



TOGETHER, WE CAN

ADVOCATE.



CONNECT.



EMPOWER.





ABOUT WPCNHF



Who We Are

The Western Pennsylvania Chapter of the National Hemophilia Foundation (WPCNHF) is a nonprofit consumer advocacy and service organization founded in the 1950's and incorporated as a 501(c)(3) nonprofit organization in 1976. We were founded to help meet the vast education and support needs of the bleeding disorders community in Western Pennsylvania.

What We Do

Our mission is to enrich the lives of those with bleeding disorders in Western Pennsylvania and respond to the needs of the community in a dynamic environment.

WPCNHF serves families with bleeding disorders in 26 counties of Western Pennsylvania. Membership is free for people with bleeding disorders. Bleeding disorders can affect anyone, regardless of age, gender, or race. We provide patient assistance to our members with bleeding disorders as well as hold a variety of educational events that cover a wide range of topics. Because bleeding disorders impact nearly every area of our members lives, we strive to provide relevant and timely information about everything from raising affected children, to dealing with financial stress, to joint health and treatment concerns, and much more.

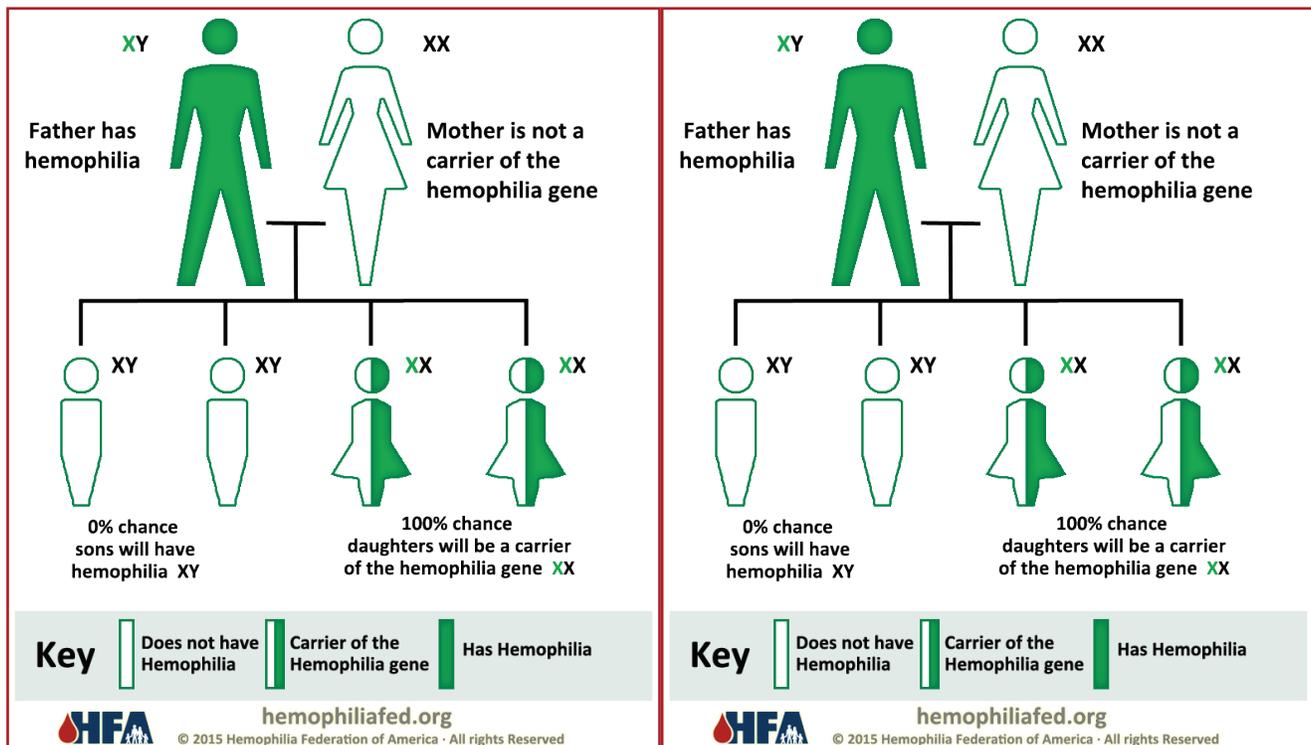
In addition to large, chapter-wide events, we have several small support groups that meet throughout the year such as the men's group, women's group, and a New Parent Network program that specifically addresses concerns of parents of children under the age of 8.

