

LEH 84

NHF's State Advocacy and the Bleeding Disorders Community

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Submission Group

Law/Ethics/Health Policy

Abstract

Objective: NHF Chapters must develop, support, and sustain influential advocacy programs to protect and enhance access to health care for the bleeding disorders community. **Method:** NHF supports the development of state health care policy advocacy programs with in-kind and financial assistance. NHF's State-Based Advocacy Coalition (SBAC) program and the standard advocacy expectations our Chapters are the pillars of a robust framework of state advocacy programs. The standard advocacy expectations provide clear expectations and identify best practices for advocacy programming. These include: an advocacy committee of staff and volunteer advocates that meets monthly, multi-year strategic planning, clear engagement with legislative and administrative policymakers, an advocacy annual budget, and more. Chapters are also expected to actively engage their network of Hemophilia Treatment Centers, and all Industry partners. The SBAC program provides funding and in-kind support from NHF for chapters to either start an advocacy program or grow and maintain an advanced one, using the standard advocacy expectations as a guide. NHF provides extensive in-kind support for SBAC grantees, as well as assisting all other chapters with their specific advocacy needs. **Summary:** Since the inception of the SBAC program NHF has seen participation by and enthusiasm among community members in advocacy events and programming grow. Nearly 500 volunteers participated in NHF's Washington, DC Days in recent years. Chapter run State Advocacy Days are more prevalent and well-attended. At least 1000 advocates now travel to their state Capitol each year to participate in chapter Advocacy Days. There are 15 grantees participating in the SBAC program covering 20 states. Collectively, NHF has trained more than 5,000 volunteer advocates across the country. Increasing numbers of volunteer advocates have turned out in state capitols for several years to make their voices heard and influence health care access. In addition, NHF's investments in public policy resources have allowed us to encourage and support state regulatory advocacy, e.g. with state Medicaid offices. These new efforts have demonstrated tangible results in the form of protecting and enhancing patients' access to care. The promotion and support of state chapter advocacy programs by NHF, especially among the SBAC-participating states, has advanced the public policy interests of the bleeding disorders community. Objectively, we've seen the increased numbers and enthusiasm of volunteer advocates. Anecdotally, there are many stories of chapters playing a key role in state health care policy, **Conclusion:** Successful state advocacy work has led to improved access to quality healthcare. Start-up and ongoing support from NHF have played a critical role in that success. The continued refinement of our Chapter standard advocacy expectations and in-kind support of NHF policy staff will continue to be key to advancing state advocacy programs uniformly around the country.