

NHF/DVC

The Winning Spirit

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National Hemophilia Foundation
Delaware Valley Chapter
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The State of Healthcare Reform How Will It Affect People With Bleeding Disorders? *By Melanie Padgett Powers*

With the loss of the Democrats' filibuster-proof majority in Congress and the public's clamoring for Washington to make jobs priority No. 1, healthcare reform has been waylaid the past few months. However, the National Hemophilia Foundation (NHF) remains committed to fighting for healthcare and insurance reform, including eliminating lifetime caps and annual limits, eliminating pre-existing condition exclusions, prohibiting insurance ratings based on health status and allowing dependents to stay on their parents' health insurance plans longer.

"NHF has primarily focused on the private insurance reforms, because those are the key issues for our community," says NHF Washington representative Johanna Gray. "We've taken the lead on lifetime insurance caps, which have been a huge issue."

NHF has advocated for healthcare reforms through:

- Meetings with US representatives and senators and their staff
- Letters to congressional leadership from NHF CEO Val Bias
- Letters to Congress with coalition partners, such as the Raise the Cap Coalition, which includes more than 60 healthcare organizations
- Blast emails to the bleeding disorders community encouraging consumers to contact their senators and representatives to ask them to support healthcare reform
- Washington Days, NHF's annual advocacy event on Capitol Hill

In 2009, the House and Senate passed separate healthcare reform bills,

bringing the US closer to healthcare reform than it had been in decades. In early 2010, the two chambers were scheduled to iron out the differences in conference committee between the bills—HR 3962 and HR 3590. However, the Senate unexpectedly lost a Democratic seat in January when Republican Scott Brown was elected to the late Sen. Ted Kennedy's seat in Massachusetts.

With the Senate now made up of 59 Democrats and 41 Republicans, the Democrats do not have the 60 votes needed to prevent a Republican filibuster and bring a healthcare reform bill to a vote, throwing healthcare reform into a tailspin. Continue to stay informed through NHF's Advocacy and Legislative Updates.

Differences between the Senate and House Bills

NHF has made it clear to Congress which provisions of the two healthcare reform bills it supports. Most of the provisions NHF supports are in the House bill. A major concern is that the Senate bill grandfathers existing private insurance plans, meaning existing plans would not have to follow any of the new insurance reforms, including elimination of lifetime and annual caps and pre-existing condition clauses. Here is a synopsis of some of the provisions included in the two versions.

Lifetime caps: The House bill would eliminate lifetime caps in new and existing plans in 2010, which NHF supports. The Senate bill would eliminate

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Graphic Artist: www.chaley.com

We gratefully acknowledge the pledge of support from the following manufacturers for 2010.

Baxter Bioscience	CSL Behring
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Proplex T	Helixate FS
Feiba VH	Humate-P
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Albumin (Human)	Novo Nordisk
Advate	NovoSeven® RT
Bayer Corporation	Pfizer
Kogenate FS	Benefix™
Koate-DVI	Xyntha

Each spring, we introduce our readers to the HPPS participating companies for the coming year!! Each of these companies provides pharmacy and home supportive services to local patients affected by bleeding disorders and has qualified as a 2010 participating company. Each company meets the very high standards of service set by Hemophilia Patient and Program Support, Inc (HPPS).

Meet these companies by going to our website www.hemophiliasupport.org and clicking on the companies' logos. You will be linked directly to their site where you will find detailed information on the services that each company provides. Be an educated consumer

and get the information you need to make informed decisions about what you need in a pharmacy. If you or your family member has a bleeding disorder and you haven't registered with the HPPS program in the past, e-mail your contact information to hemophilia@navpoint.com By registering, you will be informed of important issues and events throughout the year.

Hemophilia Patient and Program Support, Inc. is dedicated to providing support to patients and programs within the geographic boundaries of the DVC. Become a member today!!

