NATIONAL BLEEDING DISORDERS FOUNDATION

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NBDF Policy Update

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Pennsylvania Stakeholder Meeting
Harrisburg, PA

BLEEDING.ORG

What a Year…

Now - Marketplace Changes:

- Fight over eAPTC's
- Expiration(?) of eAPTC's, or uncertainty, during open enrollment
- Marketplaces less robust
- Junk insurance!
- Immigration status and ACA

State Budgets:

- Massive financial strains on state budgets nationally
- Some states trying tactics, such as AFP's, to fill budget gaps
- More healthcare cuts????

Blood safety? Emerging therapies?

<u>April:</u>
Cuts to federal programs and Reductions-in-Force.

Dealing with a (shutdown) Congress/Gov't mainly only taking up funding bills.

July: HR 1 –

- Work requirements by 2027, many states moving sooner.
- $625M in cuts over 10 years
- Marketplace changes
- Provider tax limits

What happened this year?

- New Administration and new Congress – Republican trifecta, narrow margins in House and Senate
- Policy change through Executive Orders – 210 issued in 2025 alone
- Agency RIFs and proposed reorganizations upend DC and impact federal bleeding disorders programs
- President signs into law a bill that makes deep cuts to healthcare
- Combo of policies set to trigger steep increases in cost of Marketplace insurance

What types of policies are taking effect?

Medicaid changes will limit eligibility, impose new paperwork and costs

ACA policy changes will impact enrollment in and affordability of **Marketplace coverage**

ACA policy changes will increase costs for people with **job-based insurance**

Policy changes phase in as soon as August 2025, in January 2026, and over next 10 years

Medicaid changes of concern / OBBBA

Community engagement / Work reporting requirements for Medicaid expansion **applicants and enrollees**

More frequent eligibility reviews for Medicaid expansion enrollees – at least every 6 months

Many classes of lawfully present **immigrants** lose eligibility for Medicaid and CHIP

Mandated cost-sharing (services and Rx) for Medicaid expansion enrollees

< Other policies will have indirect impacts via lowered funding for state Medicaid programs >

What should Medicaid enrollees be doing to protect their coverage?

- **OBBBA's policy changes are not yet in effect! – but start planning/acting as if they are.**
- Know the name of your Medicaid program
- Make sure that your **contact information is updated** with the state, and make a practice of **logging into your Medicaid account** every few months to check for updates.
- Be sure to **open all mail and emails** from Medicaid and/or your state's health department. If you receive any communication, **respond within the deadline** (typically 10-30 days).
- Begin keeping detailed **records of your monthly work or qualifying activities** (pay stubs, schedules, attendance sheets, etc.)

Marketplace changes

OBBBA plus new rule: technical changes with big impact

Some changes paused for 2026 by court action

More expensive

- New methodology → higher premiums (Marketplace) and higher OOP max (Marketplace + employer plans)

