Your Future, Our Mission WASHINGTON Our DAYS NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders

YOUR HEALTH! YOUR FIGHT! YOUR VOICE!

National Hemophilia Foundation's 2023 Washington Days – Welcome Webinar Advocacy Training







OUR MISSION NUESTRA MISIÓN

The National Hemophilia Foundation (NHF) is dedicated to finding cures for inheritable blood disorders and to addressing and preventing the complications of these disorders through research, education, and advocacy, enabling people and families to thrive. La Fundación Nacional de Hemofilia (NHF) se dedica a encontrar curas para los trastornos sanguíneos hereditarios y a abordar y prevenir las complicaciones de estos trastornos a través de la investigación, la educación y la abogacía permitiendo que las personas y familias prosperen.



ATIONAL HEMOPHILIA FOUNDATION for all bleeding disorders

BOMARIN

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THANK YOU TO OUR SPONSORS

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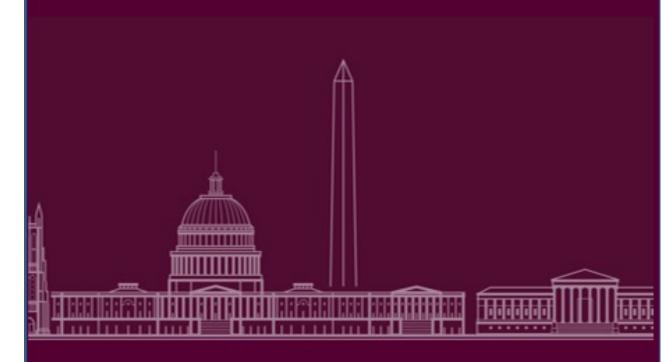








Biotechnology Innovation Organization



How does this work? What can I expect?



- Leave the policy materials and the meeting schedules to us!
- All of you in your groups will have a schedule of meetings for the day.
 - Please do not deviate from this schedule. You will meet with your groups ahead of time to discuss!
- We will also have trainings ahead of your meetings, and on Friday morning to recap and how you can bring the enthusiasm back to your communities!
 - This training won't go past noon, we know this can be a big week, but stick with us!





Members vs. Aides

Most times, you will not be able to meet with your Representative. However, do not think that meeting with a staffer is a waste! Oftentimes, speaking to a staffer may be **more effective** than speaking with your representative directly!

Guidelines to a Successful Office Visit

- **<u>Constituency matters!</u>** This is why you will talk amongst your groups before your meetings.
- <u>Time is of the essence:</u> Typically, you will have between 15-25 minutes for your meeting.
- <u>Use an ice-breaker</u>: It's okay (and encouraged) to ask a staff member "How much do you know about bleeding disorders? This can help guide the conversation and help you focus on particular impacts in your story.







Remember.. Only YOU can tell your story!

This is where visuals and photos really matter! Now, don't bring your entire photo album, but a few that can help congressmembers or staff members truly visualize your story.

- Photos of factor or treatment, or your treatment regimen.
- Ultimately, this is all up to you and what you're comfortable with, but it DOES make an impact.





We are here to support you!

• This will NOT be the last training ahead of going into meetings, we are just getting started! We have multiple opportunities for training and learning ahead of going with your groups on the 9th!

Wednesday, March 8 4:30 PM - 6:30 PM Hill Visits and Issues Training

Wednesday, March 8 6:30 PM - 8:00 PM Dinner with State Team

Thursday, March 9 8:30 AM - 9:30 AM Legislative Briefing (to be held at the Hyatt)

Thursday, March 9 until 4pm

Thursday, March 9 4:00 PM - 6:00 PM Optional Post-Appointment Check-In

Friday, March 10 9:00 AM -12:00 PM Advancing Your State's Advocacy Agenda



Some Additional Tips...

- Remember, not knowing is okay! Your group will support you; we will support you, and it can be helpful for follow-up
- Keep the connection going!





