The Winning Spirit Newsletter

Summer 2023

EASTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

41 COUNTIES

1 MISSION

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UPCOMING EVENTS

22 JULY
SATURDAY
ADVENTURE SPORTS

9 SEPTEMBER
SATURDAY
ADVENTURES IN LEARNING

12 SEPTEMBER
TUESDAY
ANNUAL GOLF CLASSIC

30 SEPTEMBER
SATURDAY
UNITE WALK

3-5 NOVEMBER
FRIDAY-SUNDAY
WOMEN'S RETREAT

28 NOVEMBER
TUESDAY
GIVING TUESDAY

(TBD) DECEMBER
HOLIDAY PARTY

For a complete list of events planned for this year, please visit our events page: epbdf.org/event

Letter from Executive Director

Sarah Ross Pilacik

Dear EPBDF Community,

Summer is HERE! As we enter the third quarter of the year, I wanted to take a moment to reflect on our advocacy efforts, impactful educational events, programming, and financial assistance initiatives which have shaped our organization's second quarter. Together, we have made significant strides in our mission to empower and support this community.

Advocacy:

Advocacy remains at the core of our organization's work, and the second quarter was no exception. I am proud to announce that through our advocacy efforts, Western and Eastern PA Foundations have trained fifty Advocacy Ambassadors and Attended thirty-three legislative meetings since March in Washington DC and Harrisburg. We held our first ever joint Advocacy Ambassador Retreat in March, at Bedford Springs, where fifty incredible Advocacy Ambassadors were trained and equipped with resources to advocate on behalf of the bleeding disorders community. Just a few days later, many of us were together again on the Hill. We saw the passing of PA Senate Bill 225 which works to reform the prior authorization process to expedite approval of patient care and reduce administrative burdens for hospitals, physicians, and other health care providers. We saw a 6% increase to the hemophilia line item in the state budget. These funds go directly to our state HTCs for patient care and a portion is used as an emergency fund to help patients experiencing financial hardship due to their bleeding disorder. Our work is far from over, we are working hard to garner support for an increase to the hemophilia line item in the state budget and to get legislation passed to stop copay accumulators and maximizers. We need to continue building strong relationships with legislators and we need your help. One thing you can do is sign up for our advocacy action alerts found on our website and further in this newsletter. I want to stress the importance of understanding what copay accumulators and maximizers are so that you can recognize the language in fine print in your policies. If you have any questions or are unsure, please email me.

Education:

Along with providing our community opportunities to learn from and meet industry at our "mini programming events" on weeknights and weekends, we also held our Patient Education Day at the Sheraton Valley Forge on April 29. This was a strong program which included participation from staff at three Hemophilia Treatment Centers. I would encourage the community to keep your eye out for our next Patient Education Day and make it a priority and commitment to attend. As a former educator, I believe, truly, that knowledge is power and the more this community knows the better you can advocate for yourselves and your loved ones on many levels. Even though all may seem well, things can change quickly, and I want this community to be prepared. All education events are posted and sent in our weekly communication, and we encourage you to attend. There are some great ones coming up soon and even this summer!

Programming:

We have been busy with our programs as well! This year, we held our Bowling for Bleeding Disorders fundraiser, Spring Fling Family Day, Summer Kick-off, and the Annual Meeting. On the horizon we have our Annual Golf Outing fundraiser, Unite Walk fundraiser, and Women's Retreat. All can be found on our website.

Financial Assistance:

We are proud to continue to provide patient financial assistance to our community through close work with our Hemophilia Treatment Centers. In addition, we are gearing up for scholarship season, so please make sure you are going to our website to learn about the process and submitting applications by August 15th. Scholarships are available to students with a bleeding disorder who attend college or trade school, reside in our 41-county coverage area, and are treated at one of our six HTCs. And congratulations to any new high school or college graduates! Remember - knowledge is power! We would not be able to provide this

CONTINUED ON PAGE 4

kind of financial assistance without the generous donations from both our internal community and community at large, as well as through our fundraising efforts. If you have ideas or know of companies or foundations that might consider our Mission something they would donate to, please contact us. As well, our Annual Campaign has been ongoing since January 1 and any donations are very much appreciated.

The Board of Directors and staff met for a productive Board Retreat on April 1 and came away with a strong list of action items, one which was fulfilled by distributing Welcome Folders to all HTC's which we hope will be provided to patients during their visits so that they learn about EPBDF and our services. We also discussed the creation of an advisory board - more info on that forthcoming! I want to thank the Board for their continued support and guidance as Lisa and I both move into our second year with the Foundation.

We are excited to tell you that the Men's and Women's groups are up and running! The goal is to have one per quarter and so far, we are on course, with the next happening on June 28. Thank you to Nora Bullock, Melanie Rosen, Chris Templin, and Frank Lentini for championing this group! More information about these groups is on our website.

Please consider our website as a resource to you, including events and registration links, as well as Mental Health and Women's Initiatives. We invite you to actively participate, contribute your unique perspectives, and join us in making a positive difference in the lives of people with hemophilia and bleeding disorders.

It has been a true pleasure seeing so many faces of people I consider friends at our Annual Meeting on June 21, as well as other events so far this year! Thank you for accepting Lisa, Keyai and I into this community. We are here for you, and we really love what we do each day to work for you.

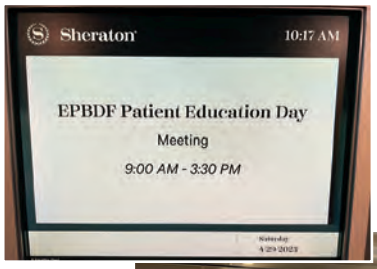
Wishing you a safe summer and a reminder to GET UP and go after what is important to you! Life is not a dress rehearsal.

With warm regards,

Sarah
Executive Director

Patient Education Day

4/29/2023



Phillies Ticket Winners

4/27/2023

Spring Fling Family Day

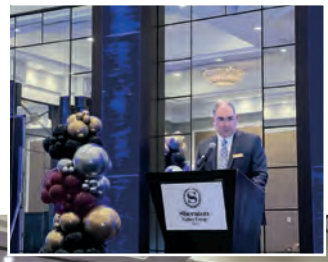
5/6/2023

Harrisburg Day

6/7/2023

Annual Meeting

6/21/2023



Summer Kickoff

6/3/2023

Mental Health Round-up

By Charlie Gilbert, LCSW & Ben Villareal Social Work Student

Have you ever wondered what the effect of having a life-long bleeding disorder might be on your mental health? Are people with bleeding disorders subject to more stress and trauma than others and does that lead to anxiety or depression? These kinds of questions are at the forefront of efforts by clinical researchers across the country to compare the rates of anxiety and mood disturbance among various disorders and the general population. Recent and Post-pandemic data on these subjects and overall quality of life are now becoming available and suggest that indeed, people with bleeding disorders are at much greater risk of developing mental health disorders.