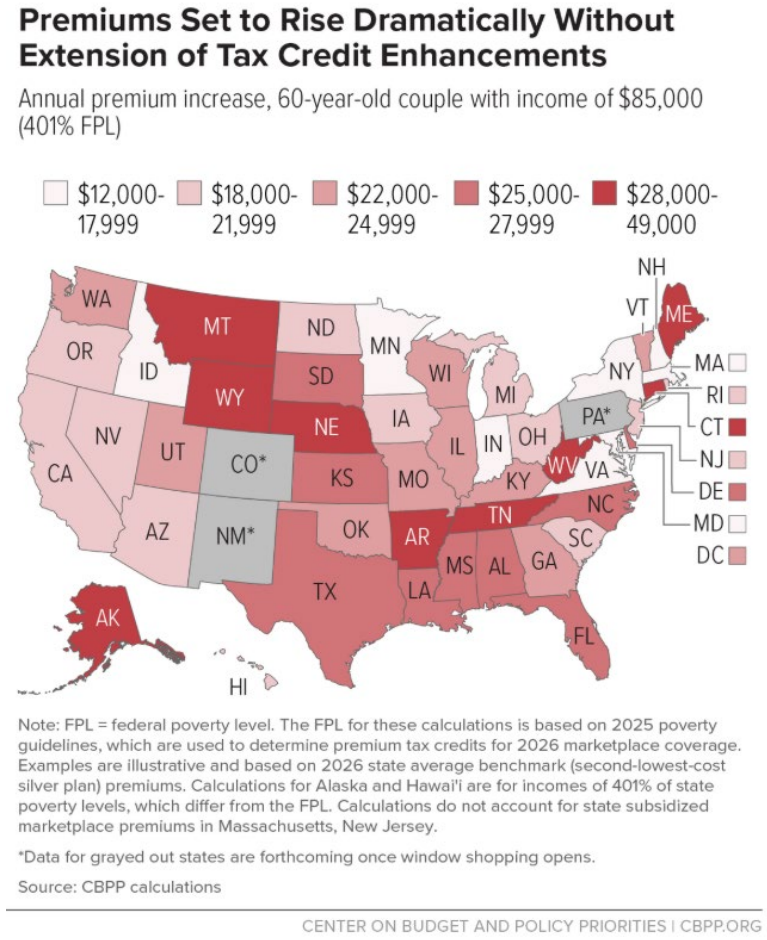
Harder to get and to keep

- More paperwork
- Immigrants excluded from coverage

Less comprehensive

- AV can be lower, i.e., lower value for your premiums
- Gender affirming care excluded from “essential health benefits”

Why it would be bad for the enhanced tax credits to expire?



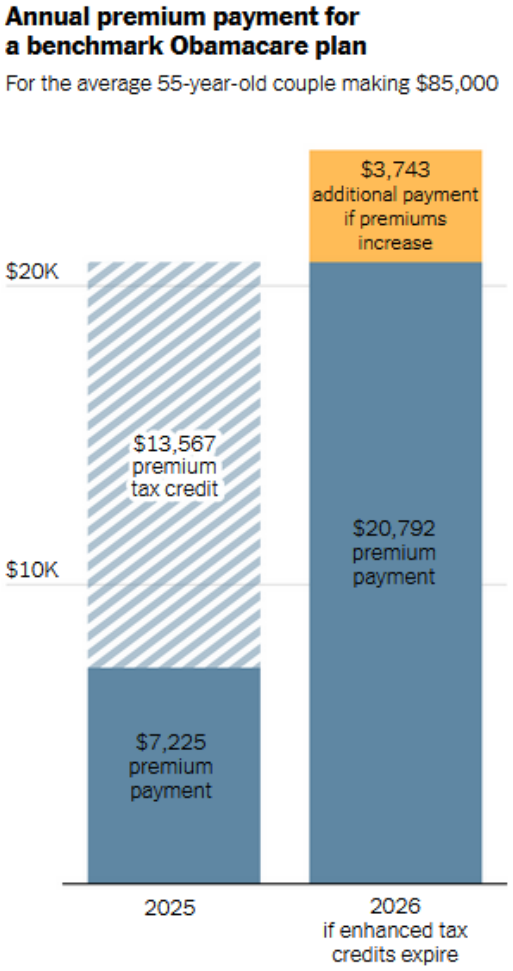
Bad Today:

Premiums will skyrocket for people with bleeding disorders and others – a projected average 114% increase – becoming unaffordable for many.

