



WHAT CAN YOU DO?

Your voice is critical to our efforts to restore federal services and support for the hemophilia treatment centers and access to care for bleeding disorders patients.

Contact Your Congressman & US Senators

Look up your representatives – if you don't already know who represents you, look it up at GovTrack.us

There are four primary ways you can contact your representatives:

1. Call their office
2. Schedule an in-district meeting
3. Conduct an in-district drop by visit
4. Submit your comments via email

1. Calling Your Member of Congress

Find their office number on their website (if you use GovTrack.us the number is provided) or call the Capitol Switchboard at (202) 224-3121 and ask to be connected.

When calling:

- Ask to speak with the staff responsible for health policy
- Introduce yourself – clearly state your name, where you live and that you are a constituent
- Identify the issue – state what you're calling about and your position, include a personal story
- Make a clear ask – request a specific action and ask if the Member supports this position
- Provide your contact information – request a return call or written response to ensure your voice is heard

2. Visiting Your Representative In-Person

Find your Representative's local office. Call the office and ask how to schedule a meeting. Most likely you will need to email the scheduler or submit an online form to make your request.

When making your request be sure to include your name, organization (if applicable), purpose of your visit, names of all the participants, your available days & times and your contact information (include your address so they can verify you are a constituent.)

At the meeting:

- Introduce yourself – clearly state your name, where you live and that you are a constituent



- Share Your Story – personal experiences help the issue to be relevant and have greater impact
- Make a clear ask – request a specific action and ask if the Member supports this position or action
- Answer questions honestly – if you don't know the answer, offer to research & follow up later
- Offer to be a resource – let the Member or staff know you're available for future discussions on this and related issues

After the meeting:

- Send a thank you email – reiterate key points and thank them for their time
- Provide follow up information – if there were any outstanding questions, include the requested information
- Keep in touch – stay engaged with the legislator's office to build a lasting relationship (ideas include signing up for their email list and attending local town hall meetings)
- Capture the moment & post on social media – snap a photo or selfie at your meeting (with permission if inside the office) and post it on social media, tagging and thanking the Member
- Let us know – follow up with your local chapter and HCC to let us know who you contacted and how your meeting went. You can also tag us in your social media posts.

3. Conducting a “Drop by” Visit

If you cannot schedule a meeting, you can still participate by dropping off materials at the office during business hours.

To drop by:

- Find your representative's local office on their website or use [GovTrack.us](https://govtrack.us)
- Bring informational materials – have a one-page document summarizing the key issues and your request
- Ask staff to pass along your materials – there should be staff monitoring the reception area, politely introduce yourself with your name and where you're from (be sure to identify as a constituent), explain why you are there and ask them to pass along the materials
- Follow up – Get a business card for the appropriate staff person and send an email to confirm the materials were received
- Capture the moment & post on social media – snap a photo or selfie at the office (with permission if inside the office) and post it on social media, tagging and thanking the Member
- Let us know – follow up with your local chapter and HCC to let us know who you contacted and how it went. You can also tag us in your social media posts.



4. Send an Email

While the other methods are likely to have greater impact, if you can't call or visit the office, you can also send an email. To send an email:

- Find your representative's local office, use [GovTrack.us](https://govtrack.us) – the website should have an email or online contact form
- Introduce yourself – clearly state your name, include your full address and identify as a constituent
- Identify the issue – state what you're calling about and your position, include a personal story
- Make a clear ask – request a specific action and ask if the Member supports this position or action
- Provide your contact information – request a return call or written response to ensure your voice is heard

WHAT DO YOU SAY?

There are three critical issues facing the bleeding disorders community right now. You can choose to discuss one, two or all three – that you feel comfortable discussing or which most connects to your personal experience. While these are simple talking points, you can expand them using the leave behind documents, which you can also share directly with your Representatives and their staff.

Save Medicaid

I am a person living with [Name your bleeding disorder or your connection to the bleeding disorders community. Share some of your story briefly].

I care about Medicaid. Medicaid helps [me/people with bleeding disorders] get the services they need. Medicaid helps keep people with bleeding disorders out of the emergency room and hospitals, as well as making it possible for [me/them] to avoid missing school and work.

17 million people with disabilities and older adults use Medicaid to pay for their health care. Over 6 million kids with disabilities have Medicaid as their health insurance. Medicaid pays for 70% of long-term health services—most of these services are not covered by Medicare or private insurance. Medicaid is critical for children's hospitals and to our entire system of pediatric care. People with private insurance will also be hurt by cuts to Medicaid.