If you are a patient in a Hemophilia Treatment Center (HTC) chances are pretty good that you have been asked to be a part of a study of symptoms of anxiety and depression. Treatment Centers want to understand the relationship between age, race, bleeding disorder history and diagnosis, and treatment effects. While the mission of HTCs is to provide specialized, multi-disciplinary healthcare to meet the physical, psychosocial and emotional needs of persons with hemophilia (PWH), they also know the pain, suffering, disappointment, stress and frustration experienced by these same persons throughout their lives. What can we expect to be the outcome of this situation? Here's what the experts are beginning to see.

Although very little is known about the number or rate of PWH seeking or receiving treatment for depression and/or anxiety, the National Center for Health Statistics (NCHS) tracks the general population utilization of mental health services. In 2022 approximately 5% of Americans reported frequent feelings of depression and another12.5% acknowledged feelings of worry, nervousness or anxiety. Looking at treatment, 12.6% of adults reported being counseled by a mental health professional. Among the US population in general, the percentage of adults (18> Yrs) reporting any mental health treatment by any provider in the past year increased by 4.7% since 2019 to 23.2% in 2021.

A recently published study by a national group of Hemophilia experts concluded that depression and anxiety rates in persons with von Willebrand disease (vWD) were much higher than that reported for the US population in general. In fact, while 7% of US adults reported high depression scores, 63.6% of vWD adults reported clinically significant depression scores on a standardized test (PHQ-9). When tabulating anxiety scores, 53. 9% of vWD adults versus 6.1% of US adults tested (GAD-7) in the clinically significant range. Among those same vWD men and women, scores for depression were roughly equal while women's scores for anxiety were considerably higher than men's scores. Also related to the higher rates of depression and anxiety among persons with vWD, were having specific symptoms of joint problems and spouse/partner status. As might be expected, persons experiencing joint pain and lacking a marital partner reported more depression and anxiety symptoms and lower quality of life scores.

In a recently published systematic review of 28 studies conducted over three decades, 2926 persons with Hemophilia A and B, were assessed for the presence of depression, anxiety, both combined and ADHD. The prevalence was reported as follows:

- Depression 41.7%
- Anxiety 16%
- Anxiety & Depression 39.7%
- ADHD 15.3%

The above findings suggest, that 2 out of every 5 PWH may suffer from depression and/or anxiety and this is often linked to poor treatment adherence and additional functional impairments. Quite a few of the studies considered what might be the effect of comorbidities such as HCV, HIV and arthritis, but only HIV was studied extensively with a general consensus that it does not significantly increase the prevalence of depression.

One other study that bears mentioning looked at the relationship between depression, anxiety, pain and

adherence to recommended treatment in Hemophilia A and B. In this report of a convenience sample of 200 participants attending Hemophilia-related educational meetings, respondents completed a battery of questionnaires including quality of life, depression, anxiety, pain and social support scales. Depending on whether the patient used on-demand or prophylaxis treatment regimen, they also completed the VERITAS-PRN or VERITAS-Pro to assess adherence to clotting factor replacement therapy. In short, the findings revealed that depression, anxiety, pain and low treatment adherence were significantly interrelated. No real surprises here for the bleeding disorder community. However, it was noted that 28% of participants reported moderate to severe depression and 13% had moderate to severe anxiety and more than half of these individuals had never received a diagnosis for these illnesses.

This study points to the critical numbers of persons with undiagnosed depression and anxiety in this population and the need for additional surveillance, by individuals and families and our Hemophilia Treatment Centers. For many members of the bleeding disorder community, adding one more diagnosis seems burdensome and irrelevant, especially one that carries a certain stigma in our culture. Both depression and anxiety contribute to a lower quality of life for patients and families and this saps motivation, pain resistance, energy and self-concept. Treatment is available for these medical ailments and yet so many from this group fail to see the potential improvements in their lives and the lives of their families that would accrue from acceptance.

Why is this important to PWH or family of PWH?

Research has identified PWH as an at-risk group for developing symptoms of depression and anxiety. It is important for PWH and their family members to be mindful of how these symptoms can present to best prevent the development of additional stressors and illness. People in the bleeding disorder community face a variety of adverse challenges that can lead to health complications that can make producing positive health outcomes more difficult. Getting to appointments at HTCs is a major component of treating these bleeding disorders, but without addressing the mental health side there can be gaps in overall quality of life. Comprehensive treatment combined with adequate mental health care when needed will lead to better health outcomes in PWH. Because of the overall risk for experiencing anxiety and depression, awareness of potential changes is crucial in preventing mental health disorders. Family members of PWH can be especially effective in helping identify significant behavioral and emotional changes which might lead to more severe problems. Here are a few that things that both PWH and family of PWH can do to help recognize depressive and anxious symptoms:

Things you can do to help:

1. Be mindful of your own internal feelings & mood.
2. Look for changes in mood, sleep, or diet in family members with bleeding disorders.
3. Get to appointments at the HTC to address any symptoms with the social worker.
4. If you observe any noticeable symptoms, get help!

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Meet Our Advocacy Ambassadors

Advocacy Ambassadors are volunteers in a leadership position responsible for helping to establish and build a strong grassroots network of bleeding disorders advocates within Pennsylvania. The goal is to help increase awareness of Hemophilia, von Willebrand disease, and other factor deficiencies and the challenges persons affected and their families face. Ambassadors serve as liaisons between the Pennsylvania Bleeding Disorders Foundations and the public, state agencies and officials working towards improving the quality of life of individuals and their families who are affected by bleeding disorders. Both Foundations are committed to our volunteer's engagement and contributions to the bleeding disorders community. We are committed to providing a worthwhile and impactful volunteer experience through the Advocacy Ambassador Program.

