

What is Advocacy?

Advocacy means supporting a cause by pleading or arguing in its favor.

Advocacy may be as simple as making sure you as an individual get the care you want and need – being an advocate for yourself.

For many people, however, advocacy involves a broader scope — being an advocate for the hemophilia community.

Advocacy may mean working with legislators, regulators, insurance companies, or healthcare organizations.

Advocacy work may occur at the local, state or national level. Whatever the scope or level, there are several important steps for any type of advocacy work.

Step 1: Be informed

The first step in any type of advocacy work is learning. Gather as much information as possible about an issue. And don't forget that the world of hemophilia is always changing, so you'll need to keep learning. Being informed is a continuous process.

How do you start? Your local or state hemophilia organization can also help with providing current research about a wide range of medical, political, and financial issues relating to hemophilia.

Step 2: Identify resources

As you learn, you will also begin to identify resources that can help with your advocacy effort. If you are considering a legislative initiative, you will find that a successful legislative campaign requires strategic coordination. Hemophilia chapters and organizations may be in the best position to coordinate these efforts by ensuring that consumers, healthcare professionals, and medical providers are all actively engaged in the process.

Washington Days, the National Hemophilia Foundation's annual legislative conference, offers many ways to learn about and be involved in the legislative process. This event includes meetings with legislators, educational updates and briefings, and advocacy training sessions.

Step 3: Get started

The landscape for hemophilia — legislation, reimbursement, medical advances — is constantly evolving. With all the changes occurring, it is more important than ever to get involved in finding solutions and ensuring options for the hemophilia community.