I urge you to do everything in your power to protect Medicaid. Cuts to Medicaid of any kind—through FMAP changes, work requirements, block grants, or per capita caps—are unacceptable. Please do not vote to cut Medicaid!

The Elimination of the Division of Blood Disorders

I am [calling/visiting/emailing] as a member of the bleeding disorders community and as a constituent to ask that you protect the federal hemophilia programs at the CDC. The recent HHS restructuring eliminated essentially all of the staff at the CDC's Division of Blood Disorders, where the hemophilia programs are housed. These programs:

- *Help to collect important data on bleeding disorders, which in turn helps lead to new and more effective treatments.*
- *Provide funding for education and outreach to increase patient and provider understanding of hemophilia.*
- *Help to protect the safety of our nation's blood supply.*

I am relying on you, as my Senator/Representative in Congress, to take action to ensure that the staff for this program are reinstated and to work to protect the funding for this critical program.

Reauthorization of the Enhanced Tax Credits

I am [calling/visiting/emailing] as a member of the bleeding disorders community and as a constituent to ask that you reauthorize the enhanced tax credits passed by Congress in 2020. For our family, health insurance is a necessity. Every family should be able to afford quality health insurance, regardless of their income or zip code. Unless Congress acts soon, millions with pre-existing conditions (like hemophilia) who purchase their insurance on the marketplace will lose access to care.

I am relying on you, as my Senator/Representative in Congress, to take action to ensure that these enhanced tax credits are reauthorized.

RESOURCES

Thanks to the United States Hemophilia Treatment Center Network (US HTC�), the Hemophilia Federation of America (HFA), the National Bleeding Disorders Foundation (NBDF) and the Plasma Protein Therapeutics Association (PPTA) for their important work on these issues. These resources were compiled from materials produced by these partners and other trusted sources.

[US HTC�](#)

[Hemophilia Federation of America](#)

Join the [HFA Advocacy Network](#)



[Report your advocacy to HFA](#)

[CDC Reductions Mobilization Playbook](#)

[CDC Reductions Leave Behind](#)

[National Bleeding Disorders Foundation](#)

[Subscribe to emails](#)

[Protein Plasma Therapeutics Association \(PPTA\)](#)

[Federal Advocacy Resources](#)

CONTACT:

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SHARE ON SOCIAL MEDIA

Twitter/X/BlueSky Posts:

Example 1: Just met with @[RepresentativeHandle] to urge action on the CDC cuts that eliminated the Division of Blood Disorders. We must protect blood safety monitoring and surveillance like Community Counts. #SaveCDCBloodDisorders

Example 2: Congress is rushing to recklessly cut Medicaid. Children, seniors and the disabled will lose coverage and all of our costs will increase. #SaveMedicaid

Facebook Posts:

Example 1: Just met with @[RepresentativeHandle] to urge action on the CDC cuts that eliminated the Division of Blood Disorders. We must protect blood safety monitoring and surveillance like Community Counts. #SaveCDCBloodDisorders

Example 2: Congress is rushing to recklessly cut Medicaid. Children, seniors and the disabled will lose coverage and all of our costs will increase. #SaveMedicaid

Instagram Posts:

Example 1: Just met with @[RepresentativeHandle] to urge action on the CDC cuts that eliminated the Division of Blood Disorders. We must protect blood safety monitoring and surveillance like Community Counts. #SaveCDCBloodDisorders

Example 2: Congress is rushing to recklessly cut Medicaid. Children, seniors and the disabled will lose coverage and all of our costs will increase. #SaveMedicaid

HASHTAGS

#SaveCDCBloodDisorders

#SaveMedicaid
#ProtecttheACA
#Hemophilia
#BleedingDisorders
#PatientAdvocacy

HANDLES

In addition to the sample posts listed above, you may also tag these accounts in your tweets and/or graphics.

X: @HemoCouncilofCA @nbd_foundation @hemophiliafed

Instagram: @HemoCouncilofCA @nbd_foundation @hemophiliafed

Facebook: @HemoCouncilofCA @NationalBleedingDisordersFoundation, @hemophiliafed

LinkedIn: @hemophilia-council-california, @nbd, @hemophiliafederationofamerica

GRAPHICS

