

Dear
 Eastern PA
 Bleeding Disorders
 Foundation Community:
 I am eager to know you, learn
 from you, understand what you
 need and how I can best support this
 community. Thank you for welcoming
 me with open arms and minds.
 With Kindness, Sarah



Dedication and Personal Support

Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. These Pfizer colleagues are committed to continuing Pfizer's more-than-20-year history of listening to the hemophilia community and working to meet its needs.



Annie Sukhnandan

NY Metro, NJ, E. PA

annie.sukhnandan@pfizer.com

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"I've been a passionate and dedicated advocate for the rare disease community for over 16 years."

My work is guided by:

Compassion

Listening to your needs and addressing questions and concerns that you may have

Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, The Coalition for Hemophilia B, and others

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HemMobile is not intended for curing, treating, seeking treatment for, managing, or diagnosing a specific disease, disorder, or any specific health condition. Pfizer will not have access to any personal information you enter into HemMobile.

MARCH BOWLING EVENT

We loved seeing some of our community come out to Berwyn Tavern to hear Peter Dyson speak about his journey with hemophilia, have dinner, and then bowl at Devon Lanes on the last Wednesday of March.



Sponsored by:



Thanks to Allyson McHugh for the photos!

SAVE THE DATES!



2022 Golf Outing
September 13, 2022
RIVERCREST GOLF CLUB & PRESERVE
Registration Begins at 10 am
Lunch, Dinner & Competitions
Registration Late April



2022 Family Camp
September 23 - 25, 2022
CAMP KWEEBEC
157 Game Farm Road, Schwenksville, PA 19473
Registration to follow in May

IN THE WORKS:

Save One Life Bike Riding Event (Fall), The Women's Retreat (Fall), Annual Meeting/Family Dinner (Fall/Winter) ...and more!

ADVOCACY

Special thanks to Western PA Bleeding Disorders Foundation for allowing Eastern PA Chapter to use this piece. Please check out the powerful ways our PA neighbors are working to advocate, educate, and support people affected by bleeding disorders by going to their website: Western PA Bleeding Disorders Foundation (wpbdf.org)