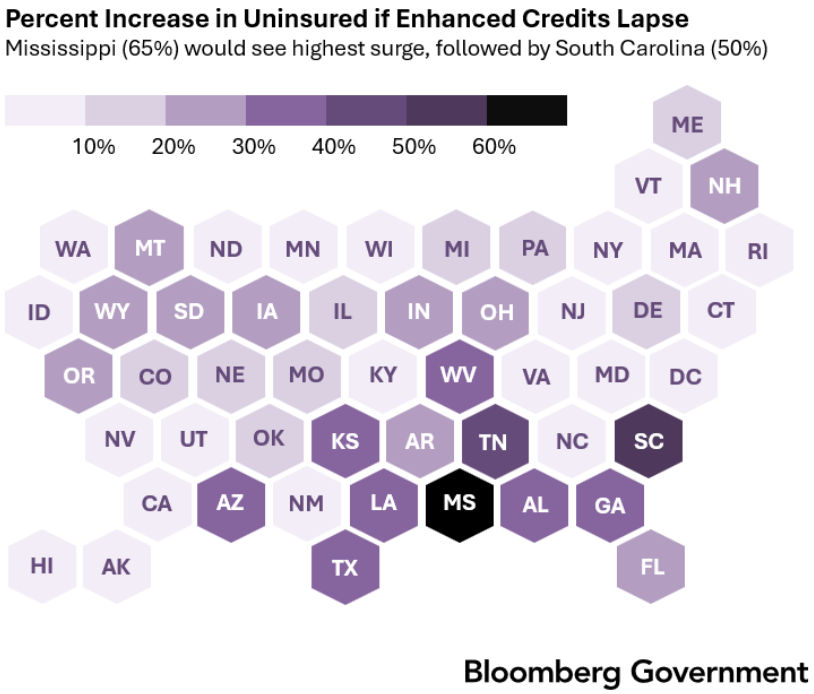
An estimated 4.2 million Americans will drop their coverage.

Bad Tomorrow:

Healthier people will flee the Marketplaces due to high premiums, creating a **"death spiral" of sicker and smaller risk pools and ever higher premiums.** Eventually, the destabilized Marketplaces won't be an option for people who rely on them.



Federal Priority – APTC's



- **Pennsylvania:**

For a **60 year old couple** earning **$85,600** a year

Annual Premiums would Increase by
$24,162 **365%**

For a **family of four** earning **$133,750** a year
(ages 45, 45, 15, and 10)

Annual Premiums would Increase by
$14,572 **134%**

For a **family of four** earning **$66,000** a year
(ages 45, 45, 15, and 10)

Annual Premiums would Increase by
$3,025 **318%**

By law, the enhanced APTCs (eAPTCS) expire December 31, 2025. **Nearly 4 million Texans rely on eAPTC's.**

In 2026: unless Congress acts NOW to extend the eAPTCs, premiums will skyrocket for subsidized enrollees, becoming unaffordable for many → **An estimated 4.2 million Americans will drop their coverage.**

Longer term: Marketplaces will shrink and destabilize → **"death spiral" of ever-costlier and smaller risk pools, ever higher premiums.**

Summing up: steps to take during this Fall's Marketplace Open Enrollment

Anticipate higher premiums

- Consult with your HTC social worker;
- See if premium assistance programs are available if you anticipate difficulties affording premiums in 2026.

Update financial info on file with the Marketplace

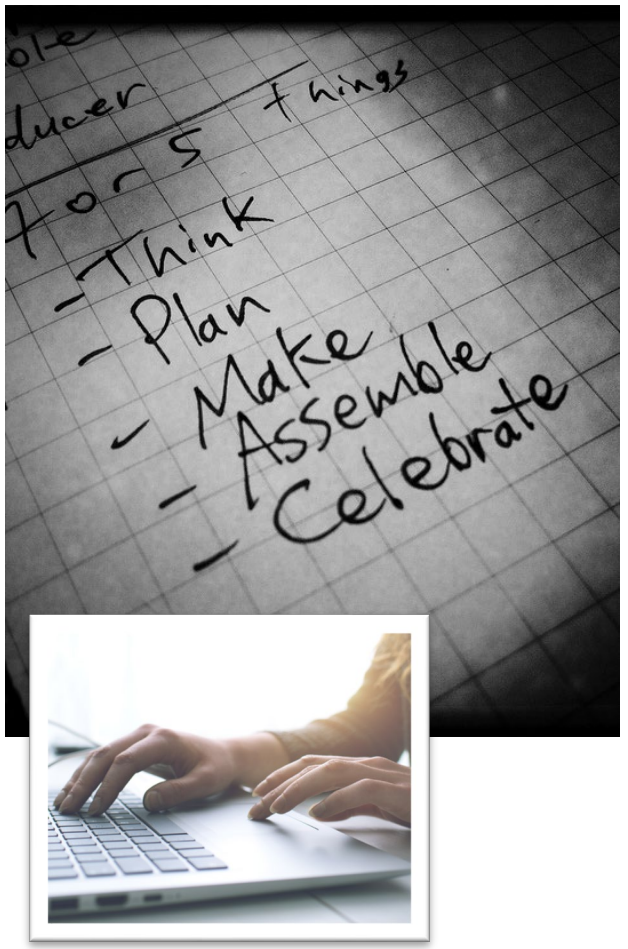
- Make sure you have filed your taxes, updated your 2025 income projections, and reconciled any previously-received premium subsidies
- Project your income as accurately as possible for 2026.
- Read all notices you receive!