Bleeding Disorder Legal Hotline

The Delaware Valley Chapter is pleased to announce the Bleeding Disorder Legal Hotline. This free, confidential phone line is manned by an attorney, Beth Sufian, in Houston, Texas. She has over 17 years of experience helping people with chronic conditions understand the laws intended to protect them regarding health insurance and school/work issues. This Hotline was initiated by the Lone Star Chapter of the National Hemophilia Foundation in 2006. Hotline callers have reported that the information was helpful and would have been difficult to find without the help of this service. The Hotline can provide information on the issues listed below:

1. Obtaining and maintaining private health insurance.
2. Obtaining coverage from insurers for medical treatment.
3. How a small business can obtain health insurance.
4. Legal rights regarding Medicaid & Medicare.
5. Applying for Social Security benefits.
6. Appealing a denial of application for Social Security benefits.
7. Protection in the workplace from discrimination.
8. Family Medical Leave/Reasonable Accommodations in the workplace.
9. Insurance issues related to transitioning young adults.
10. Legal rights of children with medical conditions in the school setting.

The Bleeding Disorder Legal Hotline is open to people affected with a bleeding disorder and the medical professions that provide care for them. Quite simply, the Hotline is designed to bridge the gap between the laws and the people who need to know about them. Call 1-800-520-6154 and get informed.

The Hotline is recognized by the National Hemophilia Foundation as a valuable resource to the bleeding disorders community.

CHAPTER HAPPENINGS

Here's what's been happening!!

Bowling for Fun, Saturday February 27th ! A fantastic day at Thunderbird Lanes in Northeast Philadelphia on Saturday, February 27, 2010! Bowling, pizza, prizes and more! Thank you to Cheryl & Keith Littig, Pat & Chuck Felthaus and all the great volunteers & friends who bowled to support the DVC!!



NHFs Washington Day, Thursday, February 25th! Delegations of Chapter members and volunteers from all over the country met in Washington, DC to voice their position on healthcare reform issues for people with bleeding disorders and support for continued funding to the hemophilia treatment centers.

Volunteers participated from both Pennsylvania and Delaware (see front page article for the issues). A big thanks to all of our members and friends from Pennsylvania and Delaware who took the time to participate with us. Great picture of Luke Vannicola with Senator Kaufman (DE).



Here's what's coming up in 2010!

Annual Family Dinner, Tuesday, May 4th! Please join families from around the Chapter area for this wonderful evening. You will receive an invitation from your treatment center. This year, we will focus on "Life Perspectives" and will also give a special tribute to three wonderful hemophilia physicians, Dr. Barbara Konkle, Dr. Catherine Manno and Dr. Philip Blatt. Don't miss this!

Broad Street Re-Run, Saturday, May 15th! This 5 Mile Run, ½ Mile Kids' Run and a 1 Mile Family Walk is in its second year! Join us at the Pavilion Shopping Center in Lansdale, PA on South Broad Street. Test your fitness level and run the 5 mile event or walk the 1 mile family walk. Bring the kids too!! ½ mile kid run with medals to all kids given by (none other than) Super Mario and Luigi from Nintendo!! Great food and goodie bags to all pre-registered....register today at www.broadstreetrerun.com.

Grilling for a Cure/Horseshoes for Hemophilia, Saturday, May 22nd! Here's an event that you won't want to miss!! Two great events in one....bring a team to BBQ if you think you are up for this cooking challenge or sign up as a team to play horseshoes. Even better, if you can't cook or play, join us for a great fun-filled day for the entire family. Moon bounces, games, DJ, live band and tons of food. \$10 commemorative beer mug available for purchase. See all the details at www.hemophiliasupport.org or call Tom Rowe at 267-249-8389.



Carlino's Golfing for a Cure, Monday, June 7th! Dust off those golf shoes and join us for this event, sponsored by Carlino's Foods in Ardmore, PA. This event will be held at Edgemont Country Club in Edgemont, PA. Food, fun, golf. What could be better?



2010 Chapter Calendar

May

- 4 Family Dinner!
- 15 Broad Street Re-Run!
- 22 Grilling for a Cure/Horseshoes for Hemophilia!

June

- 7 Carlino's Golf!
- 25-30 Woods Camp for Kids Session #1!