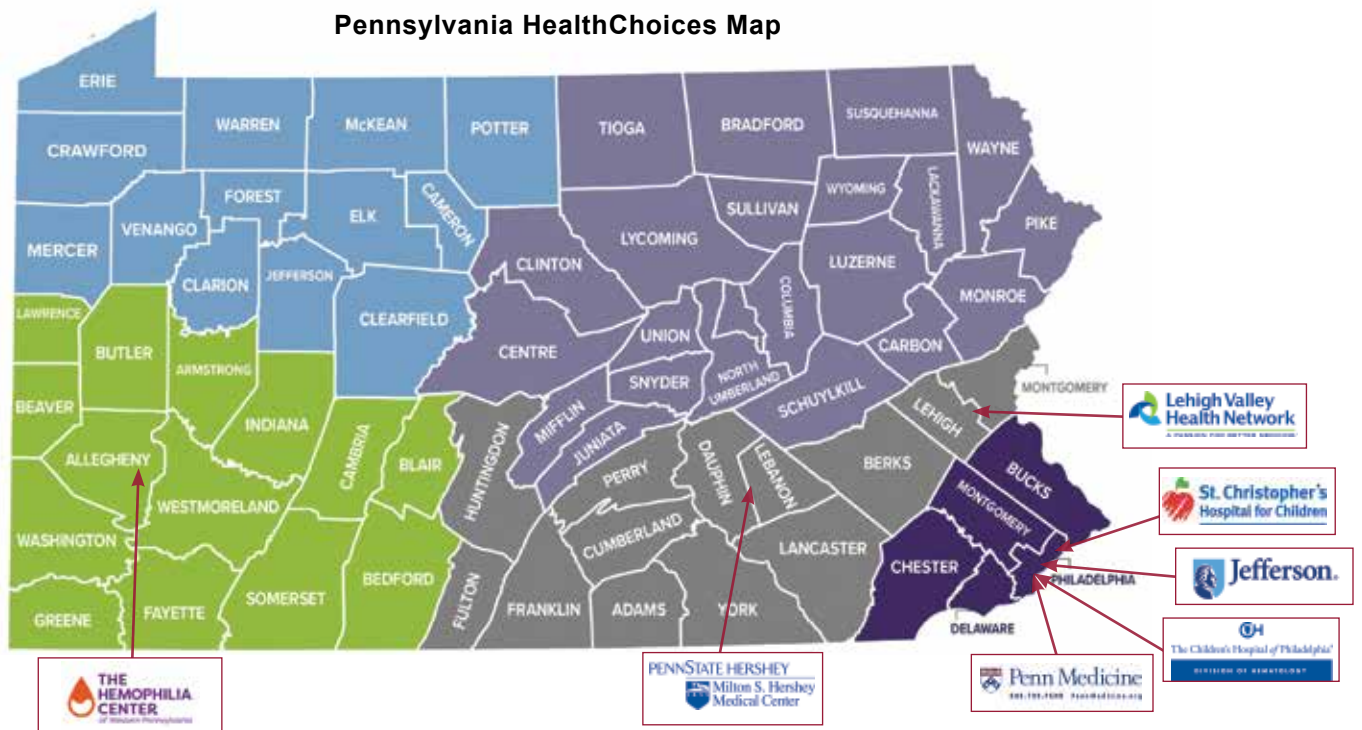
There are approximately 30,000 patients with hemophilia and thousands more with other inherited bleeding disorders in the United States. More than 3,000 of these individuals reside in Pennsylvania and receive care at one of the 7 Hemophilia Treatment Centers. We have Centers all throughout PA with 4 in Philadelphia County, 1 in Allegheny County, 1 in Dauphin County, and 1 in Lehigh County. We all know how important the HTC's are to us and the multidisciplinary care received there. CDC studies even demonstrate a 40% reduction in mortality and medical complications in patients who receive their care at an HTC and the overall costs of care are reduced as well.

In 1974 we were one of the first states in the United States to establish a state hemophilia program. If you have ever advocated with us in

the past, you know well we have always asked for that line item to be maintained at \$959,000 – it has been over a decade since we have seen an increase in the line item and before that it was even higher. This year we are asking the General Assembly to increase the \$959,000 line item by \$41,000 to \$1,000,000. These funds are used to support patient centered care including the Consumer Advisory Council, mental health support, unified care plan, and direct patient assistance. Going into another year of the Covid-19 pandemic, patient barriers have increased the need for direct patient support is greater now than ever before.

The Department of Health is once again trying to implement the HealthChoices Five Regions this year. The Specialty Care Programs funds have

Pennsylvania HealthChoices Map



been distributed in previous years through a state procurement process known as a Sole Source request. This ensured that if the hemophilia line item was in the state budget, all 7 hemophilia treatment centers in Pennsylvania received state funding. The Department of Health is trying to replace this with a new grant process called Request for Applications (RFAs). The RFAs will use a regional approach, based on the Pennsylvania HealthChoices five regions.

PROBLEMS WITH THIS MODEL:

- There are 7 federally supported hemophilia treatment centers (HTCs) but only 5 HealthChoices regions, with 4 HTCs located in Philadelphia.
- While applicants may apply for multiple regions, having only one grant awarded per region is problematic when four world class HTCs are in one region (Philadelphia). As proposed, the four HTCs in Philadelphia will be pitted against each other competing for funding.
- When we voiced this concern in the meeting with the Department of Health they told us they expect the Treatment Centers to team up to apply for funding. But this only creates more problems as who will be responsible for the administrative burden and how will the funding be divided between them? This one-size fits all approach that the Department of Health is requiring for all specialty care programs clearly doesn't work for hemophilia and will only jeopardize our HTCs funding. Lost funding can result in staff positions being eliminated which could ultimately result in loss of comprehensive care.