Don't wait until the last minute to enroll

- Allow time to gather all necessary info, and to deal with any technical difficulties that may arise.
- Don't want/need Marketplace insurance for 2026? Remember auto-reenrollment happens after 12/15; cancel before 12/31.

Make an ACTIVE CHOICE

- Go into your healthcare.gov account and **MAKE AN ACTIVE CHOICE** by Dec. 15, even if you are choosing to stay with your existing plan for 2026.



Skinny Formularies – USP DC

- **Letter to USP DC from bleeding disorders organizations re. class rules**
  - In the meantime, we now have examples of plans excluding ALL bleeding disorders therapies, in order to dissuade bleeding disorders patients from purchasing their plan.
  - E.g. – Ambetter of Tennessee (also has plans in PA, including marketplace).
  - **2026 Ambetter formulary lists one CFC (Afstyla) and TXA for ALL bleeding disorders**
  - Ambetter's 2026 formulary **drops 11 different agents** from 2025.
  - Patients in TN received notices that their drugs are no longer covered OR request an exemption AFTER December 31st.

- **With Ambetter, our best example thus far, their clinical and payment policies state that there is a procedure for granting PA for non-formulary treatments.**
  - Problem: Nobody can do this at scale!

  - Formularies are the primary tool for discrimination against those with high-cost conditions such as bleeding disorders.

Federal Programs and FY26 Appropriations

- **HRSA – Hemophilia Program**
  - Provides $5 million/year in funding to HTC network and supports coordinating center.
  - Funding allows HTCs to participate in the 340B program.
  - The Senate FY26 bill would maintain the HRSA hemophilia program; the House FY26 bill is less clear.