July

- 10-15 Dragonfly Forest Camp!

August

- 5-10 Woods Camp for Kids Session #2!

September

- 10 Planning for Your Future!
- 20 DVC Golf Classic!
- 24-26 Family Camp!

October

- 2 DVC Walk!
- 9 Couples' Retreat!
- 22 Fall Gala!

November

- 11-13 NHF Annual Meeting New Orleans!

December

- 4 Holiday Party!

Check out the Chapter Calendar to see additional events for 2010!

The State of Healthcare Reform

lifetime caps in new plans six months after the bill is enacted. Existing plans would be allowed to have lifetime caps indefinitely.

Annual limits: The House bill would eliminate annual limits in new plans in 2013 and existing plans in 2018. The Senate bill would eliminate annual limits in new plans in 2014. Until then, annual limits would be restricted by the US Department of Health and Human Services to a level that guarantees access to medical services with a minimal impact on premiums. Existing plans would be allowed to have annual limits indefinitely. NHF supports the House bill with one exception. NHF calls for the implementation of the Senate provision that would restrict annual limits, before the House bill would eliminate annual limits in 2013.

Pre-existing condition exclusions: The House bill would eliminate pre-existing condition exclusions in new plans in 2013 and existing plans by 2018. Beginning in 2010, it would limit the time that plans could look back for pre-existing conditions from six months to 30 days and would shorten the time plans could exclude coverage of benefits, from generally 12 months to three months. In the Senate bill, existing plans could continue to use pre-existing condition exclusions indefinitely. The Senate bill would eliminate pre-existing conditions in 2014 and exclusions for children immediately. NHF supports the House bill and the Senate clause eliminating exclusions for children immediately.

Guaranteed issue and renewal: The House bill would require “guaranteed issue,” meaning no one could be denied health insurance, and guaranteed renewal of insurance policies regardless of health status, use of health services or any other related factor in 2013. The Senate bill would require guaranteed issue and renewal as of 2014. NHF supports the House bill.

Extension of dependent coverage: The House bill would allow dependents

to remain on their parents’ insurance until age 27, beginning in 2010. The Senate bill would allow coverage up to age 26. NHF supports the House bill.

Out-of-pocket caps: The House bill would set a maximum annual out-of-pocket cap at \$5,000 for an individual and \$10,000 for a family; the levels would be indexed to inflation. The Senate bill would set the maximums at \$5,950 and \$11,900. NHF supports the House bill.

Important To Remain Vigilant

No matter what path healthcare reform takes in the months and years ahead, it’s important for NHF consumers to continue to fight for reform. If healthcare reform does pass, it will still be important for NHF to monitor the implementation of the bill.

“The states will be required to implement a lot of the healthcare reform provisions, so it’s going to be very important for each state chapter to monitor that in their state,” says Michelle Rice, NHF regional director. “That’s where they need to get to know their insurance commissioner, their Medicaid officials and their state legislature. They need to be staying in close contact with those people and with other health groups in their state to make sure as things roll out that the people in that state are protected.”

Rice also reminds people that even if healthcare reform passes, reform won’t happen overnight. “A lot of these provisions are on time delay. Once a bill passes, there’s still a lot of work to be done. The community must remain diligent in monitoring the implementation process in order to identify potential problems as they arise.”

It will continue to be important for members of the bleeding disorders community to stay involved. While NHF works diligently on Capitol Hill and your local Chapter at the state level, it’s the young man scared about becoming too old to stay on his parents’ health insurance and the dad explaining how his son capped out on his insurance plan when he was still

in elementary school that make a difference to lawmakers. It’s critically important that those with bleeding disorders and their family members continue to share their stories with their representatives and senators.

“People in the hemophilia community make wonderful advocates, telling their story, telling their family members’ stories, relating them in ways that members of Congress can relate to and make them want to help,” Gray says. “Part of the reason that NHF has been successful historically is that our community members are engaged and are really effective in their advocacy.”