Luckily, we did fund a way to avoid this. We were able to get language in the fiscal code that reads: "FUNDS APPROPRIATED FOR HEMOPHILIA

SERVICES SHALL BE DISTRIBUTED TO GRANTEEES IN THE SAME PROPORTION AS DISTRIBUTED IN FISCAL YEAR 2019-2020." This language guarantees that all 7 Hemophilia Treatment Centers will receive funding.

This year we are asking the General Assembly to:

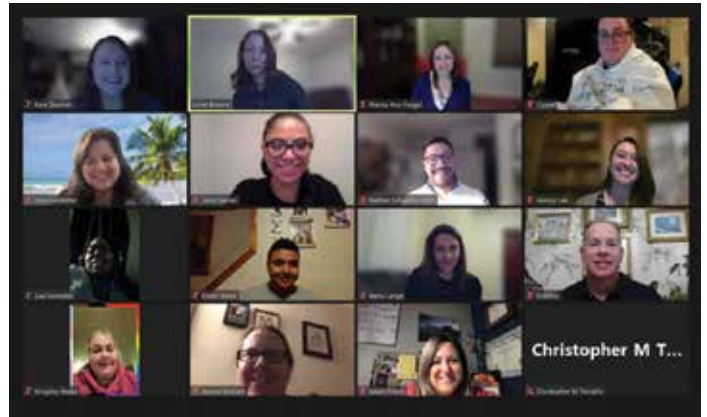
- (1) Keep the Hemophilia Program as a separate line item
- (2) Increase the fiscal year amount from \$959,000 to \$1,000,000
- (3) Keep the distribution of funds, as in previous years, to all seven-state supported hemophilia treatment centers

On February 8th Governor Tom Wolf announced his proposed budget plan. We were happy to see the Hemophilia line item separated out at level funding of \$959,000 which gives us a good starting point. In preparation for that we had sent letters and met with Representative Dan Frankel and Senator Jay Costa asking them to reach out to the Governor's office in support of our three asks. Both are very supportive of our asks and did agree to reach out to the Governor's office as well as the Appropriation Chairs. For us to move forward in our advocacy initiatives for year, we need community members like you to join us in meetings with your local legislators. We would be happy to assist in getting the meeting scheduled and provide all the resources needed to ensure a successful meeting. We would meet with you ahead of time and we can do this all virtually to run through your talking points, make sure you feel comfortable and prepared, and understand all the issues. If you are interested, please email saraph@hemophiliasupport.org, or call the Chapter office at 484-445-4282.

ADVOCACY

Advocacy Ambassadors

Our chapter teamed up with the Western Pennsylvania Bleeding Disorders Foundation (WPBDF) for Advocacy Ambassador training over Zoom on February 23. Kara Dornish, from the WPBDF, kicked off the evening by discussing the local issues that are impacting this year's state budget. Kerry Lange and Erik Ross, from Million & Goodman, presented a talk called "10 Steps to Effective Meetings" which taught us how to best represent the needs of the bleeding disorders community. Community members Marisa Ferger, Delores Johnson, and Ethan Webb told the group about their experiences as advocacy ambassadors. Finally, Janet Barone and Kara Dornish, from the WPBDF, held some mock legislative meetings that showed us the dos and don'ts of how to talk to our elected officials.



It was an educational evening filled with some entertaining moments.

If you are interested in becoming an advocacy ambassador, please email Sarah Pilacik at sarahp@hemophiliasupport.org.

A Guide to Grassroots Advocacy for the Bleeding Disorders Foundations

On January 5, 2021, the Pennsylvania General Assembly began a new two-year legislative session and

we have just started year two, which is an election year so the legislative calendar and opportunity to get issues approved tightens. Over the course of a legislative session, our state legislators will consider multiple pieces of legislation that could have a significant impact – positive or negative – on the Eastern and Western PA Bleeding Disorders Foundations. Whether you're supporting or opposing a bill, regulation or budget item, grassroots advocacy is now more important than ever.

