



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

WASHINGTON DAYS SOCIAL MEDIA TOOLKIT

— MARCH 8-10, 2023 —

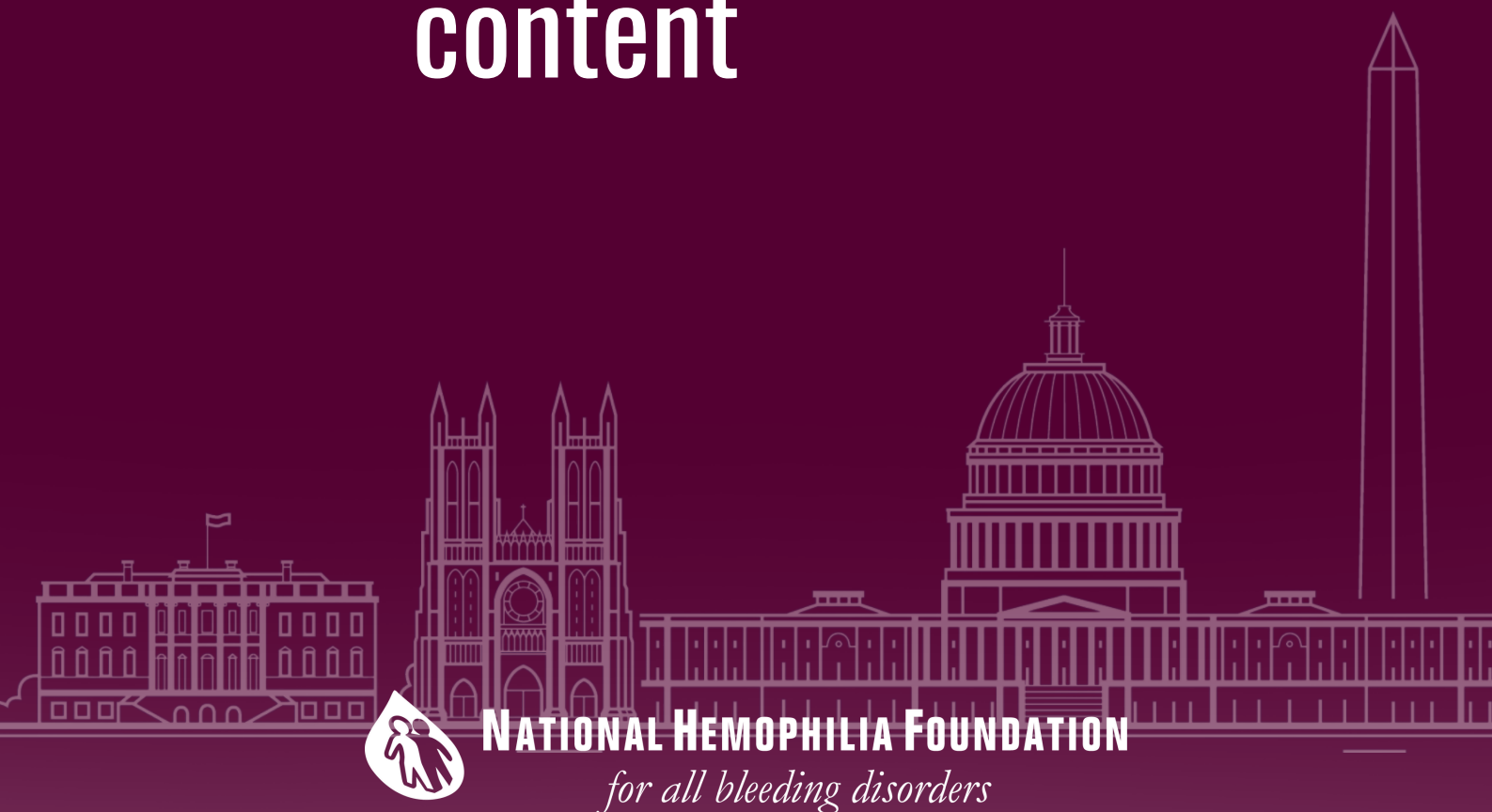
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About the toolkit

Welcome!

Thank you for joining your fellow advocates at NHF's Washington Days! Go ahead and give yourself a big pat on the back for taking the next step in the advocacy journey. Throughout your time at Washington Days, this toolkit will be your go-to resource to support you in your efforts to discuss issues important to our community such as federal funding for bleeding disorder programs and supporting policies that increase affordability of coverage, and access to care.

This social media toolkit contains information and resources to push out and amplify your social media campaign to raise awareness about inheritable blood and bleeding disorders and spread the message of Washington Days.

It provides a starting point and ideas on how to create your own individual campaign, including visuals and wording that you can use for your social media posts. Finally, it presents more advanced social media tools you can make use of, such as Twitter chats, Instagram or Facebook Stories, Instagram reels, and much more!

With the key resources you need to participate at your fingertips, you are sure to have a successful Washington Days! You will also find minor information on the issues NHF is focusing on during Washington Days this year. We are here to help you have successful visits with your members of Congress; and, even more, have fun!

Do not feel overwhelmed! No one is expecting you to memorize every talking point and every policy priority. Have this toolkit on hand to help you as you go through your meetings and throughout your day. They can be a helpful guide, and we can't wait to see you document your experience.

Thanks for your advocacy! It makes an incredible impact.

Join the Washington Days Conversation

During Washington Days, NHF's social media channels aim to raise awareness of the importance of maintaining federal funding of bleeding disorder programs and supporting policies that increase affordability of coverage, and access to care.

