




Welcome to the 2025 Stakeholder Meeting!

Thank you for being here!

Agenda

- 10:00 AM – Welcome and Ice Breaker | Sarah Pilacik
 - 10:10 AM to 10:20 AM – Survey Results and Collaboration | Kara Dornish
 - 10:20 AM to 10:30 AM – BDSUMHAC | Kristine Tanase
 - 10:30 AM to 11:15 AM – Federal Updates | Matt Delaney, NBDF
 - 11:15 AM to 12:00 PM – State Updates | Kerry Lange, Milliron Goodman
 - 12:00 PM to 1:00 PM – Lunch and Open Discussion
 - 1:00 PM to 2:00 PM – Pennsylvania Health Law Project Presentation
 - 2:00 PM to 3:00 PM – Guided Discussion and Closing
- 

Insurance and Access Challenges

1.) Prior Authorizations

2.) Copay accumulators, maximizers, and alternative funding programs

3.) Coverage instability

4.) Insurance complexity

5.) Drug formulary exclusions and yearly reauthorization requirements

Deepening Patient & Family Needs

Mental Health Strain is Increasing
Financial Pressures Are Significant
Populations Needing Focused
Support

- Young Adults
- Older Adults



Gaps in Education & Awareness

Families need more support understanding:

- their insurance coverage and navigation
- advocacy opportunities
- less common bleeding disorders beyond hemophilia



Advocacy Priorities for 2026

1.) Increasing the state hemophilia line item and securing stable funding for all seven HTC's.

2.) Ending copay accumulators, maximizers, and alternative funding programs

3.) Prohibiting insurers from altering coverage or premiums mid-plan year.

Collaboration

Many of you expressed enthusiasm for continuing and expanding collaboration between the Foundations and the HTC's, including:

- Participating in legislative visits
- Assisting with grassroots advocacy
- Educating patients and families
- volunteering at events
- providing patient or family testimonials or assisting with letters, emails, and phone calls to lawmakers

The heart you bring to this work and your willingness to engage is one of our community's greatest strengths here in Pennsylvania.



Collaboration

Community connection is stronger than ever, when patients, families, HTCs, and Foundations are working closely together.



Brought to you by the Eastern PA Bleeding Disorders Foundation and the Penn State Health Hemophilia Treatment Center of Central PA



Agenda

11:30am – Check-in opens
12:00pm – Lunch served
12:15pm – HTC welcome
12:15pm-12:45pm – Advocacy and the patient perspective
12:45pm – Adventure Sports rules review
1:00pm-3:00pm – 2-hours for bumper boats, mini-golf and go-carts
3:00pm – Conclusion



This event is FREE thanks to the Eastern PA Bleeding Disorders Foundation 😊

Join the bleeding disorders community for a day of family fun, networking and advocacy at Adventure Sports! We can't wait to see you again this summer!

RSVP by calling Meredith Getz at 717-531-1643 or emailing at mgetz1@pennstatehealth.psu.edu by **Tuesday, July 1, 2025**.

Please include the full names of all attendees and how many wristbands are requested.





Collaboration

Events like the **PA Bleeding Disorders Conference** and this annual **Stakeholder Meeting** have been highly valued for education, networking, and engagement.



What's Working Well

Advances in **treatment options**, including Hemlibra and long-acting factor products, give providers and families hope.

The growing focus on **women and girls with bleeding disorders** is improving diagnosis and care.



Addressing Your Concerns

What We're Doing



Substance Use & Mental Health Access Coalition

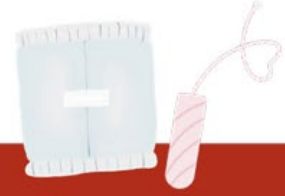
Because everyone deserves equal access to the inpatient/residential mental health and substance use disorder treatment they need.

Financial Stress & Access to Care

Transportation support: We can cover rides to and from doctor or HTC appointments, including reimbursements, vouchers, or rideshare services. Please never let transportation costs be a barrier to care.