Once upon a time, it was not out of the ordinary for incumbents to serve twenty or thirty plus years. Long-serving veteran members were often valued not only for their experience and expertise

on issues, but also as legislative champions. However, politics, retirements and frustration with the legislative process have paved the way for an influx of new members. Since 2010, both chambers of the General Assembly have seen historic turnover; 75% of the House and nearly 70% of the Senate have a decade or less experience.

With every freshman class, challenges lie ahead. There is a learning curve, new set of priorities, and competing interests. Without outspoken advocates, issues can quickly get lost in the thousands of bills introduced each legislative session.

Elected officials want to hear from their constituents – the people that elected them and can re-elect them. Building strong, personal relationships with legislators and their staff is one

of the most important, yet overlooked, aspects of working in the public utility or authority arena.

In the short-term, you are putting a face on an issue that allows legislators to connect beyond the facts and figures. In the long-term, you are developing legislative champions that will seek your advice before addressing issues affecting the bleeding disorders community.

We strongly encourage you to get to know your legislators – whether it's coffee to introduce yourself, a meeting (in-person or virtual) to discuss an issue or inviting your legislator on a tour of your hemophilia treatment center (HTC). All are examples of community and grassroots advocacy and effective ways to build relationships with your legislators.

Finally, we'd like to share a few grassroots tips we've learned along the way:

10 TIPS ON EFFECTIVE GRASSROOTS ADVOCACY

1. Before contacting your legislators, do a little homework. Research their biography, committee assignments, cosponsor memos and legislation sponsored. This will offer some insight into their legislative interests. You might also discover that you attended the same school or have a hobby in common. The Pennsylvania General Assembly <https://www.legis.state.pa.us> is also a great place to start.
2. If you do not know or have never met your legislators, you should attempt to make your first meeting a friendly, get-acquainted occasion. This could be as simple as introducing yourself as a constituent at a town hall meeting or local event. Follow-up by scheduling a personal meeting in their office or a virtual meeting through ZOOM or TEAMS.
3. Take advantage of additional opportunities to connect with your legislators – whether inviting your legislators to attend an open house, an award ceremony, or a Foundation event. Likewise, opportunities might arise through involvement with professional organizations, civic or charitable organizations, or political parties.

4. The hometown connection is essential to getting a legislator's attention, so always identify yourself as a constituent – where you live and how you are connected to the community.

5. You are the expert on your issue and knowing what you or the bleeding disorders community needs. You are meeting with the legislator as a constituent. You do not have to be an expert in the legislative or regulatory process.

6. If discussing an issue, be brief, clear, and accurate. Telling your story by sharing your experiences, struggles and solutions is the most persuasive message. Allow the legislator to offer his or her view on the issue and ask questions. If the legislator asks questions that you cannot answer, be honest and provide the requested information later.

7. Your legislator may not always agree with your position. Be persistent, but not argumentative. Provide points supporting your issue. Ask thought provoking questions that will encourage him or her to contemplate your position. Keep in mind that a legislator who opposes you on an issue today may become a valued ally on a different issue tomorrow.

8. Get to know your legislator's staff. They usually have more time to devote to your issues and have more time to learn the details of an issue before briefing their legislator.

9. Always express appreciation. Follow-up with a thank you letter or e-mail that briefly restates your main points and includes any information you offered to provide.

10. Once acquainted with your legislators, it is important to maintain an ongoing relationship. Stay informed about your legislator's activities by subscribing to his or her newsletter. Attend and participate in town hall meetings. Invite your legislators to your office to meet with your colleagues.

Erik Ross
Senior Associate
Milliron & Goodman Government Relations

WORLD HEMOPHILIA DAY

April 17, 2022

World Hemophilia Day was recognized on April 17th. Several buildings cross the Commonwealth were lit up red to spread awareness and support. Governor Wolf also issued a proclamation, as seen here:



SCHOLARSHIP RECIPIENTS Q & A

Thank you to the following college students for responding to a brief Q & A! We wish you the best as you wrap up your 2021-22 school year and hope to see you at some of our events!



