected, and valued.
- Experience translating complex scientific/regulatory information for legislative and lay audiences.

Strongly Preferred:

- Rare disease, orphan drug policy, or patient organization experience.
- Multi-stakeholder coalition leadership experience.

Skills & Knowledge

- Deep understanding of federal legislative and regulatory processes, gained through direct Hill or agency experience.
- Knowledge of healthcare policy, patient advocacy, and rare disease issues.
- Strong relationship building, communication, and public speaking skills.
- Experience developing advocacy materials and training programs.
- Excellent project management and organizational abilities.
- Ability to work independently in a remote environment.

Why Join BSF?

We firmly believe that people do their best work when they are encouraged to have balance in their lives and exercise agency in the conduct of their job-based activities. We are a completely virtual work environment (which we have done successfully for 21 years) and value flexibility, collaboration, and inclusivity.

BSF is an equal opportunity employer and prohibits employment discrimination based on race, color, gender, age, religion, sexual orientation, ethnic or national origin, disability, veteran's status or any other protected status. We are committed to attracting and retaining professionals who bring diverse perspectives and talents to achieving our mission. Importantly, all BSF employees must be completely bought into our mission and recognize their invaluable role as BSF representatives within and outside of the organization.

Interested in Applying?

Send email with resume to emily.milligan@barthsyndrome.org with subject "Applicant for Health Policy and Patient Advocacy Manager".