Utility Bills



Period Products

for women with bleeding disorders



Transportation

Transportation for bleeding disorder-related medical appointments



Medical ID Jewelry



Knee, elbow, and ankle braces



Medical supplies not covered by insurance

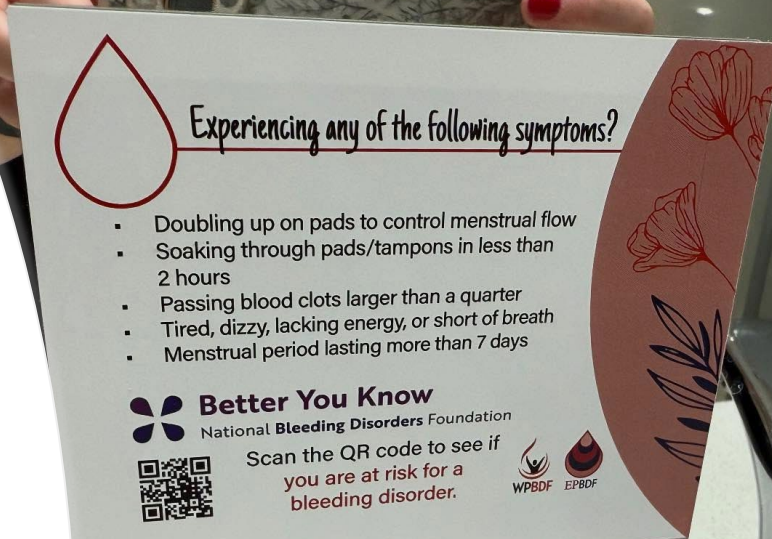


Advocacy Opportunities

- **Pennsylvania Statewide Advocacy Ambassador Education and Training - Harrisburg Hilton on Monday, May 4, 2026, followed by legislative meetings at the Capitol on Tuesday, May 5, 2026.**
- Washington Days advocates will be chosen from trained Advocacy Ambassadors

Women, Girls, and People with the Potential to Menstruate Initiative

- Our initiative continues to grow:
- Over **258 school districts** in Western PA have received period packs and educational resources.
- We host at least one **outreach event per month**, often pairing education with volunteer projects assembling period packs and nosebleed kits.
- We partner with school nurses, providing education virtually and in-person, including at the statewide PASNAP conference.