Tejas Sharma
Sophomore
Villanova University

(TS)



Michael Iannuzzi
Sophomore
Rowan College at
Burlington County

(MI)



Elliot Copeland
Junior
Penn State University

(EC)



Justine Lampe
Freshman
Indiana University

(JL)

Q: What is the name and location of the school you attend?

TS: I am a sophomore at Villanova University in Villanova, PA. I am majoring in Computer Science. I want to be a software engineer/Executive.

MI: I am a sophomore at Rowan College at Burlington County in Mount Laurel, NJ. I am a Communications major and want to be an actor when I grow up!

EC: I attend Penn State University Park and am a rising senior. My major is Political Science and I want to make people's lives better.

JL: I am a Freshman at Indiana University, Bloomington, Indiana. My major is Accounting, and I would like to be a CPA.

Q: What is one piece of advice you would give a high school senior RIGHT NOW as they prepare for graduation and college?

TS: Try a lot of things to give you an idea of what you want to do 10 years from now. Once you have figured it out, master the skills to help you get where you want to be.

MI: Try your best at everything you do!

EC: Don't be afraid to say no if you're not comfortable with an opportunity or a situation

JL: Don't stress - wherever you go, you'll have friends, opportunities and fun!

Q: Are you involved with a hemophilia foundation?

TS: Yes - The Eastern PA Foundation

MI: Yes - The Eastern PA Foundation

JL: Yes - The Eastern PA Foundation

Q: What is your involvement?

TS: I spoke as a speaker at the last annual conference, and I attended a few events.

MI: Volunteering with the foundation.

JL: My family goes to events, and I volunteered pre-COVID and also did the virtual cooking class.

Q: What is one piece of educational or advocacy advice you would pass on to future college students who have a bleeding disorder?

TS: During college, a lot of people begin to do crazy things due to the newfound freedom, and sometimes you get a lot of 'fear of missing out' as everyone around you tries new things. However, it's important to recognize your abilities, and if you think something is risky, it is beneficial to say no to things.

MI: I would say to keep fighting, to help out others as much as possible, and that you can do anything you put your mind to!

EC: You are not alone- there is strength in numbers, and we need to support each other!

JL: As a carrier, I haven't had the kind of experience to offer advice.

Q: Did you do anything good for April Fool's Day, or hear of anything good? Make it appropriate please for ALL readers!

TS: I really loved this web cartoon, but the author wrote the last chapter and ended the series a year ago. On April Fools, the studio suddenly released a new chapter. When I opened it, it just had a meme and 'April Fools' underneath. They got me good....

MI: Someone told me that a teacher pranked their students with a word search that had no words in it.

JL: I told my Dad I was dropping out (I think he recovered).

COVID-19 and Hemophilia

Preparedness and Self-Care in a Pandemic

This information is provided for educational purposes only and is not intended to replace discussions with a health care provider. Speak to your treatment team if you have any questions about your/your child's care.

This content is brought to you by Pfizer.

The COVID-19 pandemic brought with it many lessons that can be carried into the future, including ones on preparedness, health care provider (HCP) communication, and self-care.

HCP Communication

Good communication with your hemophilia treatment center or care team can be an important part of living with hemophilia. During a pandemic, your team can help you understand possible risks based on your condition, as well as advise on treatment and vaccination.