What are Bleeding Disorders?

→ A disorder where an individual's blood is unable to clot properly due to a lack of clotting factor.

People with a bleeding disorder do not bleed faster than normal, but they do bleed longer.

 **Hemophilia** — A genetic disorder caused by a missing or defective factor. The type and severity depends on which protein is involved and what degree they are deficient. The most common forms are Hemophilia A (Factor VII deficiency) and Hemophilia B (Factor IX deficiency). This disorder is commonly passed down from parents to children, but about 1/3 of cases are caused by a spontaneous mutation.



More than **3,000 people** living with Hemophilia, or other bleeding disorders, reside in *Pennsylvania*.

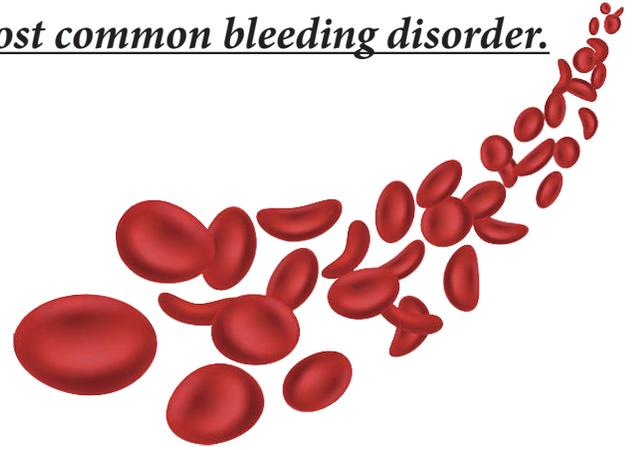
✘ Hemophilia A is **4 times** more common than Hemophilia B

✘ More than half of hemophilia A patients are diagnosed with the *severe form* of hemophilia.

von Willebrand Disease — The most common bleeding disorder.

Individuals with von Willebrand disease (VWD) have a problem with a protein in their blood called von Willebrand Factor (VWF) that helps control bleeding.

VWF helps cells in the blood, called platelets, mesh together and form a clot to stop the bleeding.



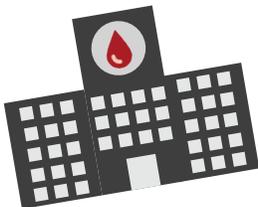
It is estimated that up to 1% of the world's population is affected by VWD but because many suffer from mild symptoms, only a small number know they have it!

9 OUT OF 10

people with VWD have not been diagnosed.



Many people with VWD may not know they have the disorder because their symptoms are very mild. VWD Type 1 is the most common with mild symptoms. VWD Type 3 is the most serious form of VWD as a patient can suffer from a joint bleed without an initial injury.

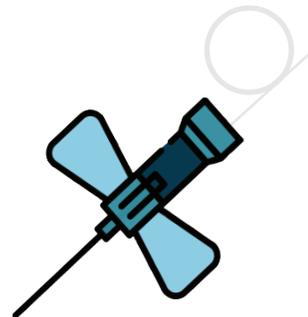


Treatment for Bleeding Disorders

The best place for patients with hemophilia to be diagnosed and treated is at one of the federally-funded **hemophilia treatment centers (HTCs)** that are spread throughout the country. HTCs provide comprehensive care from skilled hematologists and other professional staff, including nurses, physical therapists, social workers and sometimes dentists, dieticians and other healthcare providers.

The main treatment for hemophilia and rare clotting factor patients is through an infusion of clotting factor, commonly referred to as factor. Recombinant factor products, which are developed in a lab through the use of DNA technology, preclude the use of human-derived pools of donor-sourced plasma. And while plasma-derived products are still available, approximately 75% of the community takes a recombinant product.

Treatment for VWD differs from hemophilia treatment and depends on the diagnosis and severity. VWD treatment is an injection of a natural hormone that stimulates the release of VWF from cells.



Challenges of the Bleeding Disorder Community

Those diagnosed with a bleeding disorder face the risk of various physical complications such as joint damage, inhibitors, and viral infections, but there are many more emotional and psychological effects that can burden our community members.



Feelings of Isolation

Imagine receiving news about your health – or the health of a loved one – that will impact you for the rest of your life. You have a bleeding disorder. Your career, hobbies, where you live, family planning, and many other life decisions are now all affected. Your doctor can prescribe a treatment regimen, but where do you turn for help in between office visits? Who has the most relevant experience or practical knowledge to help you navigate life with a chronic illness? Where can you share your concerns? This is where WPCNHF programs and support groups step in.