NYCHemophiliaChapter @NYCHemophilia

Thank you to Juan Negrete in @SenSchumer's office for meeting with NY #bleedingdisorder families yesterday to talk about protecting access to healthcare for people with pre-existing conditions. #NHFWD #RedTieCampaign



THANK YOU!

We can not do this without you! Whether you've advocated before, or if this is your very first time... YOU make a difference!

We are about to go over the issues... so don't fret! Allsun will also be covering how social media can be a powerful advocacy tool, and how we plan to share the same message across Washington.

If you have any questions, please put them in the Q&A section. We can't wait to see you in Washington, DC!



The Issues





WASHINGTON DAYS ISSUES



Washington Days 2023 will focus on:

- Educating Members of Congress about bleeding disorders awareness and federal programs (including funding) that benefit our community
- Seeking support for H.R. 830, the HELP Copays Act



Bleeding Disorders 101

- Start meetings with introductions and explain how bleeding disorders affects you/your family:
 - What bleeding disorder affects you/your loved one?
 - Where do you get care the name/location of your HTC?
 - What is your daily life like?
 - What worries you about living with a bleeding disorder?
- Our community is a model for policies affecting other high-cost chronic conditions



Federal Hemophilia Programs: CDC Background

Centers for Disease Control and Prevention (CDC): CDC protects America from health, safety and security threats and fights disease

Bleeding disorders activities

- Funding for HTCs for data collection and research, i.e., Community Counts project
- Funding for patient education and outreach programs, and for the lab and research done by CDC staff



CENTERS FOR DISEASE CONTROL AND PREVENTION



Federal Hemophilia Programs: HRSA Background

Health Resources and Services Administration (HRSA): grants and programs to improve health care for people who are geographically isolated or economically or medically vulnerable

Funding for HTCs to provide critical, multi-disciplinary services not usually reimbursed by insurance, such as PT assessment, case management, and social work services

HRSA administers the 340B Drug Discount Program

- HTCs are eligible to participate in program due to HRSA grant Program income helps stretch "scarce federal resources" and support multi-disciplinary, comprehensive care provided to all patients





Health Resources & Services Administration

Federal Hemophilia Programs: NIH Background

National Institutes of Health: NIH is the nation's medical research agency — making important discoveries that improve health and save lives

Important Initiatives:

2018 State of the Science meeting to develop research agenda to prevent and eradicate inhibitors

New research on development of inhibitors starting with pregnancy Supported genetic testing for My Life, Our Future participants

Support overall funding for NIH



National Institutes of Health





Federal Funding Update



- Fiscal Year 2023 (FY23):
 - Congress passed and the President signed the FY23 Omnibus bill in December 2022
 - Funding for hemophilia programs mostly remained the same as FY22:
 - \$5.1 million for HTCs (CDC, Division of Blood Disorders)
 - \$3.5 million for hemophilia activities (CDC, Division of Blood Disorders)
 - \$4.9 million for hemophilia Program (HRSA)
- FY24 (starts 10/1/23)
 - President Biden's budget expected in early March
 - Congress will start consideration in March





CENTERS FOR DISEASE CONTROL AND PREVENTION





Federal Programs: The ASK

- Support federal programs at CDC, HRSA, and NIH that benefit the bleeding disorders community by:
 - Ensuring that specialized care is accessible to people with bleeding disorders
 - Supporting research and data collection to improve treatment and prevention strategies

What are accumulator adjustor programs?

- A plan's accumulator tallies up a person's co-pays and cost-sharing up to their deductible and out-of-pocket (OOP) maximum
- Accumulator adjustor programs disallow co-pay assistance from counting towards OOP max





UNINTENDED CONSEQUENCES:

Patients are being targeted by health plan programs that undermine the benefits of copay assistance for medicines.