Being prepared and proactive in hemophilia care¹

One of the lessons of the COVID-19 pandemic is that it is important to be prepared, and that also applies to the hemophilia community. National Hemophilia Foundation's (NHF's) Medical and Scientific Advisory Council recommends:

- Having a 14-day supply of factor products available during crisis for those who treat at home
- If an ER visit is required, call in advance so staff knows you are coming and why; this will help them prepare
- Staying in contact with your doctor's office or hemophilia treatment center (HTC). They can explain what to do if you need to visit in person or can help get you connected with telehealth appointments, if available

Caring for yourself²

Events such as the COVID-19 pandemic can create uncertainty for many, which can stir up emotions such as anxiety, fear, anger, sadness, discouragement, or a sense of being out of control. Self-care is important to help you

address these feelings. Here are a few tips you can use to take care of your mental health:

- Set and maintain a routine
- Focus on things you can control
- Use technology to maintain social connections with your loved ones
- Focus on reasons to be grateful
- Read books or listen to music
- Take a break from news and social media if it makes you anxious
- Look for ways to help your community
- Acknowledge and appreciate what others are doing to help

Further information

Many of the larger advocacy groups have sites to keep you in the know, see below:

- **The Coalition for Hemophilia B**
hemob.org
- **Hemophilia Federation of America**
hemophiliafed.org
- **Hope for Hemophilia**
hopeforhemophilia.org
- **National Hemophilia Foundation**
hemophilia.org
- **World Federation of Hemophilia**
wfh.org

These websites are neither owned nor controlled by Pfizer. Pfizer does not endorse and is not responsible for the content or services of these sites.

Be sure to also inquire of your local chapter/advocacy organization and speak to your HTC's social worker for more information about available assistance programs.

References: 1. Supplemental MASAC statement regarding home delivery and refill under state of emergency declaration. National Hemophilia Foundation website. Published March 30, 2020. Accessed July 27, 2021. <https://www.hemophilia.org/news/supplemental-masac-statement-regarding-home-delivery-and-refill-under-state-of-emergency-declaration> 2. Reichert S. Self-care tips during the COVID-19 pandemic. Mayo Clinic Health System website. Published April 7, 2020. Accessed March 30, 2021. <https://www.mayoclinichealthsystem.org/hometown-health/speaking-of-health/self-care-tips-during-the-covid-19-pandemic>



Patient Affairs Liaisons are a team of non-sales, non-promotional field-based professionals. Pfizer's Patient Affairs Liaisons are dedicated to serving the rare disease community by connecting patients and caregivers with Pfizer Rare Disease tools, including educational resources, access support, and community events in your area.

Visit www.pfizerpal.com to connect with your Patient Affairs Liaison.

NHF WASHINGTON DAYS

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NHF WASHINGTON DAYS

On Wednesday, March 2nd, the Western Pennsylvania Bleeding Disorders Foundation participated in the National Hemophilia Foundation's virtual Washington Days. Advocates from Western PA included Lisa Gonzalez, Delores Johnson, Ethan Webb, Kyrie Holliday, Jessica Lee, Janet Barone, Kara Dornish, and Dawn Rotellini. We attended meetings with Kate Werley, Representative Mike Doyle's Legislative Director; Rachel Hugman, Representative Conor Lamb's Legislative Assistant; and Kate Samuelson, Policy Advisor for Senator Bob Casey. We asked them to maintain support for federal bleeding disorders programs at NIH, CDC, and HRSA. We asked members of House to co-sponsor the HELP Copays Act (HR 5801) and members of the Senate to introduce a companion bill to ensure that all copays count for patients.

FEDERAL BLEEDING DISORDERS PROGRAMS

We explained that there are federal programs that support our community and asked for their continued support of the following programs:

- National Institutes of Health (NIH): Funds biomedical research on bleeding disorders. NIH is working to implement a national blueprint for research on inhibitor prevention and eradication.
- Centers for Disease Control and Prevention (CDC): Funds HTC surveillance and prevention activities, and supports outreach and education programs provided by national bleeding disorders patient organizations.
- Health Resources and Services Administration

(HRSA): Provides funding for HTCs to provide multi-disciplinary services not typically covered by insurance, such as PT and social work services. Also, as HRSA grantees, most HTCs participate in the 340B Drug Discount Program, which supports comprehensive care offered to all their patients.