Expenses

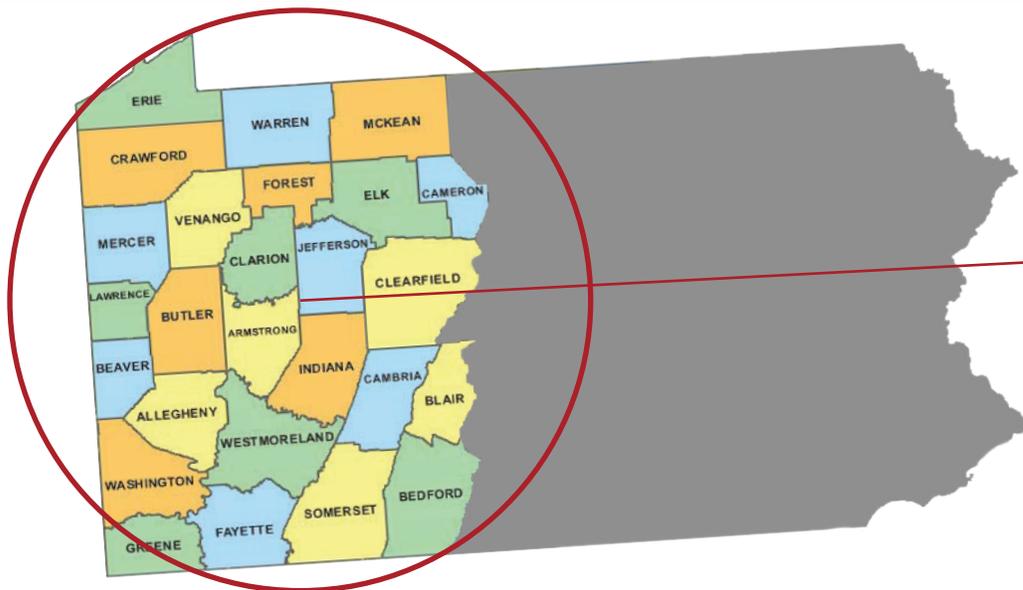
Hemophilia medication can cost anywhere from \$250,000 to 1 million dollars or more annually, depending on severity and complications such as an inhibitor. Insurance doesn't always cover a bulk of these costs, and it becomes a struggle for individuals and their families to cope with rising debt or fears being unable to afford their medication. WPCNHF works in conjunction with the Hemophilia Center of Western Pennsylvania (HCWP) to offer a patient assistance program.



Advocacy

Individuals with bleeding disorders often have to fight battles with insurance companies to stay on the medicine that works for them. A few big issues right now are Co-Pay Accumulators and Step Therapy. These are *one-size* fits all insurance policies that force patients to use generic medications instead of name brands; however, there is **no generic version** for hemophilia medication. Prescribing factor is complex and should be left up to a hemophilia specialist in consultation with their patient. Switching someone from one product to another for non-medical reasons can worsen their condition and may require additional doctors' visits, hospitalizations, permanent injury, or even death.

The Western PA Chapter of the National Hemophilia Foundation is here to support patients during times of hardship and provide a strong, supportive network to alleviate these stresses.



WPCNHF serves 26 counties in western Pennsylvania. We currently have over 1,500 Chapter members.

Programs and Services

In order to uphold our mission statement, WPCNHF provides multiple programs and services to support those affected by bleeding disorders. These include educational programs, advocacy training, and patient assistance. The following is a brief synopsis of these programs and services to better understand the role our organization plays in the community.

Educational Programs:

We offer a variety of relevant and timely educational sessions for members of our chapter. We provide general programs for all our members to enjoy that occur regularly throughout the year. These topics change based on time of year and member feedback. These can include, insurance sessions, joint health, emergency preparedness and much more. **It is important to us that our educational programs are offered to Chapter members at zero cost to them.** This ensures everyone has access to important, and sometimes lifesaving, information. The cost to host these programs is aided by our sponsors who assist in covering the cost of the venues, meals, speakers, etc., but we are constantly looking for new ways to support our educational sessions.

We offer specific support groups such as our New Parent Network, Teen Group, Men's Group, Women's Group, Young Adults, and programs for the Amish community. that focuses on education relevant to these individuals while also fostering a sense of community and empowerment.

At our 2019 three day Education Weekend conference, we offered 18 different education sessions to our members!