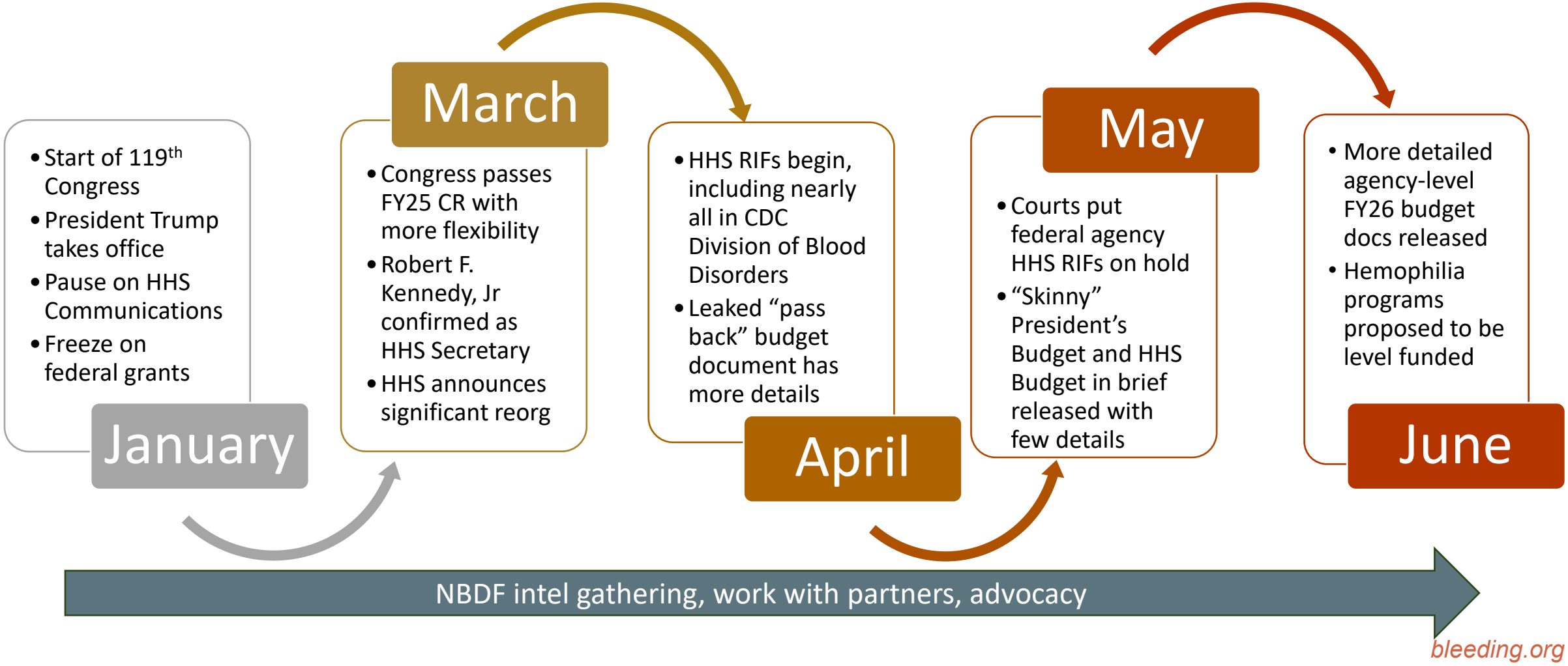
- **CDC Division of Blood Disorders and Public Health Genomics – Hemophilia Programs**
  - The Division provides $5.1 million for HTC surveillance and prevention activities and $3.5 million for outreach and education programs.
  - On April 1, nearly all of the blood disorders staff were put on administrative leave.
  - Funding maintained in both House and Senate FY26 bills.

HRSA
Health Resources & Services Administration

CDC
U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION

DEPARTMENT OF HEALTH & HUMAN SERVICES · USA

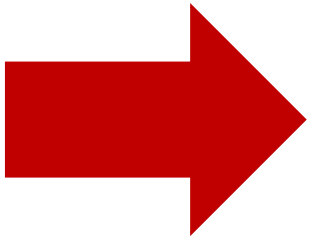
A Challenging Year for Federal Bleeding Disorders Programs