BLEEDING DISORDERS CONCERNS ABOUT AFFORDABILITY

People with bleeding disorders must have access to comprehensive health insurance that covers their life-saving treatments and expert care provided at hemophilia treatment centers (HTCs). Annual treatment costs exceed \$350,000 per year for a person with severe hemophilia. Therefore, people with bleeding disorders hit their annual out-of-pocket (OOP) maximum each year. For 2022, the OOP limit is \$8,700 for an individual and \$17,400 for a family.

Thus, many community members worry about:

- Having access to and affording comprehensive insurance coverage
- Paying their OOP costs for treatment
- Hitting their OOP limit, often in the first month
- Needing financial assistance to afford their OOP costs

WHAT ARE COPAY ACCUMULATOR ADJUSTOR PROGRAMS AND HOW DO THEY IMPACT PATIENT ACCESS?

- Many people with bleeding disorders and other chronic conditions need copay assistance programs to help them afford their high OOP costs.

continued on page 13



Are you a Pennsylvanian
living with a rare disease or
caring for someone who is?

TAKE THE CONFIDENTIAL PA RARE DISEASE SURVEY NOW

10 minutes of your time will help the PA
Rare Disease Advisory Council to gain
a better understanding of the needs of
Pennsylvanians living with a rare disease.



It's easy!

Just scan the QR code using a mobile
device or visit pardac.org/survey/

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.

ALL COPAYS COUNT COALITION

- An increasing number of private health insurance plans are implementing copay accumulator adjustment programs that disallow copay assistance from counting towards a patient's deductible and OOP maximum.
- When copay assistance is not allowed, many patients cannot afford their treatments and stop taking them or reduce the prescribed dosage. This often leads to complications and has unintended consequences (i.e., increased ER visits, joint bleeds/damage, and missed days from work/school) that harm patients and increase overall costs.
- This also affects people with other expensive conditions. NHF helps lead the All Copays Count Coalition, which has 120+ members representing people with cancer, MS, HIV/AIDS, arthritis, lupus, and other rare and chronic conditions.

THE HELP COPAYS ACT

Plans should be required to count all copays (regardless of who pays) towards a person's OOP maximum. The Help Lower Patient Copays Act (HELP Copays Act) is a bipartisan, two-part solution that:

- Clarifies the ACA definition of cost sharing to ensure payments made "by or on behalf of" patients count towards their deductible and OOP max.
- Closes the EHB loophole to ensure that any item or service covered by a health plan is part of the EHB package so that all related cost sharing counts towards a patient's cost sharing limits.

In the House, HR 5801 was introduced by Reps. McEachin (D-VA) and Davis (R-IL). We are asking Representatives to co-sponsor the bill. In the Senate, we are asking Senators to introduce a companion bill.

2022 BLEEDING DISORDERS CONFERENCE

Houston, TX + Online Aug. 25-27

Join the fun at the 74th Annual Bleeding Disorders Conference (BDC) this summer in Houston, Texas!

From August 25-27, you'll be able to reconnect with your community, learn in sessions designed just for you, and more!

For those unable to travel, the conference also features a virtual registration option. However you choose to attend, you don't want to miss this year's event!

Register the whole family at hemophilia.org/bdc.



DID YOU KNOW?

.5% of each Amazon Smile purchase can go towards our foundation.

Here's how:

1. Visit smile.amazon.com
2. Sign in with the same account you use for Amazon.com
3. Select Eastern PA Bleeding Disorders Foundation
4. Spread the word!



NEW CONTACT INFORMATION?

If you have an updated address, email address or phone number, please send to Sarah Pilacik @ sarahp@hemophiliasupport.org.

SAVE THE DATE

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for the **WORLD** 

Presented By



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October 1



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Use code **PADay** for 25% off registration.

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www.saveonelife.org

All proceeds of the PA ride benefit Save One Life and the Eastern & Western Pennsylvania Bleeding Disorders Foundations.





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