

What is advocacy? Your voice!

Advocacy is your voice being heard by elected officials on issues that directly impact our community. We want to make sure that the needs of those with inherited bleeding disorders are met at both the state and federal level; our needs range from access to factor products to prevent and treat bleeding episodes to assuring that policies, regulations, and laws help people with Inherited bleeding disorders live healthy, productive lives.

Advocacy begins with you. First, in educating yourself about key issues, laws and regulations that impact your daily life and second, learning how to speak up and out for what you need. **We can empower you and help you develop the skills you need to take action.**

Advocacy means representing all members of our inherited bleeding disorders community by creating lasting and meaningful relationships with each other and our wider communities – not just elected officials. **Raising awareness of what inherited bleeding disorders** are, and what our daily lives look like among our friends, in our neighborhoods and towns helps to bring attention to our issues. We need everyone who believes in us, and in our issues to join us in advocacy – there is room for all to help.

This advocacy guide contains the basics for self-advocacy, but is not all-inclusive; additional advocacy resources are available on the National Hemophilia Foundation's website (<https://www.hemophilia.org/Advocacy-Healthcare-Coverage>) and the Hemophilia Federation of America's website (<http://www.hemophiliafed.org/advocacy/>).

Why do we need to advocate for inherited bleeding disorders in Virginia?

Our General Assembly delegates and senators are **citizen legislators**. That means, they either have “day jobs” or are retired persons. The Commonwealth compensates them at approximately \$17,000 per year, so you can see, they are motivated to serve by more than financial reward. This also means, there is no way for them to be an expert in absolutely every issue area over which they govern.

Our legislators (and their staff) are in influential positions to create policy, raise money, allocate funds, and make the laws by which we live, work, and play. We, on the other hand, are in an influential position because we vote for our legislators, and if we do not like the positions they take and believe they are not providing the right leadership for us, we can vote them out of office. That means

that **legislators will listen to the constituents who vote for them, because they want to be re-elected.**

Legislators vote on thousands of issues during each session of the General Assembly. They count on their constituents and lobbyists to provide the information they need to make informed decisions on which positions to take. This is where advocacy comes in – **we have the ability and responsibility to educate legislators by telling our stories** of how current and proposed legislation will impact our lives. Your role in this effort is to help provide them with the information that will help them make informed decisions on issues that our community is supporting or opposing.

How do I know what advocacy issues are important to my community?

If you live with hemophilia or an inherited bleeding disorder, you've experienced firsthand what issues are important to you. These may be concerns related to appropriate healthcare insurance and factor availability or such things as learning to live as a productive citizen, access to a good public education, and employment opportunities. These, and more, are opportunities to hone your advocacy skills.

Advocating by yourself is a tough job. This is why, getting to know others in the bleeding disorders community is vitally important – building a support system helps you feel connected and realize we all face similar issues. Talk, consult national bleeding disorder websites, and figure out, together, what issues impact your daily life.

Who is the ideal grassroots advocate/activist?

Citizen activists who become excellent grassroots advocates have much in common with their Virginia legislators. We live in the same geographic areas, may know some of the same neighbors, and may attend the same place of worship. **Most of all, citizen activists and legislators are all citizens.**

Why is knowing this information important?

It's important because you may already have an "in" with your legislator that you can use to increase your visibility and influence. Furthermore, unless the legislator is a person with hemophilia, married to a person with hemophilia, or has close contact with people with hemophilia or inherited bleeding disorders, he or she is not likely to know very much about our issues and concerns. You can provide information on the subject from your perspective. **As a grassroots advocate, your aim is to become your legislator's "best friend"** when it comes to this information. Grassroots activists also work to get their legislators elected and

re-elected in a variety of ways including campaign contributions, distributing literature, phone calling and working at local polling places.

How do you know you've become a key contact on inherited bleeding disorders for a legislator?

You call your legislator's office, are greeted enthusiastically by his/her aide by your first name, and can reasonably expect a return call by the legislator within 30 minutes. ***This is a major accomplishment!***

What are 10 tips for advocating for hemophilia?