Brian Bullock
ARDMORE, MONTGOMERY COUNTY

Nora Bullock
ARDMORE, MONTGOMERY COUNTY

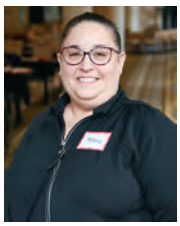
Joseph Butler
RED LION, YORK COUNTY

Marisa Ferger
STATE COLLEGE, CENTER COUNTY

Frank Lentini
ANNVILLE, LEBANON COUNTY

Joe Pileri
PHILADELPHIA, PHILADELPHIA COUNTY

Chris Ramsey
BRYN MAWR, DELAWARE COUNTY



Melanie Rosen
KING OF PRUSSIA, MONTGOMERY COUNTY

Joey Smiles
WYOMING, LUZERNE COUNTY

Chris Templin
BIRDSBORO, BERKS COUNTY

Everett Upton
WHITE HAVEN, LUZERNE COUNTY

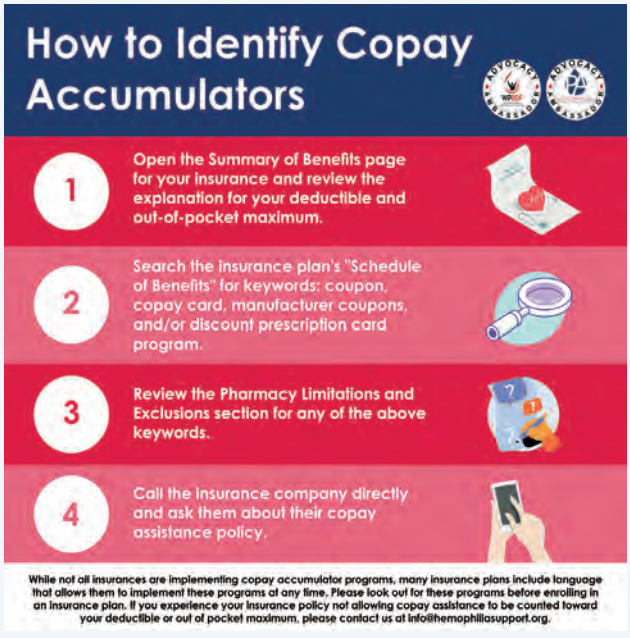
Sherry Upton
WHITE HAVEN, LUZERNE COUNTY

Constance Williams
DOVER DE, KENT COUNTY

Copay Accumulator Adjuster Programs Clearing Up the Misconceptions

Copay Accumulator Adjustment Programs are affecting a tremendous number of patients with a diverse set of health conditions – most affected are those with chronic and/or rare disorders.

- Allowing Health Plans to utilize Copay Accumulator Adjuster programs leaves a lot of patients vulnerable and unable to access their medication. Patients are choosing between paying their rent/mortgage, putting food on the table, or paying for their medication.
- Bleeding Disorder patients meet their OOP maximum the first month or two of the year. They depend on Copay Assistance Programs to help them meet their deductible.
- Currently, over 63% of marketplace plans in Pennsylvania have copay accumulator adjustment policies.[1]



1. THE AIDS INSTITUTE. "TAI REPORT: COPAY ACCUMULATOR ADJUSTMENT PROGRAMS." FEBRUARY 2023.

ADVOCACY UPDATE

State Legislation

On Wednesday, June 7, 2023, Advocacy Ambassadors from both the Western and Eastern Pennsylvania Bleeding Disorders Foundations traveled to Harrisburg to take part in the Pennsylvania All Copays Count Coalition's State Advocacy Day in Harrisburg. Thank you to the following advocates for joining us at the state Capitol: Nora Bullock, Marissa Ferger, Cassandra Miller, John Christopher Ramsey, Joseph Smiles, Maria Shoemaker, and Christopher Templin.

The PA Bleeding Disorders Team had 20 meetings. They met with the offices of Representative Abby Major, Representative Valerie Gaydos, Representative Greg Vitali, Representative Tim Briggs, Representative Mark Gillen, Representative Scott Conklin, Senator Elder Vogel, Senator Lindsey Williams, Senator Marty Flynn, Senator Wayne Fontana, Senator Christine Tartaglione, Senator Lisa Boscola, Senator Joe Pittman, Senator Devlin Robinson, Senator Nikil Saval, Senator Anthony Williams, Senator Amanda Cappelletti, Senator Carolyn Comitta, Senator Judith Schwank, and Senator Wayne Langerholc.

Our Asks

Copay Accumulator Reform

During our visit to the state capitol, we asked our legislators to support ending the dangerous practice of copay accumulators in Pennsylvania. Drug manufacturers can offer copay assistance programs to assist patients with the purchase of their prescription medications. The goal is to alleviate a person's out-of-pocket expenses and have the assistance dollars count toward the deductible. The purpose of the assistance programs is defeated if/when insurers implement copay accumulator programs, preventing the drug manufacturer's assistance from counting toward the insurance deductible and out of pocket maximum.

Senator Judy Ward (R-Blair) introduced SB 372 (the HELP Copays Act), which amends the Insurance Company Law by requiring insurers to count the drug manufacturers assistance program towards the deductible and out-of-pocket costs. The bill was introduced and referred to the Senate Banking & Insurance Committee on February 21, 2023.

Ask: **Senate**; Ask Senators to cosponsor SB 372.

House; ask Representatives to sign onto Representative MaryLouise Isaacson's (D-Philadelphia) memo calling for accumulator reform in the House.

We need patient stories. If you are experiencing a copay accumulator or maximizer please reach out to Sarah Ross Pilacik , EPBDF Executive Director, at sarah@epbdf.org or 610-770-5215.

Your stories are crucial as we are working to get this legislation passed. It is also important that you file a complaint with the insurance commissioner if you are experiencing a copay accumulator or maximizer.

