



Washington Days Frequently Asked Questions

Who should come to NHF's Washington Days?

NHF's Washington Days is an opportunity for people affected by bleeding disorders to advocate for issues that matter to them. This includes people with hemophilia, von Willebrand disease (VWD) and other bleeding disorders; parents, children and teens—both can be great advocates—and other family members. Friends, treatment center staff and anyone who is involved in and cares about the bleeding disorders community are also encouraged to attend.

What happens at NHF's Washington Days?

Wednesday evening there will be two training sessions – one on maximizing your experience and how to effectively use social media for advocacy, and one on issues and logistics. Dinner will be provided following the second session. On Thursday, we'll hit Capitol Hill. All participants will have a full day of meetings scheduled, usually together with people from the same state. Some meetings will be with the legislators themselves; others will be with a member of their staff who deals with healthcare issues. Wherever possible, you will visit with your own representatives and others from your state, although you may be asked to visit other offices as well.

Do I have to make my own appointments?

NHF schedules your meetings with the offices of your two US Senators and your member of the House of Representatives. Again, you will travel as a team with other delegates from your state to each meeting. We will use your zip code to determine your member of Congress.

What if I've never done this before?

If you've never attended NHF's Washington Days before, this is an important time to start. The community is facing significant challenges to access to care, and we need your voice. The great thing is, no experience is necessary. All participants will receive training on how to present the issues. The most important thing you can do as an advocate is tell your own story. One important thing to remember is that you will not be alone for any meetings; you will be joined by the other NHF community members from your state, and in some cases NHF staff or leadership.

What issues will we be advocating for this year?

Our advocacy this year will focus on the debate surrounding the repeal and replacement of the Affordable Care Act (ACA). We'll discuss the ways that the ACA has affected the bleeding disorders community and ask that important policies be maintained. We'll also be discussing the replacement proposals and the ways that they might harm or hurt people with bleeding disorders. Since the ACA situation is evolving daily, we will brief participants on the latest ACA developments and share the detailed policy issues during the Wednesday evening training. We will also wear red ties in honor of the Red Tie Challenge and Bleeding Disorders Awareness Month and include materials about HTCs and the federal programs that support them in our leave-behind materials.

Is there anything I need to prepare in advance or bring with me?

Since this is mostly about telling your story, not much preparation is needed. In the past, many participants have brought copies of pictures of children and other affected family members as a way of personalizing their story. Others have brought copies of the explanation of benefits (EOB) from their insurance company to emphasize how expensive bleeding disorders are. Since our advocacy will mainly focus on the issues relating to protections provided under the Affordable Care Act (ACA), you can begin to think about how you would explain how ACA policies like the elimination of lifetime and annual caps and elimination of pre-existing conditions exclusions have mattered to you and your family. We will be providing talking points and materials about our advocacy issues and will explain them in detail during the Wednesday evening training.

What should I wear?

Congressional staffers dress professionally. Most of them wear suits or dress slacks and ties. Most people feel comfortable wearing similar clothing but certainly don't rush out and buy a suit if you don't have one. A dress pants, a button down shirt and a tie will work just fine for most men. Women often wear a dress pants or a skirt with a shirt or sweater. We will provide red ties for you to wear in your meetings. Please do wear comfortable shoes. There will be lots of walking!