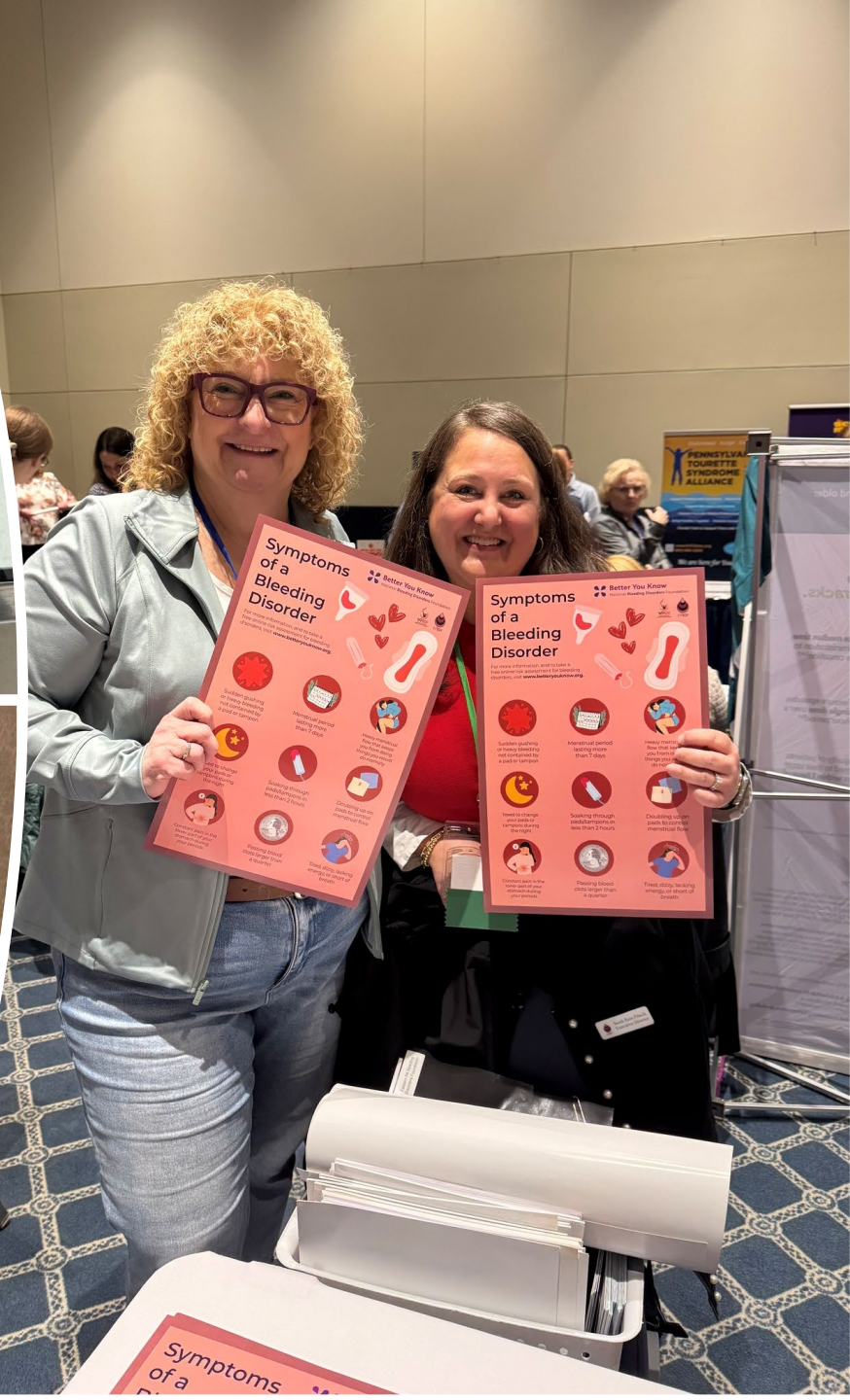


- Doubling up on pads to control menstrual flow
- Soaking through pads/tampons in less than 2 hours
- Passing blood clots larger than a quarter
- Tired, dizzy, lacking energy, or short of breath
- Menstrual period lasting more than 7 days



Better You Know
National Bleeding Disorders Foundation

Scan the QR code to see if
you are at risk for a
bleeding disorder.



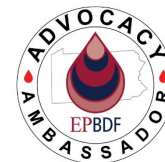
Women, Girls, and People with the Potential to Menstruate Initiative

- In Western PA 258 school districts have received resources.
- 88 school nurses responded to our survey, reporting:
 - **8 students** sought evaluation for a potential bleeding disorder after receiving a period pack.
 - **3 students** were subsequently diagnosed with a bleeding disorder.
 - **10 students** sought evaluation after receiving a nosebleed kit.
 - **1 student** was diagnosed with a bleeding disorder as a result.



Policy & Educational Materials

Let us know what you need!



Copay Accumulators 101

How do copay accumulators affect the bleeding disorders community?

How to file a complaint with the **Insurance Commissioner**.

/Consumers/insurance-complaint



Customer Service

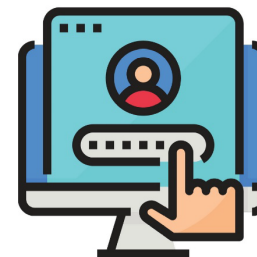
using [Pennsylvania Consumer Services](#)
the department's fast and secure online customer

Registration is completed, you will be able to
respond with the department on an

[Frequently Asked Questions](#) page for help!
[Insurance Department Complaint Process](#)
insurance company? Please visit the
before submitting.

Step Three:

Login in or, if this is your first time visiting the website, make an account. The CSO Tool will guide you step by step in filing your complaint.



CSO tool, you can choose to download a complaint form

Email:
ra-in-consumer@pa.gov



Mail:
Pennsylvania Insurance Department
1209 Strawberry Square
Harrisburg, PA 17120

Feel free to reach out to the Pennsylvania Insurance Department toll-free at 1-877-881

What is a copay?

Copay, copayment or insurance is a dollar amount set by a health plan that a patient pays out-of-pocket to access a covered medical service or medication.

Copay assistance is different from a pharmacy discount card, which changes the patient's cost for a medicine based on a rate negotiated by the discount company.

What is a copay assistance?

Copay assistance is often available to insured patients who are having trouble accessing their medicine because of a high out-of-pocket or cost-sharing requirement for covered medicines.

Why is Copay Assistance Needed?

People with bleeding disorders must have access to comprehensive health insurance that covers their life-saving treatments. Annual treatment costs can exceed \$500,000 per year for a person with severe hemophilia. Therefore, people with bleeding disorders hit their annual OOP max each year, often in the first month or two of the year.

For 2025, the OOP limit is \$9,200 for individual and \$18,400 for family coverage. That amount far exceeds what most Americans can afford to pay - especially each year. Most people with bleeding disorders need copay assistance programs to help afford their high OOP costs.

Legislation

Senator Judy Ward and Senator Maria Collett reintroduced Co-pay Accumulator Legislation (SB268). This legislation requires insurers or pharmacy benefit managers (PBMs) to count any amounts paid by the enrollee or paid on behalf of the enrollee by another party (i.e., drug manufacturer) when calculating an enrollee's overall contribution to the plan's deductible or out-of-pocket limit.

How Do Copay Accumulators Affect Pennsylvania Patients?

Copay accumulator adjustment programs implemented by insurers in recent years allow patients to utilize copay but no longer apply those dollars toward the deductible and cost-sharing requirements for their treatments. Oftentimes, patients are unaware their health plan includes a copay accumulator program, as the language is often buried or misleadingly worded in legalese.

Patients are often surprised at the amount they must pay when their copay assistance runs out but are not notified in advance. They are then forced to pay the full cost of the medicine until they reach their deductible again.



Copay accumulators force many to abandon the treatments that would keep them healthy and productive.

Patients are asking the PA General Assembly to:

support Copay Accumulator legislation (SB 268/Awaiting a Companion House Bill) to ensure that all copays count for patients.

Thank you!!