Brenda Neubauer is a good example of an effective advocate. Long active in advocacy efforts from her home in North Dakota, Neubauer became even more energized after one of her sons, who has severe hemophilia B, reached his \$2 million insurance cap when he was 12 years old. Jacob, now 15, had been under his father’s self-insured plan. But because Neubauer’s law firm has a different type of insurance plan, she was able to secure new insurance with a \$2 million cap.

“Basically, by a fluke, we were able to get him another \$2 million [with the same company] because one was a self-insured plan and one was a small-group employer plan. Otherwise he would not have been eligible for any more coverage,” Neubauer said. “That really was a wake-up call that I needed to get more involved.”

Through participation in NHF’s Washington Days, Neubauer called on her senator for help. She began to call and meet regularly with Sen. Byron Dorgan (D-ND) and his staff to discuss how to help people who hit their insurance cap. In 2008 and 2009, Dorgan introduced bills that would increase lifetime caps, which helped raise the profile of a then-controversial issue.

Now, with Congress in a deadlock over healthcare reform, Neubauer says she feels unsettled but knows she can’t

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HB 620 the Hemophilia Standards of Care Act Update

As of this date, *HB 620* is in the Senate Public Health and Welfare Committee waiting for consideration by the Pennsylvania Senate. Please contact your state Senator and ask for his/her support of this medical standard of care for people with bleeding disorders in Pennsylvania.

***HB 620* establishes an essential medical standard of care for citizens of Pennsylvania affected by hemophilia and other bleeding disorders. *HB 620* passed unanimously (197-0) in the PA House of Representatives on August 5, 2009. This medical standard of care is in alignment with the Standards of Care for Persons with Hemophilia established by the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF). MASAC sets the treatment standards in the United States for persons with hemophilia and related bleeding disorders. These patients are medically managed through a network of specialized hemophilia centers across the United States. There are seven state-funded hemophilia programs in Pennsylvania.**

Summary of points in *HB 620*

- Patients with bleeding disorders in Pennsylvania must have access to:
- The seven state-funded hemophilia programs
- The coagulation laboratories associated with those programs
- All FDA-approved medicines for the treatment of hemophilia
- Options in pharmacy and home supportive services
- Additionally, *HB 620* addresses the need for coagulation testing and expert medical guidance in women with bleeding symptoms prior to

a hysterectomy or other surgical procedure.

Examples of Legislation That Have Been Introduced Within State Legislatures Around the Country

Provided by Kisa Carter, MPA, Public Policy Director, Hemophilia Federation of America

Nebraska Senator Abbie Cornett introduced Legislative Bill (*LB*) 1017 to provide requirements for insurers for prescription drug coverage and *LB 1088*, The Physicians and Patient Prescription Protection Act. A bleeding disorders community member testified before the legislature regarding the importance of capping out-of-pocket costs for prescription medications. Nebraska is the only unicameral legislature in the country, which means the bill must pass through only one legislative body.

Hawaii introduced *House Bill 2461*, a bill relating to health insurance and *Senate Bill 2494*. These bills require health insurers to offer the same drug coverage that an insured received under the individual's previous plan. As of March 3, 2010, each bill went through Health Committee in both chambers.

Hemophilia and Bleeding Disorders of **Alabama**, a chapter of the National Hemophilia Foundation is actively seeking passage of *House Bill (HB) 420*, a standard of care bill.

The Delaware Valley Chapter of NHF and the Western PA Chapter of the NHF in **Pennsylvania** are actively advocating for passage of *House Bill (HB) 620*, a standards of care bill. *HB 620* passed in the House in 2009, and is now waiting for consideration in the Pennsylvania Senate.

For the last several years, bleeding disorder community members in Missouri have been committed to working with their state legislature to pass *House Bill (HB) 1525*. *HB 1525* was introduced in the current 2010 session. If passed, it will establish a standard of care for people with bleeding disorders throughout the state.

The **Florida** State Legislature has introduced *Senate Bill 516* and *House Bill 275*. If passed, these bills would prevent health insurance plans limiting choice or access to prescription drug coverage.