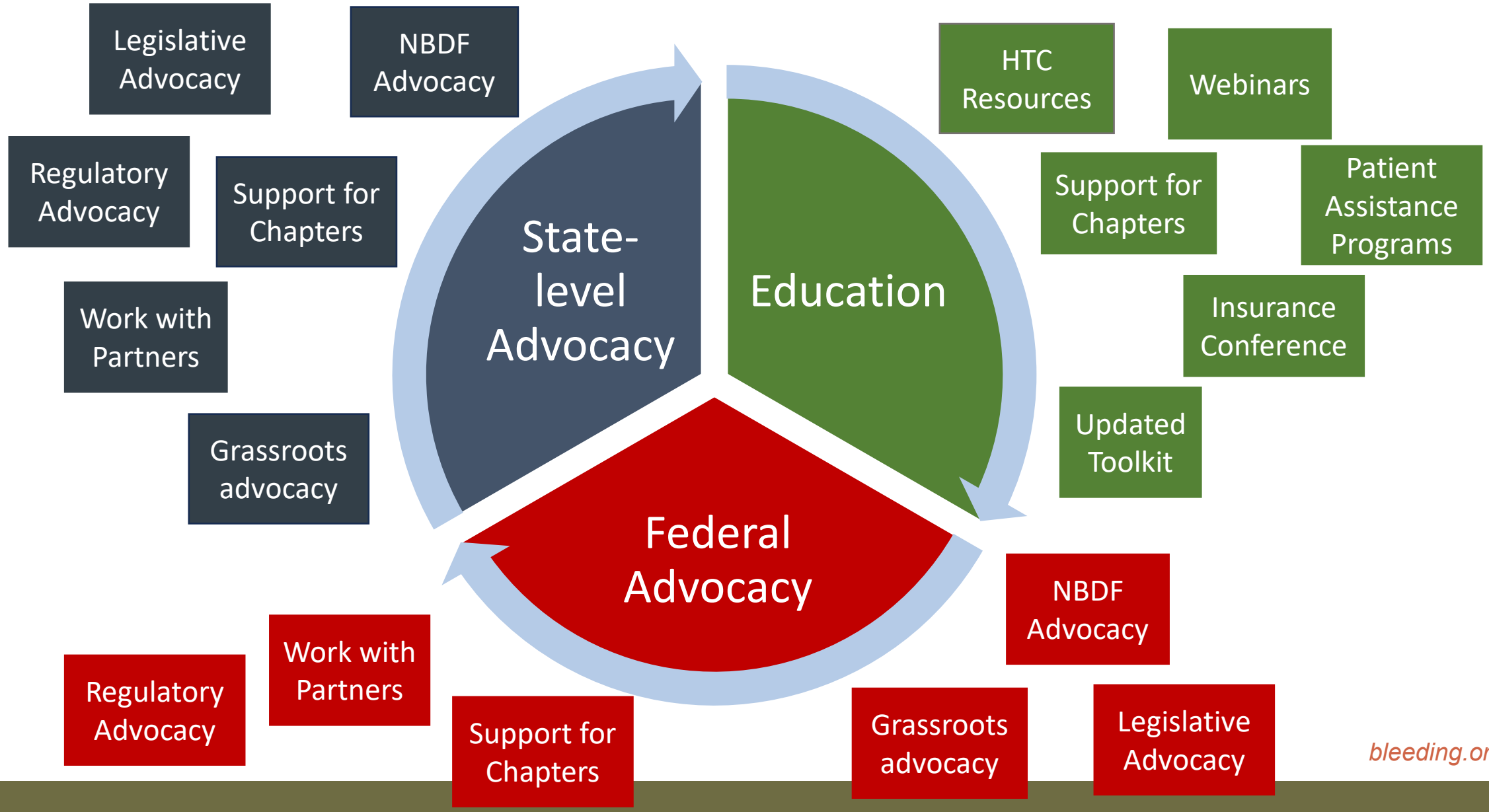
bleeding.org

Take Action to Support Federal Bleeding Disorders Programs

Ask your Members of Congress to support federal bleeding disorders programs in FY26 and beyond!