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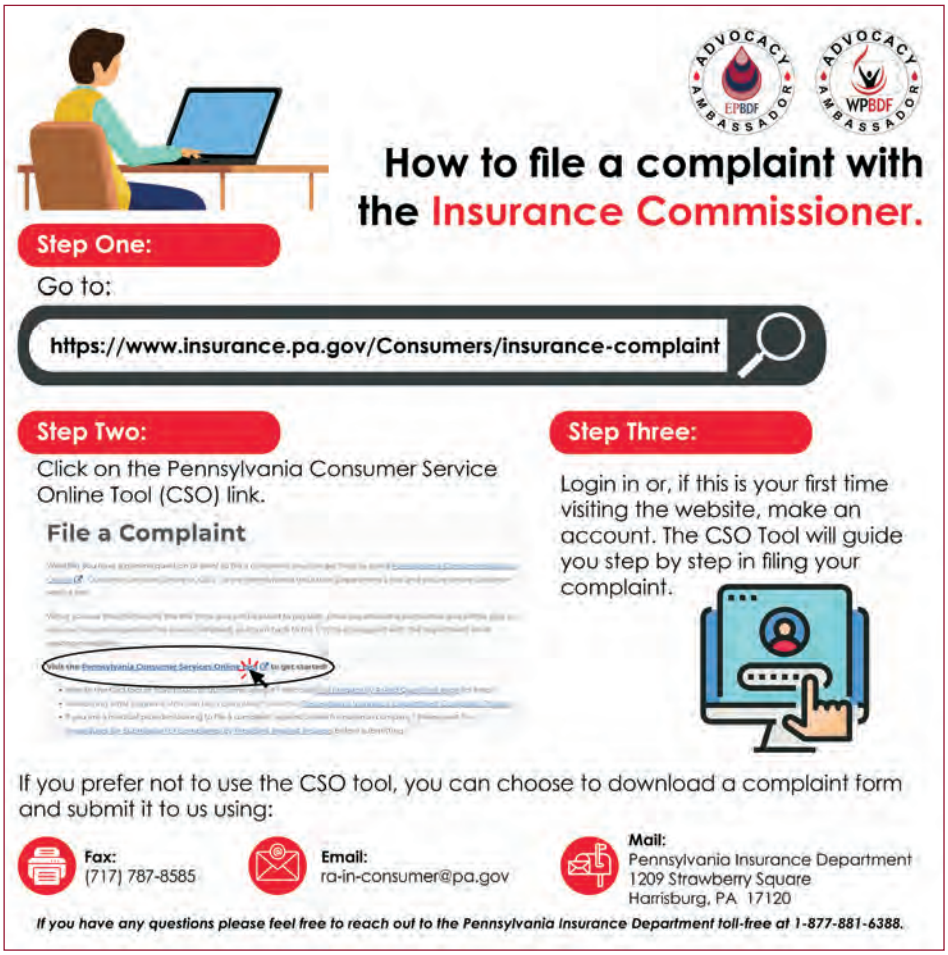
Budget Line Item

As we begin the FY 2023-24 Pennsylvania budget process, we are requesting the following:

- Increase state support from $1,017,000 to $1,250,000;
- Include language in the fiscal code to maintain the existing distribution of funding to the 7 Hemophilia Treatment Centers; and
- Maintain the hemophilia line item as a separate line item in the budget bill.

It is important to note that 100% of the Hemophilia Program line item goes directly to patient care (i.e., mostly for non-billable nursing and social work services vital for patient care) and it is critical to preserve the existing Hemophilia Treatment Center (HTC) model for the comprehensive and coordinated care for patients. A portion is also used as an emergency fund to help patients in financial hardship due to their bleeding disorder. This year, there has been an unprecedented number of requests, and it is anticipated the emergency assistance funds will be used up by the end of the month.

There are approximately 33,000 patients with hemophilia and thousands more with other inherited bleeding disorders in the U.S. More than 3,000 reside and



receive care in Pennsylvania at one of the seven-state supported hemophilia treatment centers, recognized as centers of excellence by the Commonwealth. The seven Pennsylvania HTCs are:

- The Children's Hospital of Philadelphia
- St. Christopher's Hospital for Children
- Hospital of the University of Pennsylvania
- Penn State Hershey Medical Center
- Thomas Jefferson University Hospital
- Lehigh Valley Hospital
- The Hemophilia Center of Western Pennsylvania

The seven-state supported HTCs are critical to the 3,000 Pennsylvanians who receive care at these facilities. Without this support, Pennsylvania will incur approximately 5x more costs for these citizens, from emergency and inappropriate care via Medicaid and lost tax revenue from those who become unable to remain gainfully employed. The Hemophilia Program saves Pennsylvania lives and saves Pennsylvania money.

In May, the Allegheny Democratic Delegation shared a letter of support for the hemophilia line item with the Appropriations Committee.

On Monday, June 5, 2023, the House passed a General Appropriations budget vehicle, HB 611. Under the Department of Health's budget, the hemophilia line item is proposed to be funded at: $1,250,000. This is a 23% increase from the 2022 appropriation: $1,017,000. The bill passed the House with a vote of 102-101 and was sent to the Senate. This is just the beginning of budget negotiations, and the numbers could change again. In addition, the fiscal code language hasn't been negotiated yet.

We will continue to keep you updated on its status at epbdf.org/advocacy.

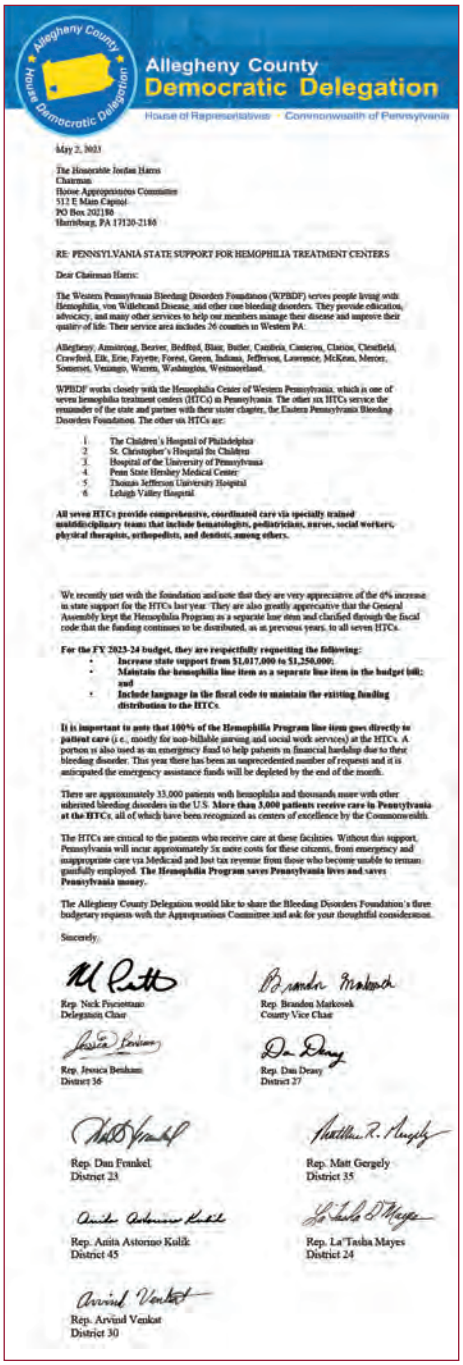
Non-Medical Switching

Pennsylvania families carefully shop for a health plan with the pharmacy benefits they need (especially if a member of the family lives with a chronic or serious illness). Every insured family signs an annual contract with their health plan, with the expectation that pharmacy benefits will remain concrete throughout the year, but that health plan's pharmacy benefits can change at any time because of non-medical decisions made by insurance companies.