1. Try to find out as much as you can about your elected officials before your visits. Google them!
2. Be prepared. Know our community's issues, know bill numbers.
3. Talk with your legislators early, optimally between General Assembly sessions. Get to know them before you need them.
4. Present both sides of the issue, but explain why your position is good public policy.
5. Be prepared with some anecdotes that help to illustrate your story.
6. Stick to the issue. See #7.
7. Do not debate your legislator on other issues like taxes, transportation or other unrelated issues.
8. Be completely honest. If you don't know the answer to a question that your legislator asks, tell him/her that you'll find the answer. Then do the searching and get back with them.
9. If your legislator doesn't agree with your position, pleasantly agree to disagree, while offering to be a resource.
10. Do not make any contribution to the legislator or candidate's campaign during your visit.

How do I contact my legislators?

Virginia General Assembly (<http://viriniageneralassembly.gov/>): This is the General Assembly homepage. It will take you on your trip throughout the General Assembly and link you to the state budget, constitution, laws, and regulations.

Who is My Legislator (<http://whosmy.viriniageneralassembly.gov/>): If you do not know who your legislators are, click on this URL. You'll need to put your street address and zip code into the spaces provided, and your state delegate and senator's names and web pages will come up. From there, you can find out your legislators' email addresses and district and Richmond phone numbers (for out-of-town legislators, the Richmond numbers work only during the General

Assembly session). On this site, you can also see the contact information for your Congressman and Senators.

How do I contact my legislator by phone during the legislative session?

When the General Assembly is in session (from approximately January 10 – March 10 depending on the year), call your legislators' Capitol numbers (found on the contact information link above).

How do I contact my legislators by phone between legislative sessions?

From March until January you can contact them by using their district numbers. See link to finding your legislator for this information.

How do I contact my legislator by email during the legislative session?

To find an email address

- Virginia General Assembly website (<http://virginiageneralassembly.gov/>)
Click on the link to the House of Delegates and Senate. Or click on (<http://whosmy.virginiageneralassembly.gov/>)

Include in your message:

- In the subject line, place the bill number and your position (support or opposition).
- In the body, state why you are writing in support or opposition. A couple of sentences is all you need.
- Be sure to include your name and snail mail address (to let them know that you are a constituent).

Do not send emails to legislators other than your delegate or senator unless you have received specific directions from Virginia Hemophilia Foundation.

How and when should I contact the Governor?

The Governor, as head of the Executive branch, is vested with the authority to carry out the laws enacted by the General Assembly. He/she develops the biennial budget and proposes budget amendments in the second year of each biennium. The Governor has veto power and line-item veto power for the budget, but his vetoes can be overridden by a 2/3 majority vote of each house.

Often advocates forget to “lobby” the Governor to sign a bill, and sometimes that can be a big mistake. For example, each year the Governor vetoes any number of bills that he/she finds objectionable for ideological, constitutional, or other reasons. So it’s important for advocates to make themselves heard when

they are supporting a bill or budget amendment that is inserted by the General Assembly.

To contact the Governor

- (<http://www.governor.virginia.gov>) and follow the hyperlink to the contact page (<https://governor.virginia.gov/constituent-services/communicating-with-the-governors-office/>). Simply fill in the page. If you are advocating for a specific measure, be sure to indicate the bill number or the budget item number.

What state agencies are involved in hemophilia and inherited bleeding disorders, and how can I find them?

State agencies with responsibility for hemophilia and other inherited bleeding disorders are part of the Executive branch of government. Each agency/entity is described below.

- **Secretary of Health and Human Resources** (<http://hr.virginia.gov/>) is the cabinet position to which departments responsible for Medicaid, public health, social services, health professions, and aging report. Each Governor appoints the Secretary for Health and Human Resources. A complete listing of the state agencies that are part of Health and Human Resources can be found at (<http://hr.virginia.gov/agencies/>).

Of particular interest for our community are the following:

- **Department of Medical Assistance Services (DMAS)** (<http://www.dmas.virginia.gov/>) is the state Medicaid agency. As such, it administers the Medicaid program. To see if you're eligible for Medicaid and what services are offered through DMAS visit this website.
 - **Virginia Department of Health** (<http://www.vdh.virginia.gov/>) is state public health agency. It provides support for the Virginia Bleeding Disorder Program (<http://www.vdh.virginia.gov/bleeding-disorders-program/>) as well as information on vaccinations and other infectious and communicable diseases.
 - **Department of Social Services (DSS)** (<http://www.dss.virginia.gov/>) is responsible for determining eligibility for Medicaid. In addition, DSS administers or partners with other state agencies in such areas as child support, child protective services, adult day care centers, licensing of assistive living facilities, neighborhood assistance programs, and many other services. DSS operates local offices throughout the Commonwealth.
-