NBDF Developing Multi-Prong Strategy re: HR1



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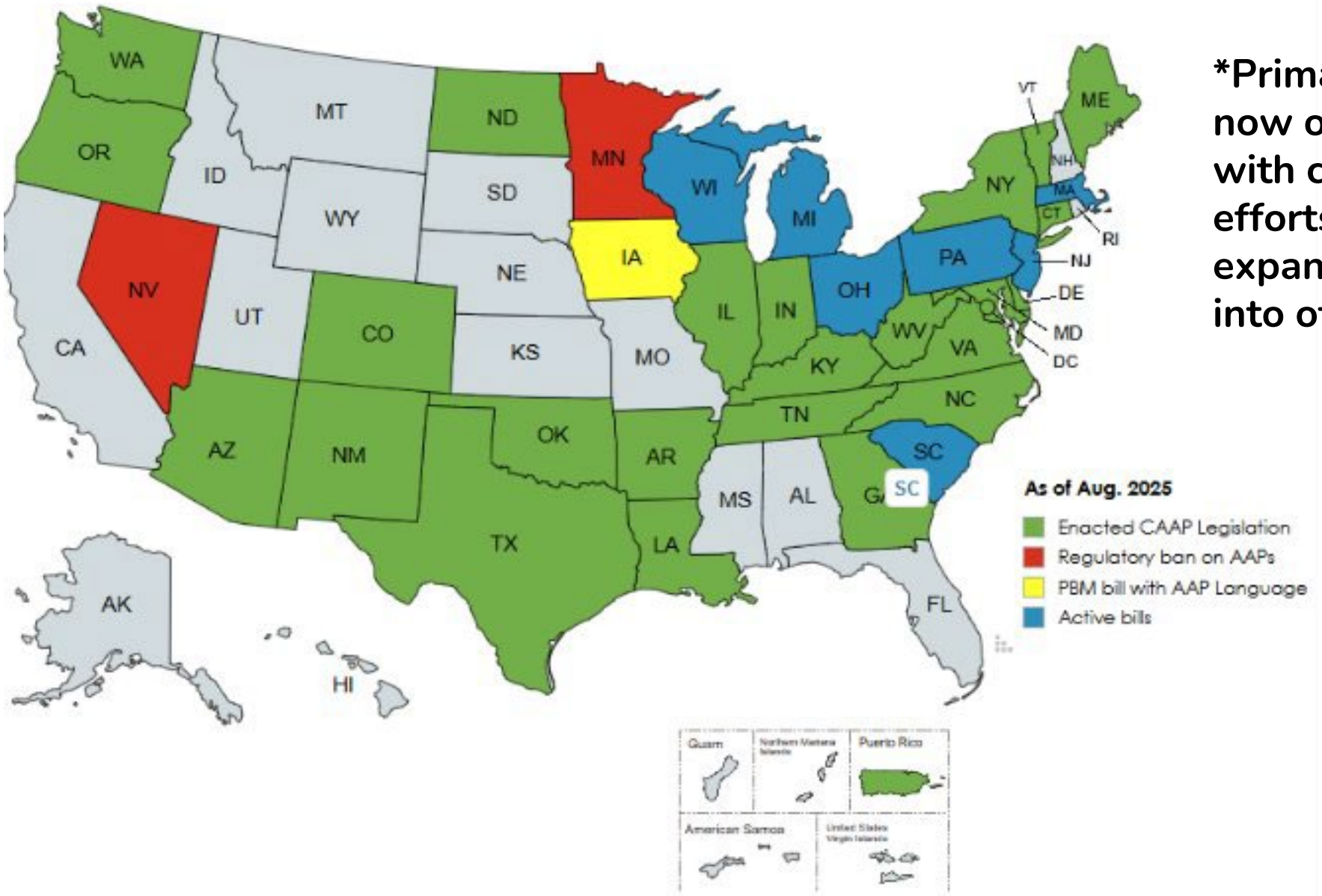
- First ever Hill Day dedicated to women and girls with bleeding disorders on April 17 (World Hemophilia Day!).
- 2025 WFH theme for World Hemophilia Day: Women & Girls Bleed too.

NBDF Priorities: Women and Girls with Bleeding Disorders

Copay Accumulator Adjuster Landscape



***Primary focus is now on states with current bill efforts in order to expand capacity into other areas.**

Help Ensure Lower Patient (HELP) Copays Act

- Reintroduced in the Senate in March by Senators Roger Marshall (R-KS) and Tim Kaine (D-VA).
- House reintroduction coming post-shutdown!
- Legislation would end the practice of copay accumulator adjustor programs and copay maximizer programs by:
  - Clarifying the ACA definition of cost-sharing to ensure payments made “by or on behalf of” patients count towards their deducible and/or out-of-pocket maximum.
  - Clarifies the ACA’s annual out-of-pocket limit applies to all prescription drugs covered in a health plan, since all covered drugs would be defined as “essential.”