Our **New Parent Network (NPN) series** focuses on parents with children, ages 0-6, who recently received a bleeding disorder diagnosis. This program allows new parents and families to network with other families, gain support through a difficult time, and learn from older families and children that their diagnosis is not isolating or detrimental to their lives.



The Chapter partners with social workers from the Hemophilia Treatment Center to host our NPN program!

The Chapter supports a week long summer camp in conjunction with the Hemophilia Treatment Center!



We provide our younger members with a **Teen Group**. Teens are welcomed to join based on age and maturity level. This program's primary focus is to educate our teen chapter members about their diagnosis, while providing them the support they need to gain independence. This is done through group outings, self-infusion trainings, and group leader positions. This program also allows our teens to connect with others their age who understand life with a bleeding disorders.

Our **Men's and Women's Groups**, led by chapter volunteers in conjunction with our Program Director, provide more specific information about bleeding disorders based on health concerns related to each gender. These groups are for men and women ages 18 and over, with or without children, and allows them to connect with other individuals to share stories and gain a new perspective on their bleeding disorder. These events mix a social/networking aspect with an educational component.



The **Amish community** within our territory is large and only recently began receiving the training and education needed to lead healthy lives with a bleeding disorder. The Amish Outreach programs have been critical in educating these communities about the importance not sharing their factor, how it is based on weight and how it is unsafe to mix different factor brands.

We provide multiple **Infusion Days** per year and give families and caregivers the opportunity to learn how to infuse themselves or others. This cuts down on trips to the Treatment Center and gives those affected by a bleeding disorder the power to take control of their diagnosis.

"It's nice being part of a community that is going through, and has been through, the same challenges that we've faced. The Chapter has helped us stay positive and keep our heads up during all the hard times."

- Lynda M.

Lynda is the mother of two boys, 27 and 29, who are diagnosed with Hemophilia B. Lynda is also a carrier.

Advocacy:

The Western Pennsylvania Chapter of the National Hemophilia Foundation (WPCNHF) joins forces with the Eastern Pennsylvania Hemophilia Chapter (EPHC) to closely follow legislation impacting the bleeding disorders community. Each year an Advocacy Stakeholders Meeting is held which includes representatives from WPCNHF, EPHC, and the 7 federally funded Hemophilia Treatment Centers in Pennsylvania to discuss the needs of the community. This meeting determines our advocacy focus and goals each year. WPCNHF has an Advocacy Ambassadors Program which focuses on recruiting, educating, and empowering key

volunteers who are passionate about legislative issues facing the bleeding disorders community. We have “grasstop” volunteers who meet with legislators year-round. We keep our Advocacy Ambassadors up to date on key issues, assign them to town hall meetings, assist them in scheduling legislative visits, give them scripts for making phone calls, and draft letters for them to sign and send. We also unite with Chapters all throughout the United States by traveling to Washington, DC once a year and meeting with legislators on the hill.

Patient Assistance Program:

The cost of factor alone is extremely expensive, sometimes even with insurance. Other expenses can pile up as families take trips to and from the Hemophilia Treatment Center. Our patient assistance program fulfills requests made by chapter members for items including, but not limited to, medical I.D bracelets, medication co-payments, knee and ankle braces, gas, utility bills, and even mattresses. This program is administered in conjunction with the Hemophilia Treatment Center. All requests are filtered through them, as they understand the Chapter is the payer of last resort. We provide a maximum of \$1,000 per member per year, with the exception of transportation assistance to and from doctor’s offices, the treatment center and hospitals, which are unlimited. We pride ourselves on the fact that we have never denied a qualifying patient assistance request, but that can put a strain on our budget. We look for support from our donors, sponsors, and fundraisers and submit grants to local foundations to make up the difference.



In our 2018-2019 year,
**WPCNHF provided
over \$17,000
in patient assistance.**

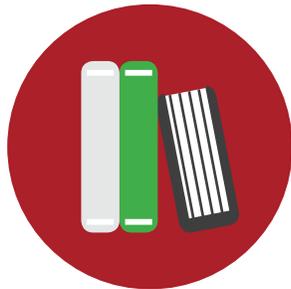


The need for our Chapter will never go away. Our membership is constantly growing as more people are diagnosed. The need for education and advocacy training is more important now than ever before as new treatments and medicines are becoming real and viable options for our patients.

Our Vision

To make the world a better place for those affected by bleeding disorders.