Insurers are increasingly making critical changes to their plans throughout the year – directly affecting the cost and accessibility of therapies for insured Pennsylvanians. Insurers are free to put additional restrictions on pharmacy coverage, raise out-of-pocket costs, or even remove coverage of a treatment altogether – at any time during the contract year.

Legislation has been re-introduced by Senator Judy Ward (SB348), the Unfair Insurance Practices Act, which would prohibit unfair methods of competition and unfair or deceptive insurance acts and practices. This bill was referred to the Senate Banking & Insurance Committee on February 10, 2023.

After working with your doctor to find a medication or treatment that worked for you, have you ever had to change your medication due to changes with your insurance plan or out-of-pocket costs? If you've experienced non-medical switching, please fill out our survey at: https://www.surveymonkey.com/r/SMXHDJC. Your story will help us better understand how non-medical switching affects the PA Bleeding Disorders community.



Allegheny County Democratic Delegation

House of Representatives – Commonwealth of Pennsylvania

May 2, 2023

The Honorable Jordan Harris
Chairman
House Appropriations Committee
512 E Main Capitol
PO Box 202180
Harrisburg, PA 17120-2180

RE: PENNSYLVANIA STATE SUPPORT FOR HEMOPHILIA TREATMENT CENTERS

Dear Chairman Harris:

The Western Pennsylvania Bleeding Disorders Foundation (WPBDF) serves people living with Hemophilia, von Willebrand Disease, and other rare bleeding disorders. They provide education, advocacy, and many other services to help our members manage their disease and improve their quality of life. Their service area includes 26 counties in Western PA.

Allegheny, Armstrong, Beaver, Bedford, Blair, Butler, Cambria, Cameron, Clarion, Clearfield, Crawford, Elk, Erie, Fayette, Forest, Green, Indiana, Jefferson, Lawrence, McKean, Mercer, Somerset, Venango, Warren, Washington, Westmoreland.

WPBDF works closely with the Hemophilia Center of Western Pennsylvania, which is one of seven hemophilia treatment centers (HTCs) in Pennsylvania. The other six HTCs service the remainder of the state and partner with their sister chapter, the Eastern Pennsylvania Bleeding Disorders Foundation. The other six HTCs are:

1. The Children's Hospital of Philadelphia
2. St. Christopher's Hospital for Children
3. Hospital of the University of Pennsylvania
4. Penn State Hershey Medical Center
5. Thomas Jefferson University Hospital
6. Lehigh Valley Hospital

All seven HTCs provide comprehensive, coordinated care via specially trained multidisciplinary teams that include hematologists, pediatricians, nurses, social workers, physical therapists, orthopedists, and dentists, among others.

We recently met with the foundation and note that they are very appreciative of the 6% increase in state support for the HTCs last year. They are also greatly appreciative that the General Assembly kept the Hemophilia Program as a separate line item and clarified through the fiscal code that the funding continues to be distributed, as at previous years, to all seven HTCs.

For the FY 2023-24 budget, they are respectfully requesting the following:

- **Increase state support from $1,017,000 to $1,250,000;**
- **Maintain the hemophilia line item as a separate line item in the budget bill; and**
- **Include language in the fiscal code to maintain the existing funding distribution to the HTCs.**

It is important to note that 100% of the Hemophilia Program line item goes directly to patient care (i.e., mostly for non-billable nursing and social work services) at the HTCs. A portion is also used as an emergency fund to help patients in financial hardship due to their bleeding disorder. This year there has been an unprecedented number of requests and it is anticipated the emergency assistance funds will be depleted by the end of the month.

There are approximately 33,000 patients with hemophilia and thousands more with other inherited bleeding disorders in the U.S. **More than 3,000 patients receive care in Pennsylvania at the HTCs**, all of which have been recognized as centers of excellence by the Commonwealth.

The HTCs are critical to the patients who receive care at these facilities. Without this support, Pennsylvania will incur approximately 5x more costs for these citizens, from emergency and inappropriate care via Medicaid and lost tax revenue from those who become unable to remain gainfully employed. **The Hemophilia Program saves Pennsylvania lives and saves Pennsylvania money.**

The Allegheny County Delegation would like to share the Bleeding Disorders Foundation's three budgetary requests with the Appropriations Committee and ask for your thoughtful consideration.