Copay accumulator adjustment programs and the essential health benefits loophole unfairly hurt patients who depend on medicines and have no other options by:



Targeting the most vulnerable patients

The largest burden falls on the sickest and most financially vulnerable patients, including those suffering from serious illness, low-income patients and people of color. Those patients rely on copay assistance, but accumulators cut that lifeline and leave patients exposed.



Undermining coverage for pre-existing conditions

By creating a backdoor way to erode coverage for seriously ill patients, big companies avoid paying for critical care for their employees. This undercuts care for those with pre-existing conditions.



Shifting costs to the sickest patients

When more costs are transferred to the sick and vulnerable, those patients lose access to lifesaving medications—driving down drug adherence and resulting in other more costly health issues.





What we want and why?

- All co-pays should count towards a person's deductible and out-of-pocket max
- Accumulator adjustor programs should not be allowed
- Without access to co-pay assistance, people may stop taking their meds or reduce doses → complications (i.e., increased ER visits, joint bleeds/damage, and missed days from work/school) that harm patients and increase overall costs.







How can policymakers help?

- Definition of "cost-sharing" can be changed by Administration
 - Include co-pays paid by assistance programs
- Notice of Benefit and Payment Parameters (NBPP) Rule implements the Affordable Care Act and sets annual rules for private insurance
 - Proposed 2024 NBPP did not include this policy

Our ASK: The HELP Copays Act

The Help Lower Patient Copays Act (HELP Copays Act) would make two very important policy changes:

- 1. Clarifies the ACA definition of cost-sharing, deductible, out-of-pocket maximum, co-insurance to ensure payments made "by or on behalf of" patients
- 2. Closes the EHB loophole to ensure that any item or service covered by a health plan is considered part of their EHB package, thus any related cost sharing counts



FAQ About the bill

- Who introduced the bill?
 - Rep. Earl "Buddy" Carter (R-GA) and Rep. Nanette Barragán (D-CA) in the House
 - We are seeking champions to introduce a Senate version
- There were also several original sponsors:
 - Rep. Yvette Clark (D-NY)
 - Rep. Diana DeGette (D-ĆO)
 - Rep. Brian Fitzpatrick (R-PA)
 - Rep. Miller-Meeks (R-IA)
 - Rep. Bonnie Watson Coleman (D-NJ)

*If you meet with these offices, say THANK YOU!





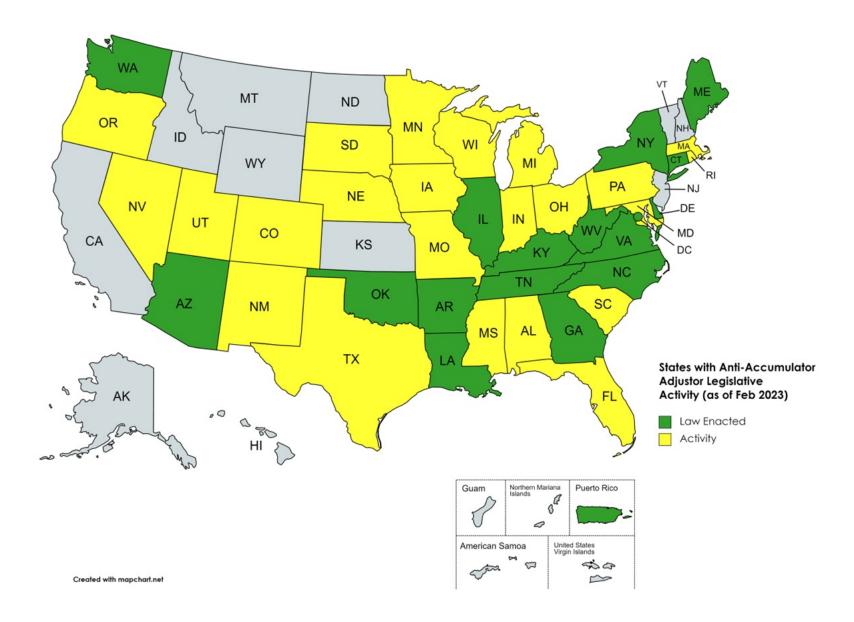
FAQ About the Bill

Does this issue affect more than just people with inherited blood disorders?

