



Your Future, Our Mission

WASHINGTON 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 – Returning Advocates

75

YEARS OF SERVICE
1948 - 2023



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders



OUR MISSION

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.

NUESTRA MISIÓN

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.

GO
TEAM



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

BIOMARIN®

sanofi

CSL Behring
Biotherapies for Life™

Genentech
A Member of the Roche Group



75
YEARS OF SERVICE
1948 - 2023



THANK YOU TO OUR SPONSORS



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



The Issues



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 HTC's 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



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 HTC's 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

- HTC's 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

HRSA

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

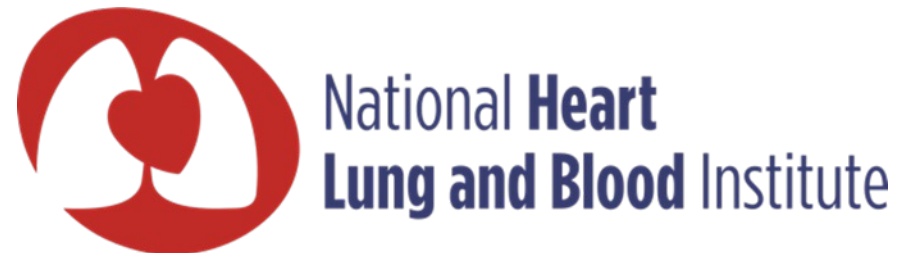
Important Initiatives:

- 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

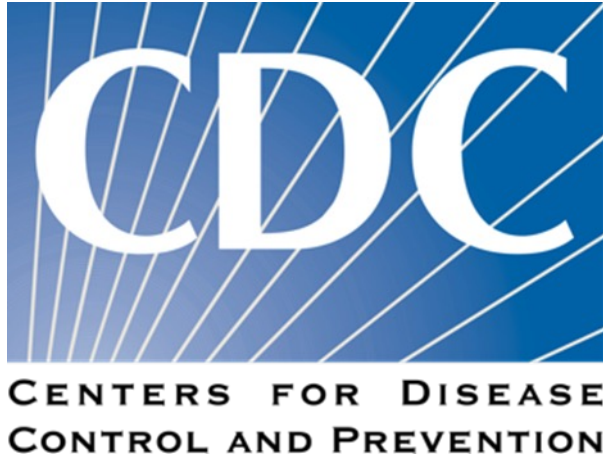


Federal Funding Update



- 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 HTC's (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





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

How to prepare

Think about your story:

- How do you explain your bleeding disorder?
- How were you diagnosed?
- What is the name and location of your HTC?
- How often do you go for visits?
- How did you learn how to infuse?
- How does having a bleeding disorder affect your daily life?



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-CO)
 - 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!





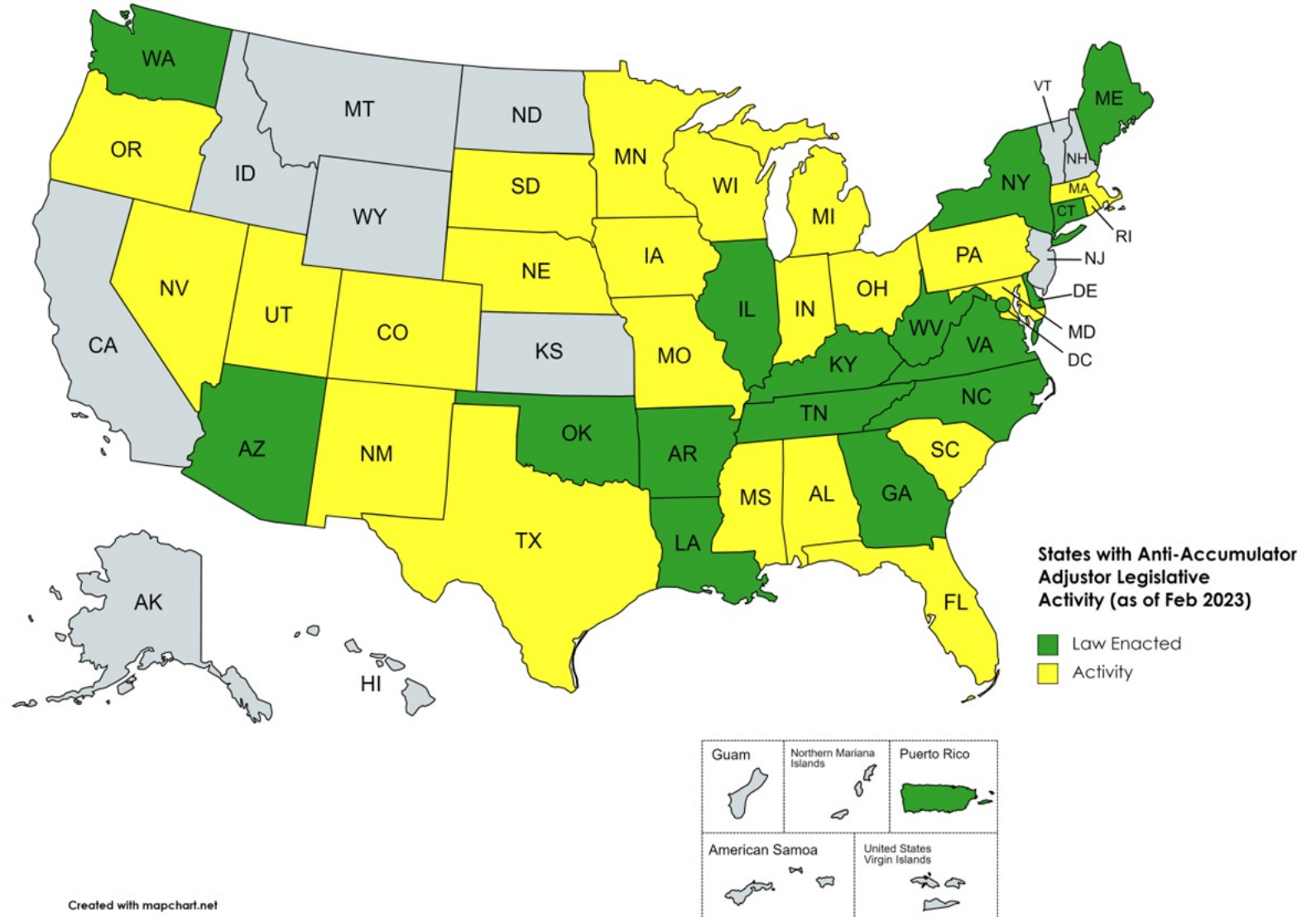
FAQ About the Bill

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



Questions

Please type into the Q&A function

Outstanding questions: advocate@hemophilia.org