Sincerely,

Rep. Nick Pisciottano
Delegation Chair

Rep. Brandon Markosek
County Vice Chair

Rep. Jessica Benham
District 36

Rep. Dan Deasy
District 27

Rep. Dan Frankel
District 23

Rep. Matt Gergely
District 35

Rep. Anita Astorino Kulik
District 45

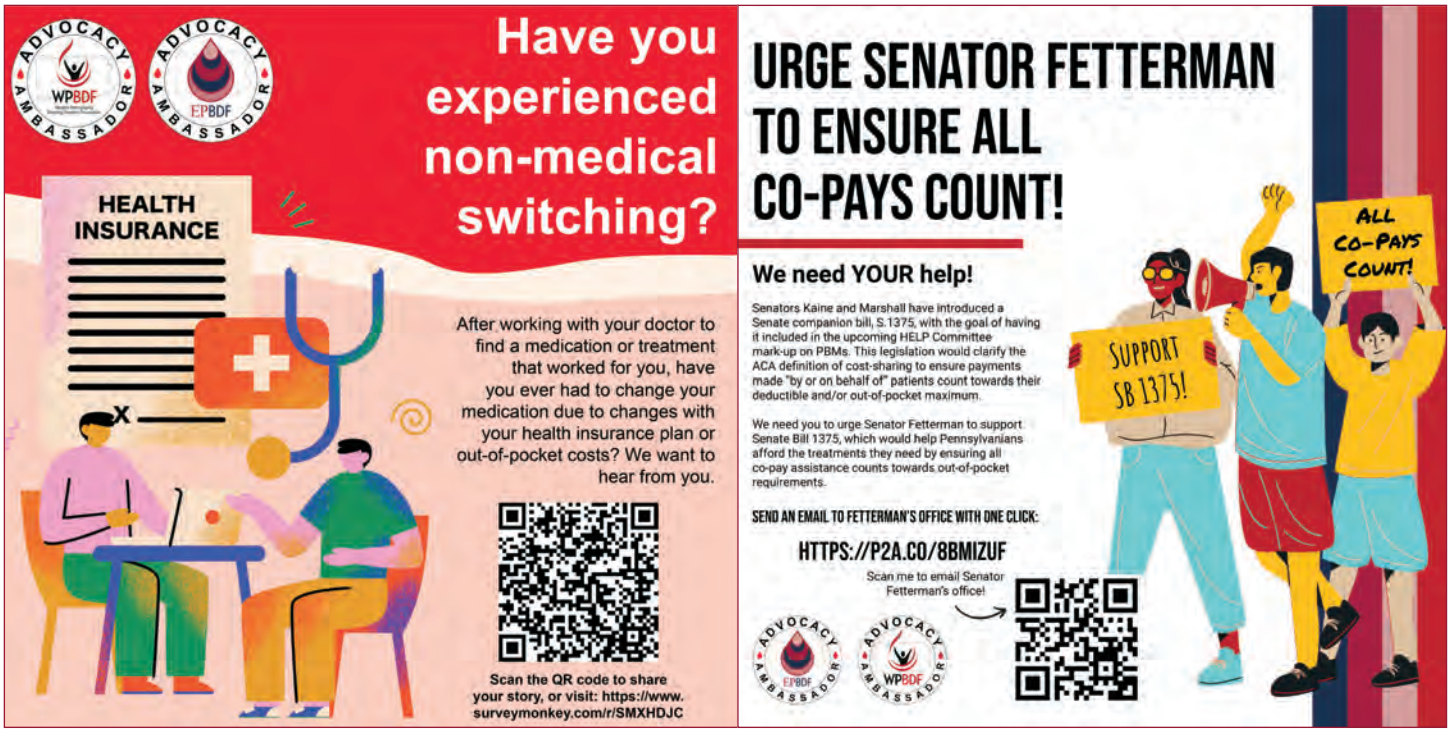
Rep. La'Tasha Mayes
District 24

Rep. Arvind Venkat
District 30

Federal Legislation

HELP Copays Act (S. 1375 and H.R. 830)

The sickest and most vulnerable patients—those who live with serious, complex chronic illness—are being targeted by health plan programs that undermine the benefits of copay assistance for medicines. The bipartisan Help Ensure Lower Patient (HELP) Copays Act eliminates barriers to treatment for patients ensuring that they can afford the necessary and life-saving medications CONTINUED ON PAGE 12



prescribed by their doctors. The legislation requires health plans to count the value of copay assistance toward patient cost-sharing requirements. This would bring much-needed relief to vulnerable patients by ensuring that all payments— whether they come directly out of a patient's pocket or with the help of copay assistance— counts towards their out-of-pocket cost.

The Essential Health Benefit (EHB) loophole allows big companies to avoid paying for critical care for patients who most need help. A loophole under the Affordable Care Act (ACA) allows many employer health plans to deem certain categories of prescription drugs as "non-essential," even when they are life-saving or necessary for people with serious pre-existing and chronic conditions. When a covered drug is deemed "non-essential," the insurer will not count any cost-sharing toward the patient's deductible and out-of-pocket maximum. This loophole also allows employers to simply not cover drugs that treat expensive health conditions. By falling into the EHB loophole, patients in these plans often must pay hundreds or thousands of dollars in out-of-pocket costs for life-saving medicines and never hit their out-of-pocket maximum.

The HELP Copays Act is a 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/or out-of-pocket maximum.
- Closes the EHB loophole to ensure that any item or service covered by a health plan is considered part of their EHB package and thus cost sharing for these must be counted towards patients' annual cost sharing limits.

Congressional action is needed to protect patients. The bipartisan HELP Copays Act can help end these harmful pricing schemes and bring much-needed cost savings to vulnerable patients.

Protect Medicaid

A recently passed House bill would cut funding to Medicaid and create new barriers to coverage and care for millions of people including many who live with serious health conditions such as bleeding disorders.

So-called Medicaid work requirements would add new administrative hurdles and extra complexity to the Medicaid program, resulting in widespread coverage losses and harm to vulnerable patients. People who live with bleeding disorders and other serious health conditions cannot afford sudden gaps in their care.

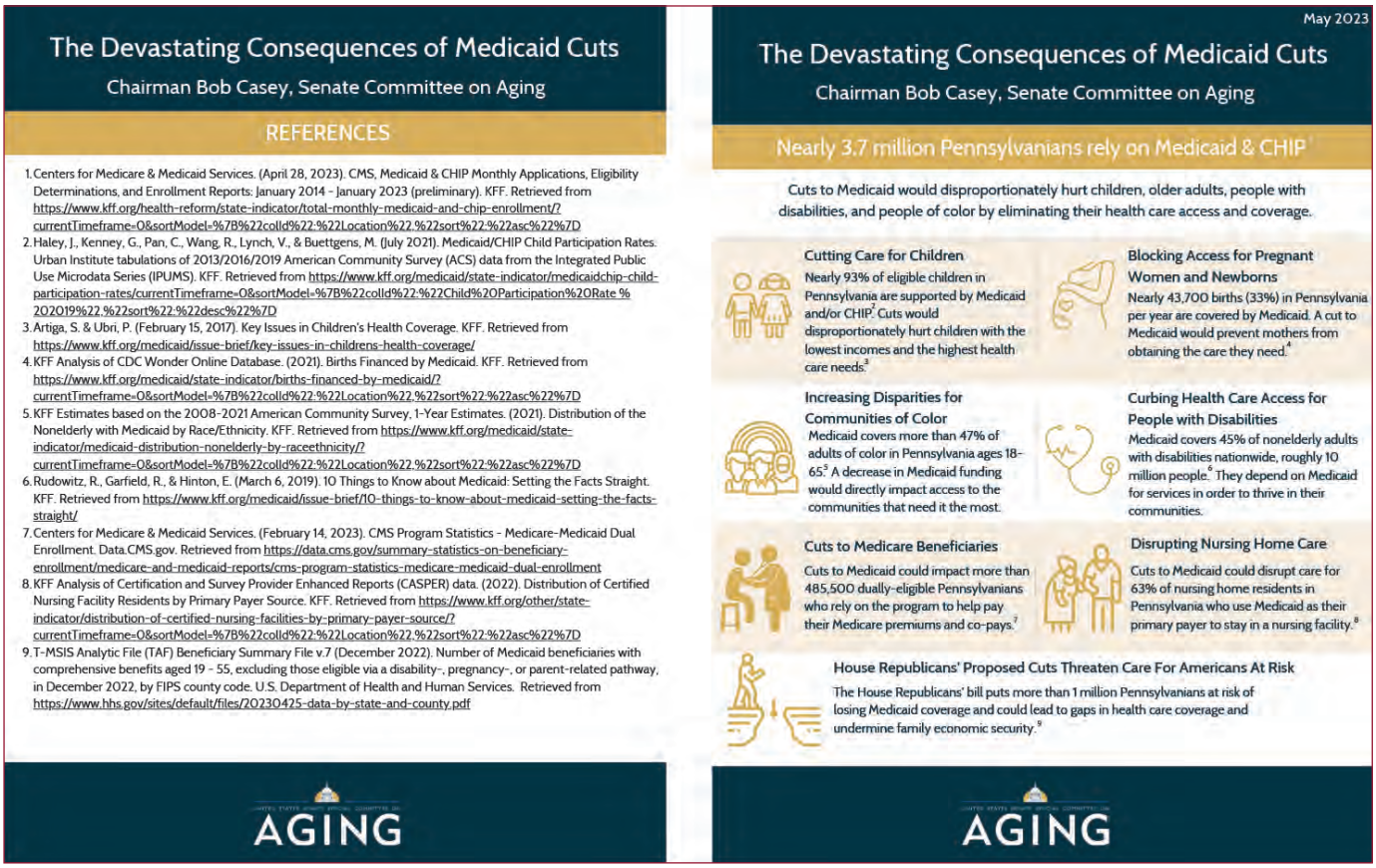
Recent experiments with Medicaid "work and reporting" requirements (Arkansas 2018) led to drastic coverage losses and yet failed to boost employment.