This will be achieved through:



Continued Education

The world is constantly changing for the bleeding disorders community. From new treatments and medicines, to insurance changes, readily available resources are invaluable to our members. Understanding their rights and making informed decisions about their care will let individuals with bleeding disorders lead their best lives possible.



Our Patient Assistance Program

Life can already be hectic enough, but extended hospital stays or an unexpected high co-pay for factor can make life that much harder. Through our Patient Assistance Program, those affected by bleeding disorders can rest easy and focus on more meaningful things in their lives, instead of being bogged down by financial stress.



Empowering the Bleeding Disorders Community

Through our advocacy training, infusion days, insurance education programs, and other services offered by the Chapter, those affected by bleeding disorders have more control when it comes to their diagnosis. They can be their own advocate and fight for their patient rights.



Fostering a Supportive Community

Being diagnosed with a bleeding disorder can be isolating, especially if you have little to no knowledge of what life will look for you or a loved one. Individuals and families can live fulfilling lives and connect with other community members to discuss hardships, or celebrate the victories, no matter how small.

Our efforts will be considered successful each year we increase the number of education programs offered, increase attendance at our educational and social sessions, continue to be able to fulfill patient assistance requests, increase the number of legislative visits we make, and receive positive results on the Needs Assessment sent to over 700 households in Western Pennsylvania.

How Can You Help?

● Monetary Donations

You can support WPCNHF through a monetary donation. We accept credit or debit card donations on our website at: wpcnhf.org. You can also send a check, through the mail to:

**Attn: Kara Dornish
20411 Route 19, Unit 14
Cranberry Twp. PA 16066**

Make checks payable to *The Western Pennsylvania Chapter of the National Hemophilia Foundation* or *WPCNHF*. Be sure to check with your employer and see if they participate in matching gifts. Some companies may double or triple the amount you donate.

● In-Kind Donations

We are always collecting in-kind donations to assist with our fundraising and programming events. Gift cards, certificates, gift baskets, etc. are great items to be used for our raffle baskets and silent auctions. Other items such as office supplies, games, or crafting supplies can also be used at our educational programs for children and families. Please don't hesitate to reach out to one of our Chapter Staff members with any questions about our current needs.

● Volunteering

A lot of what we do could not happen without our dedicated and hardworking volunteers. Our volunteers help in the office, at fundraising events, at educational programs, and even spend time away from Chapter business to raise awareness or sell tickets to other events. Check with your company and see if they offer a matching program for volunteer hours. We are happy to work with you and your team! Some events may only require a handful of volunteers, you can always reach out to our Development Director, Jessica Lee, with any questions about upcoming volunteer opportunities.



“*Giving is not just about making a donation. It is about making a difference.*”

- Kathy Calvin

CEO - United Nations Foundation

All donations are tax-exempt. Our tax exempt # is **25-1359331**. Should you require a copy of our Federal Tax Group Exemption letter, which establishes that we are a non-profit, 501(c)(3) organization please feel free to contact our Executive Director, Kara Dornish.

All donors will receive a thank you note from the Chapter stating their donation amount and our tax information for their records. Depending on the size of the donation, donors may also receive tickets and invitations to our events and programs, logos or name displayed on event marketing materials, their name printed in our quarterly newsletter, *Hemogram*, or an invitation to our annual Donor Recognition Event. We are constantly looking for new ways to express our gratitude to our donors and supporters, because we couldn't support our chapter members without them.

By supporting the Western Pennsylvania Chapter of the National Hemophilia Foundation, you are supporting our vision to make the world a better place for those affected by bleeding disorders. You are giving individuals and families affected by bleeding disorders the ability to lead fulfilling and happy lives. You give reassurance and empowerment to our community in a way no one else can. Thank you.

Contact Us



The Western Pennsylvania Chapter of the National Hemophilia Foundation

20411 Route 19

Unit 14

Cranberry Twp. PA 16066

Office Phone: 724-741-6160

Website: wpcnhf.org

Chapter Email: info@wpcnhf.org

Chapter Staff:



Kara Dornish

Executive Director

724-741-6160 | kara@wpcnhf.org



Janet Barone

Program Director

724-741-6160 | janet@wpcnhf.org



Jessica Lee

Development Director

724-741-6160 | jessica@wpcnhf.org

Board Members:

Michael Covert - *Board President*
R. Scott Domwicz
Mindy Perry-Stern

Brittani Spencer
John Younghans - *Secretary*
Jennifer Smith