Sen. Marshall (R-KS)

Sen. Kaine (D-VA)

Rep. Kean (R-NJ-07)

Rep. Barragan (D-CA-44)

State Priorities and Outlook into 2026

- **Medicaid Advocacy**
  - 50 states and 50 Medicaid programs. Encouraging chapters and provider coordination with Medicaid Directors and relevant staff.
  - States can implement requirements sooner! Pending waiver requests in: Arizona, Arkansas, Ohio, Montana, Iowa, Indiana, North Carolina, South Carolina.
  - Existing work requirements in Georgia "Pathways to Coverage"
  - We can advocate to shape the future for several facets of Medicaid programs, eligibility and requirements.

- **Copay Accumulator Adjuster Programs**
  - Prioritizing existing legislation.

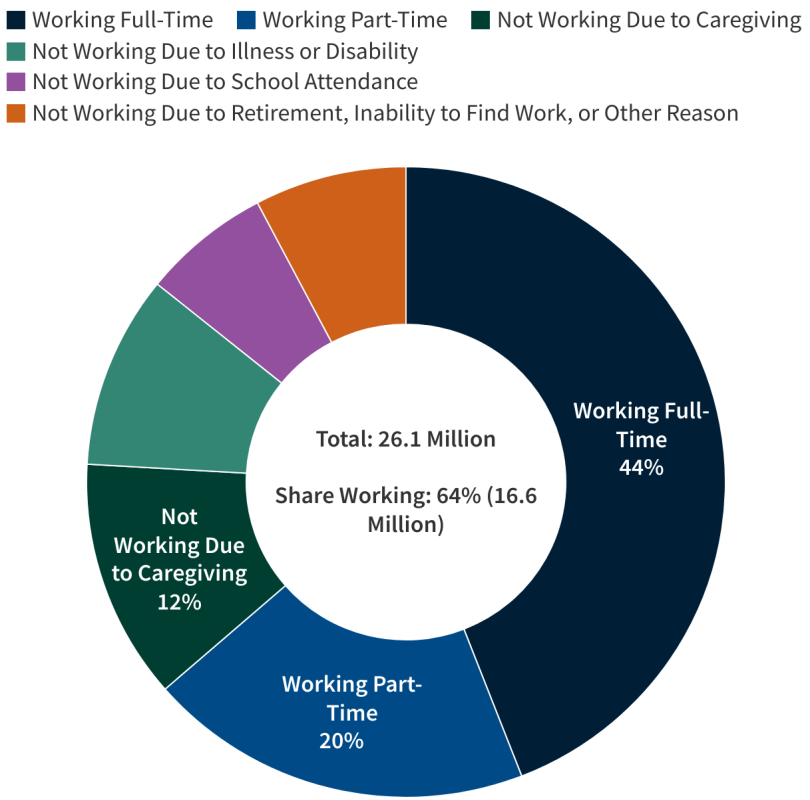
- **Maximizers and Alternative Funding Programs**
  - State AFP bills
  - Maximizer bills introduced in states with and without CAAP reforms.

- **Strained Budgets. Hard Decisions.**

Figure 1

Work Status & Barriers to Work Among Medicaid Adults, 2023

Includes Medicaid covered adults (age 19-64) who do not receive benefits from Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) and are not also covered by Medicare.



Note: Total may not sum to 100% due to rounding. Working Full-Time is based on total number of hours worked per week (at least 35 hours). Full-time workers may be simultaneously working more than one job.

Source: KFF analysis of the March 2024 Current Population Survey ASEC Supplement

KFF
pleeding.org

Given all of this… What Can We Do?

- There are so many confluent policy issues occurring essentially all at once. Where can we help **beyond Washington or in the Capitol? How can we protect our communities most immediate needs? We are focused on harm-reduction.**

- No matter the outcome of APTC's, affordability is stretched.

- **Regulators are complaints-based departments.**

What are the different communities in PA whom we represent?

- Those with varying immigration status (e.g. – DACA recipients can no longer buy marketplace coverage).
  - The (founded) fear of health data being used in immigration enforcement
- Those who may be "okay" with what is going on! How do we message?!?

<u>Bottom line: How do we reduce harm? How do we leverage stories?</u>

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Thank you!

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