In fact, over 90% of Medicaid enrollees nationally already work, go to school, engage in caregiving, or would qualify for an exemption from the House-passed requirements due to age, illness, or disability. Yet they would be at serious risk of losing coverage under the new paperwork requirements. With the post-PHE Medicaid "unwinding" underway, now is a particularly bad time to layer on additional red tape and bureaucracy.

We should not add new administrative hurdles and extra complexity to a program that's already hard to navigate!

Please raise your voice to #ProtectMedicaid from cuts and counterproductive red tape.

Go to https://act.newmode.net/action/noredtape – to send an email to your legislator today!



The Devastating Consequences of Medicaid Cuts

Chairman Bob Casey, Senate Committee on Aging

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AGING

May 2023

The Devastating Consequences of Medicaid Cuts

Chairman Bob Casey, Senate Committee on Aging

Nearly 3.7 million Pennsylvanians rely on Medicaid & CHIP[1]

Cuts to Medicaid would disproportionately hurt children, older adults, people with disabilities, and people of color by eliminating their health care access and coverage.

Cutting Care for Children
Nearly 93% of eligible children in Pennsylvania are supported by Medicaid and/or CHIP.[2] Cuts would disproportionately hurt children with the lowest incomes and the highest health care needs.[3]

Blocking Access for Pregnant Women and Newborns
Nearly 43,700 births (33%) in Pennsylvania per year are covered by Medicaid. A cut to Medicaid would prevent mothers from obtaining the care they need.[4]

Increasing Disparities for Communities of Color
Medicaid covers more than 47% of adults of color in Pennsylvania ages 18-65.[5] A decrease in Medicaid funding would directly impact access to the communities that need it the most.

Curbing Health Care Access for People with Disabilities
Medicaid covers 45% of nonelderly adults with disabilities nationwide, roughly 10 million people.[6] They depend on Medicaid for services in order to thrive in their communities.

Cuts to Medicare Beneficiaries
Cuts to Medicaid could impact more than 485,500 dually-eligible Pennsylvanians who rely on the program to help pay their Medicare premiums and co-pays.[7]

Disrupting Nursing Home Care
Cuts to Medicaid could disrupt care for 63% of nursing home residents in Pennsylvania who use Medicaid as their primary payer to stay in a nursing facility.[8]

House Republicans' Proposed Cuts Threaten Care For Americans At Risk
The House Republicans' bill puts more than 1 million Pennsylvanians at risk of losing Medicaid coverage and could lead to gaps in health care coverage and undermine family economic security.[9]

AGING

COMMUNITY SPIRIT

This section of the newsletter will be reserved each quarter for you - our community! Please send info to info@epbdf.org or to our office address, which can be found on the back of the newsletter. Examples could be accomplishments, brags, births, deaths, upcoming events, memories, history related to Hemophilia/bleeding disorders, "on this date", etc. Please indicate if you would like to remain anonymous. If additional information or clarification would be needed before publication, someone from the Foundation will contact you.

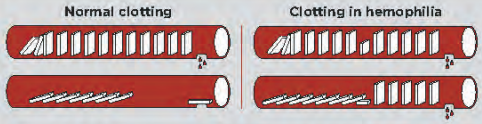
Al Kertis: My Life as a Hemophiliac

AUTOBIOGRAPHY

I was born in the spring of 1953 in the suburbs of Pittsburgh, PA, the first born for my parents. After my birth when I arrived home from the hospital my mother made the frightening discovery that my diaper was full of blood. I was immediately rushed back to the hospital at which time my diagnosis was confirmed Hemophilia Type A-moderate, although through the years I would present as severe. Hemophilia wasn't completely foreign to my mother as she had grown up with a brother, my uncle, who was a hemophiliac. It is unknown though whether the family knew enough about the genetics of hemophilia to know that there was a chance I could be a hemophiliac. Also, this was during a time when she wouldn't have known if I was even going to be a boy or girl until birth…

Please go to our website (epbdf.org) to read this autobiography in its entirety. It is in the "About" drop-down under "Community Spirit."

Bleeding Disorders: A Primer



A person with a bleeding disorder lacks a clotting protein that stops or prevents excessive bleeding. The most commonly recognized bleeding disorders are hemophilia and von Willebrand Disease.

30,000 people in the United States have hemophilia.

400,000 people in the world have a bleeding disorder. Sadly, 75% of those with a bleeding disorder have no access to treatment.

1-2% of the population is thought to have von Willebrand Disease and have not been properly diagnosed.

Treatment options vary depending on diagnosis; most patients have to take intravenous injections to replace the missing clotting protein their body lacks. It costs an average of **$300,000** per year to treat hemophilia.

30% of Hemophilia A patients will develop an inhibitor, or antibodies, to treatment. 1-2% of Hemophilia B patients will develop inhibitors. A 2014 CDC study found that anyone with hemophilia can form an inhibitor and that all patients should be tested yearly.

In 1973, the Hemophilia Act was passed to form a nationwide network of federally funded Hemophilia Treatment Centers to provide comprehensive care and medical experts for bleeding disorders patients.

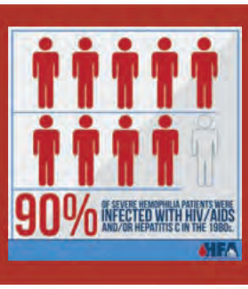
Bleeding disorders are inherited genetic conditions. However, 30% of new hemophilia diagnoses happen with no family history. Women who carry the hemophilia gene have a 50% chance of passing it along to all of their offspring. Women can and do have bleeding disorders, including hemophilia.