Participating Handles



[@NationalHemophiliaFoundation](#)



[@nhf_hemophilia](#)



[@NationalHemophiliaFoundation](#)



[@NHF Hemophilia](#)



[@NHFvideo](#)

Make sure to tag our profiles (“@”) in your social media content to make it easier for us to discover your content and to engage with you. And use the official Washington Days hashtag as well!

Hashtags

#NHFWD

By following and using the #NHFWD hashtag, you become part of the conversation, can follow along during the advocates time at the Hill, and spread your own content to a wider audience.

#NHF75

2023 marks NHF's historic 75th anniversary. Use this hashtag to continue to mark your time in our history! This is an incredible moment in the rich history of the inheritable blood and bleeding disorders community.

Washington Days 2023 Issues to Discuss

NHF's Washington Days is an opportunity for people affected by inherited blood disorders to advocate for issues that are important to them.

The issues at Washington Days 2023 will include:

- Bleeding Disorders Awareness (March is our month!)
- Federal Funding for Bleeding Disorders Program
- [HR 5801 \(Accumulator Adjuster Legislation\)](#)

Bleeding Disorders Awareness Month

Each March, NHF calls attention to inheritable blood and bleeding disorders during Bleeding Disorders Awareness Month. This month lets patients and families with hemophilia, von Willebrand disease, rare factor disorders, and more, share their lives, stories, struggles, and successes. During March 2023, NHF invites the community to “Start the Conversation” around issues and experiences related to inheritable blood or bleeding disorders. Whether your concerns or interests revolve around research, treatments, women’s health, mental health, medical marijuana, or other topics, you can play a role in starting and elevating these important conversations.

Federal Funding for Bleeding Disorders Program

Funding for several federal programs important to the bleeding disorders community. The bill includes level funding for the federal hemophilia programs at the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC).

HR 5801 (Accumulator Adjuster Legislation)

Help Ensure Lower Patient Copays Act or the HELP Copays Act

This bill requires health insurance plans to apply certain payments made by, or on behalf of, a plan enrollee toward a plan's cost-sharing requirements. Specifically, plans must apply third-party payments, financial assistance, discounts, product vouchers, and other reductions in out-of-pocket expenses toward the requirements.

Sample Social Media Posts for You to Use

These posts are suggestions for you to use on your own social media platforms! Please use the hashtags #NHFWD and #NHF75 and tag NHF's social media accounts in your posts.


Share your Capitol Hill meetings on social media!

- Take screenshots of your meetings or photos for in-person meetings and tweet or post those images with a thank you message to the office you met with.
- Mention the issues you discussed in your meeting so that the members of Congress and their staff know that you have alerted your network to the conversation and what next steps you're hoping for.

Post Suggestions

- Just met with [Representative]'s office to discuss how the HR 5801 Accumulator Adjustor Legislation is making a major impact in [our state]. We need this legislation and federal funding for bleeding disorders programs to ensure members of our community have the best care possible. #NHFWD #NHF75
- Today, I met with [Representative]'s office to discuss #HR5801 – HELP Copays Act. Double charging isn't the norm, and it severely impacts the bleeding disorders community. The spread of copay accumulator adjustor policies across the country and the federal government can step in and make #AllCopaysCount. #NHFWD #NHF75
- Just met with [Representative]'s office to advocate for the spread of copay accumulator adjustor policies across the country. With federal government support, we can step in and make #AllCopaysCount #NHFWD #NHF75
- Congress must step in and provide support the spread of copay accumulator adjustor policies across the country. Double charging isn't the norm and severely impacts the blood and bleeding disorders community. Thank you [Representative]'s office for taking the time to meet with me today. #NHFWD #NHF75
- [Your Senator's Name], #DYK double charging isn't the norm and greatly impacts the bleeding disorders community? By supporting HR 5801, you can help in the spread of copay accumulator adjustor policies across our country. #NHFWD #NHF75
- Just met with [Representative]'s office to discuss how many patients have no other options: copay assistance is most often used to afford brand medicines without generic alternatives. That's why the federal government must take action to make #AllCopaysCount #NHFWD #NHF75
- [Your Senator's Name], #DYK For low-income Americans living with chronic health conditions, copay assistance is a critical source of financial aid that enables them to afford the specialty medications they depend on. It's up to federal policymakers to make #AllCopaysCount #NHFWD #NHF75
- Thank you [Representative]'s office for meeting with me today to hear why it's critical for #Congress to support the HELP Copays Act and make #AllCopaysCount #NHFWD #NHF75



Sample Graphics for You to Use



WASHINGTON DAYS 2023



NEARLY ALL - 99.6 PERCENT - OF COPAY ASSISTANCE IS USED FOR BRAND NAME DRUGS THAT DO NOT HAVE GENERIC ALTERNATIVES.

MANY OF AMERICA'S MOST VULNERABLE PATIENTS RELY ON ONE OR MORE HIGH-COST MEDICATION EVERY DAY.



WASHINGTON DAYS 2023

WHEN HEALTH PLANS AND PHARMACY BENEFIT MANAGERS EXCLUDE COPAY ASSISTANCE PAYMENTS FROM COUNTING TOWARD A PATIENT'S OUT-OF-POCKET COSTS, THE HEALTH PLAN ESSENTIALLY GETS PAID TWICE.



WASHINGTON DAYS 2023

UNDER ACCUMULATOR ADJUSTOR PROGRAMS, MOST PATIENTS ARE CAUGHT OFF-GUARD SEVERAL MONTHS INTO THE PLAN YEAR WHEN THEIR FINANCIAL ASSISTANCE HAS RUN OUT, AND THEY ARE FACED WITH A BILL FOR THE FULL COST OF THEIR MEDICATION, WHICH CAN EASILY RUN INTO THE THOUSANDS OF DOLLARS.