The **Maryland** General Assembly introduced standards of care legislation in both chambers in February 2010. The Health Insurance - Coverage for the Treatment of Bleeding Disorders (*HB. 1127/SB. 908*). The bill seeks to ensure that insurers, non-profit health service plans and HMO's "shall provide coverage for all medically necessary and appropriate pharmacy care, home nursing services, treatment at Hemophilia Treatment Centers and clinical laboratory services that an insured's or enrollee's treating physician determines are necessary to prevent, diagnose or treat a bleeding disorder."

House Bill 5212, the Insurance Coverage for the Treatment of Bleeding Disorders was introduced in **Connecticut** in February. This bill seeks to improve access to appropriate medical care for persons with bleeding disorders.

For more information on the current status of state bills to benefit people with bleeding disorders, go to: www.hemophiliafed.org

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give up. She's been encouraging others in the bleeding disorders community to continue to stress the need for healthcare reform with their state representatives and senators. "Our community needs to mobilize and advocate as a whole. Everyone has a

stake in the final outcome of insurance reform and needs to get involved."

Neubauer says her son's strength keeps her fighting for healthcare reform. "He doesn't let hemophilia slow him down or get him down. If I don't do

this, the rest of his life he's going to be struggling to try to provide for his healthcare. It's my obligation as his mother to keep fighting for him."

Previous article taken from *HemAware.org*, an online publication of the National Hemophilia Foundation 2-1-10.

Educating Gynecologists New Information. Better Treatment. *By Heather Boerner*



The first time doctors told Sherri Revard that she couldn't have a bleeding disorder because she was a girl, she was 5 years old and had just had her tonsils out.

But it wasn't the last time.

Now 41, the hospice admissions nurse from Brownstown, Michigan, bled excessively as a teen, when severe pain and heavy periods made her miss two days of school a month. And it lasted into her 20s, when the birth of her three children—two of them twins born by Cesarean section—led to unexplained bleeding that lasted for days.

Eventually, Revard's gynecologist urged her to visit a specialist. At age 29, doctors discovered that her symptoms fit with many types of bleeding disorders, including hemophilia A and symptomatic carrier—but they diagnosed her with probable type 2 von Willebrand disease and a platelet dysfunction.

Across the U.S., women like Revard tell their doctors of heavy and painful periods, childbirth complications and other reproductive tract problems. And just as people in the bleeding disorders community are becoming more aware of women's unique experience with bleeding disorders,

a movement is under way to educate their doctors.

"Only five to seven years ago, gynecologists lacked awareness about women and bleeding disorders," says Rezan Kadir, MD, OB/GYN and member of the obstetrics and gynecology department at the Royal Free Hospital in London.

When Kadir surveyed 500 gynecologists on their knowledge of bleeding disorders, only 5% to 6% said they would arrange appropriate testing to determine if their patient had a bleeding disorder. More than half suspected nothing when a woman presented with very heavy periods and said they would not take steps to rule out a bleeding disorder.

In reality, about 15% to 20% of women with heavy and painful periods have bleeding disorders.

An April 2009 monograph on the subject published in the journal *Treatment of Hemophilia* brings the point home. "Reproductive Health in Women with Bleeding Disorders" filters all the latest research on women with bleeding disorders and lays out appropriate diagnosis and treatment methods.

It reveals:

- Adolescent girls and perimenopausal women are likely to have the most reproductive tract symptoms from their bleeding disorders because they're least likely to ovulate and therefore experience erratic and longer periods.
- Women with bleeding disorders may have no symptom other than very heavy periods, including so-called "flooding" and passing of large blood clots.
- Painful periods are more common in women with bleeding disorders than in other women. In addition,

some over-the-counter pain medications, chiefly nonsteroidal anti-inflammatories, can worsen bleeding.

- Between 2% and 25% of women with bleeding disorders experience more bleeding with ovulation and hemorrhaging ovarian cysts than women without bleeding disorders.