Yes! NHF is on the steering committee of the All Co-Pays Count Coalition, which has more than 120 patient advocacy groups representing people with cancer, MS, HIV/AIDS, arthritis, lupus, immune deficiencies...

FAQ About the Bill

Has there been activity on the state level on this issue? YES



FAQ About the Bill

Why do we need federal action?

• Laws enacted on the state level only apply to some private plans (i.e., individual and marketplace plans); we need federal action to capture ALL private insurance plans



How to Prepare?

Think about your story:

- How much do you/your family pay in monthly co-pays for your bleeding disorders treatments?
- Do you or does someone you know rely on co-pay assistance?
- Have you faced an accumulator adjustor program or the EHB loophole?
- What would happen if you couldn't access your medicines?



Summary of "ASKS"

We ask that Members of Congress support the community in two ways:

- 1. Support federal programs and funding that benefit the bleeding disorders community
- 2. Co-sponsor the HELP Copays Act (H.R. 830), or introduce a Senate version

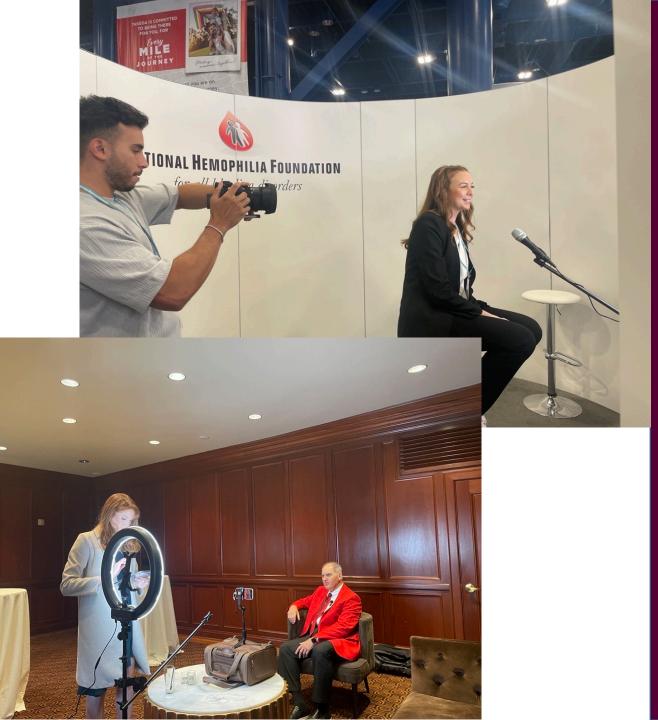


Utilizing Social Media During Washington Days

ALLSUN MURTHA | Strategic Communications Manager







ABOUT ME

- 5 years of non-profit experience
- Run NHF's social media accounts
- Host NHF's Wednesday Webinar series
- Experience working in Chapters and Marketing and Communications

TIPS TO BE SUCCESSFUL WITH YOUR SOCIAL MEDIA PLATFORMS AT WASHINGTON DAYS



Assume everything is ALWAYS public







SOCIAL MEDIA BASICS FOR ADVOCACY PURPOSES

Identify who you want to reach, and how to amplify that message.

Provide support using the toolkit which has scripted messaging and graphics.

Timing is important – use awareness events as a natural pipeline for advocacy.





UTILIZE YOUR TOOLKIT

This year, NHF is offering an official social media toolkit for all participants to use.

Components include:

- Listings of NHF platforms
- Official hashtags
- Sample posts and graphics

A QUICK BREAKDOWN OF THE TOOLKIT

HASHTAGS

Hashtags are a quick and easy way to increase your reach on social media. **#NHFWD** and #NHF75 are this year's hashtags. When you use these hashtags, your content is added to a collection of similar content.