In 1990, the Patient Notification System (PNS) was created to provide a fast, free, and confidential program alerting patients with bleeding disorders of a withdrawal or recall of therapy products or ancillary supplies.

Hemophilia A is the most common type of hemophilia.

Hemophilia B (or Christmas Disease) is another type of hemophilia.

In the 1980's many members of the bleeding disorders community contracted HIV/AIDS and/or Hepatitis C from tainted blood products. Tragically many of those infected have since died.



Hemophilia Federation of America (HFA) became an independent entity in 1994 as a place of education and support for hemophilia families. Today, HFA continues to assist, advocate, and serve as the voice of the bleeding disorders community.

GEOGRAPHIC DISTRIBUTION
BLEEDING DISORDERS PATIENTS

This data was provided to us by the CDC, and is up-to-date as of August 2022. However, it is important to note that nearly 1/3 of patients with hemophilia do not go to Hemophilia Treatment Centers (HTCs), and these numbers therefore represent an undercount.

The NIH estimates that between 1 and 100, and 1 and 10,000 people have von Willebrand's Disease (VWD), and that is often underdiagnosed.* Most agree that vWD is the most common genetic bleeding disorder and many do not go to Hemophilia Treatment Centers for care.

**http://ghr.nlm.nih.gov/condition/von-willebrand-disease*

Geographic Distribution of Patients Enrolled in CDC Community Counts Registry By State of Residence, 12/2013 - 8/2022

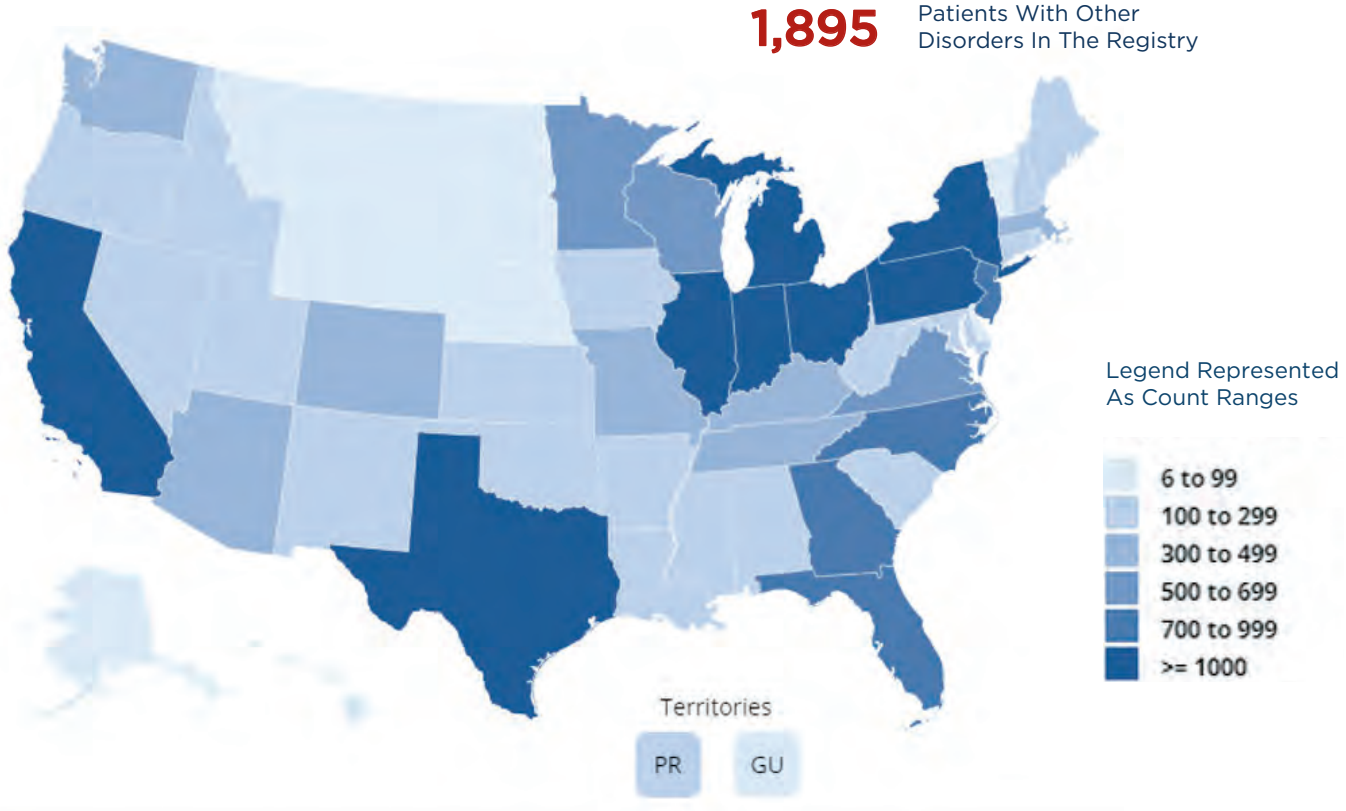
79,842 Patients Enrolled In The HTC Population Profile

22,326 Patients Enrolled In The Registry

14,794 Patients With Hemophilia In The Registry

5,637 Patients With von Willebrand Disease In The Registry

1,895 Patients With Other Disorders In The Registry



This map presents the number of individuals who attended a federally supported hemophilia treatment center (HTC) from 12/1/2013 to 08/31/2022 and who were entered into the HTC Population Profile (*https://www.cdc.gov/ncbddd/hemophilia/communitycounts/about.html*) as of 08/31/2022.Individuals were counted only once, regardless of the number of visits made to an HTC during this period.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Lorie Kerstetter

Patient advocate

About Lorie

Lorie is a Novo Nordisk Hemophilia Community Liaison whose passion for helping people with disorders began years ago when her son was born with severe hemophilia A. She wants to advocate for families in the hemophilia community and is excited to educate them about Novo Nordisk products.

Connect with Lorie

LOKS@novonordisk.com
(717)-368-2851

Hemophilia Community Liaison

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WOMEN'S GROUP

FOR MORE INFO EMAIL THE FOLLOWING COMMUNITY MEMBERS:

NORABBULLOCK@GMAIL.COM
ROSENPHOTO@AOL.COM
FRANK.P.LENTINI@GMAIL.COM

MEN'S GROUP

Do you have a great OBGYN?

Please share with us if you have an OBGYN who provides the comprehensive care and understanding which you require for your or your daughters' bleeding disorder! We would like to know the providers in PA who are taking great care of our community.

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