CHARACTER USE

Every social media platform has a limit to the total number of characters you can use. They vary depending on the platform. Sample social media posts, like those included in the toolkit, can help keep you in the character limit.

SAMPLE GRAPHICS

NHF staff has generated several sample graphics for you to include in your social media posts. Thes graphics house information about the topics of discussion during Washington Days.



Members' Official Twitter Handles

First Name	Last Name	Twitter Handle	St/Dis	Part
Alma	Adams	@RepAdams	NC12	D
Robert	Aderholt	@Robert_Aderholt	AL04	R
Pete	Aguilar	@RepPeteAguilar	CA31	D
Rick	Allen	@RepRickAllen	GA12	R
Colin	Allred	@RepColinAllred	TX32	D
Mark	Amodei	@MarkAmodeiNV2	NV02	R
Kelly	Armstrong	@RepArmstrongND	ND00	R
Jodey	Arrington	@RepArrington	TX19	R
Jake	Auchincloss	@RepAuchincloss	MA04	D
Cynthia	Axne	@RepCindyAxne	IA03	D
Brian	Babin	@RepBrianBabin	TX36	R
Don	Bacon	@RepDonBacon	NE02	R
James	Baird	@RepJimBaird	IN04	R
Troy	Balderson	@RepBalderson	OH12	R
Jim	Banks	@RepJimBanks	IN03	R
Andy	Barr	@RepAndyBarr	KY06	R

ENGAGING WITH YOUR ELECTED OFFICIALS

Confirm with officials' teams with how they like to be engaged with on social media.

Use approved hashtags and content from our toolkit.

Tweet before you go!





Lessons from today's #NHFWD advocacy day: start by listening. I thought I knew #bleedingdisorders - and was I ever wrong. Every member of our team carried a whole universe of stories. I learned so much, just by being there, and hearing about my teammates' experiences. 1/

9:25 PM · Mar 2, 2022 · Twitter for iPhone







contexts, and we all chose to be present. Made it possible to be present, to share our community's challenges and needs. 3/



Thank you Rachel Hugman w/ @ConorLambPA for meeting with us! DJ, Ethan, and Kyrie shared how the comprehensive care provided by the HTC has meant the world to them!

We appreciate your time and Rep. Lamb's continued support of federal programs like HRSA, NIH, and the CDC! #NHFWD





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UTILIZING PHOTOS IN YOUR CONTENT

- Use your personal photos in your post when you can
- Use sample graphics from the toolkit to fill in the gaps

PHOTOGRAPHY BEST PRACTICES

- Utilize the "grid" setting to keep your images center
- Ensure your photos are focused (we want to see your beautiful faces front and center!)
- Ask a friend or stranger to help take the photo if possible

HILL DAY ON THE GROUND SOCIAL PRACTICES

- Identify source information in your posts
- Keep a list of correct social media handles of your elected officials on hand
- Post frequently throughout the day
- Take photos with each other and with staff when you can
- Watch the hashtag to see what others are sharing
- Continue to tag NHF in all your posts



AFTER YOU VISIT THE HILL

- After your visit with your elected official, send a thank you tweet ASAP!
- Include any public statements you want to share, and ensure you find something positive to mention to keep the conversation going.
- Finally, watch your elected officials on their social platforms. Continue to engage with them even after Washington Days.



OTHER IMPORTANT ITEMS TO NOTE

- Geotag your content
- Check for typos
- Keep it heartfelt and focused on your story
- And most of all ... thank you for sharing your voice!

thank



LET'S STAY IN TOUCH!

- <u>Amurtha@hemophilia.org</u>
- IG &Twitter: nhf_hemophilia
- Facebook & LinkedIn: National Hemophilia Foundation
- YouTube: youtube.com/NHFvideo