Today, experts and organizations worldwide are drawing attention to women with bleeding disorders, including the National Hemophilia Foundation's Project Red Flag. —Andra H. James, MD, director of the Women's Hemostasis and Thrombosis Clinic and associate professor of obstetrics and gynecology at Duke University Medical Center, co-authored the monograph with Kadir. The two have also published several studies on women with bleeding disorders in major North American and European gynecological medical journals.

"Gynecologists should have a low threshold of suspicion," James asserts. "They should ask appropriate questions, help sort it out and consult a hematologist who has experience in hemostasis or a hemophilia and thrombophilia center for knowledge."

"I hold my gynecologist up on a pedestal because it was a learning experience for both of us," Revard says. "It's something he didn't have to take on, to learn. And I think it opened his eyes to other bleeding disorders people have."

Previous article taken from *HemAware*, a publication of the National Hemophilia Foundation, September/October 2009 edition.

Adult Stem Cells Show - Promise Stem cell study shows potential to correct blood diseases *By Molly Polen*

In December 2007, the journal *Science* published the first clear evidence that reprogrammed stem cells can correct an inherited disease. The study is the most recent in an increasing number of experiments that reprogram adult skin cells so they are capable of growing into any type of tissue in the body. In the study, researchers reversed sickle cell anemia in mice by modifying their skin cells with retroviruses. This rewound the skin cells to an embryonic state and created healthy replacement tissue.

This successful experiment emphasizes the potential of induced pluripotent stem cells (iPS), a new class of reprogrammed adult cells that can be studied without the social and ethical issues faced in embryonic stem cell research. To reprogram the cells, the researchers turned on four genes that are dormant in adult cells but active in days-old embryos. Once those genes were activated, the cells lost the characteristics of skin cells and behaved like embryonic stem cells, changing into precursors of bone marrow adult stem cells. The cells were then modified by physically rearranging two strands of DNA to replace the sickle cell gene. After that they were transplanted back into the mice to generate healthy blood

cells. Because the reprogrammed cells are taken from a patient's own cells, there is little risk of tissue rejection.

The strategy should work to treat dozens of genetic blood diseases, including hemophilia. "Our knowledge is still limited in terms of differentiating embryonic stem and iPS cells into various tissues, including the functional liver cells that would be required to try and treat hemophilia. But I am personally optimistic—I believe that the current obstacles are purely technical and we will see a lot of progress in the next two years," says Jacob Hanna, MD, PhD, of The Whitehead Institute for Biomedical Research in Cambridge, Massachusetts, and lead author on the study.

Researchers took cells from the tail of a 12-week-old mouse with sickle cell anemia, which results from a defect in one gene, and used viruses to turn on the four dormant genes. One of these genes, c-Myc, can cause tumors. After the cells had completed their transition back to an embryonic state, the investigators deleted it. When the cells were ready, they were transplanted into three mice with sickle cell anemia that were genetic copies of the donor mouse. Twelve

weeks later, the mice were producing blood cells that were free of the sickle cell mutations. Four months after treatment, no tumors had been detected.

The technique is still years away from being used to treat people, according to the investigators. Researchers need to find a way to reprogram adult cells without using and disrupting genes and viruses that could cause cancer and other problems. Also, more animal studies need to be done.

"Supporting human embryonic stem and iPS cell research and removing restrictions will be crucial to achieving the cure of inherited diseases like hemophilia," says Hanna.

Previous article taken from *HemAware.org*, an online publication of the National Hemophilia Foundation 1-4-10.



Delaware Valley Chapter Support Network

In an effort to increase our service and help to families in areas outside of the central Philadelphia area, we have established five branches of the Delaware Valley Chapter. The purpose of the branches is to help network patients and families affected by hemophilia and von Willebrand Disease (VWD). If you are a patient or parent/s of a patient and would like to socialize with others who share your issues, please contact one of the following team leaders to get involved.just networking with families just like you!! These branches are not open to any person who works or has a family member who works for any industry or company directly or indirectly involved in products or services for patients with bleeding disorders.

CAMP HILL BRANCH

Shannon & Jay Penica
717-975-2897

DELAWARE BRANCH

Gail & Luke Vannicola
302-378-1278

LITITZ/LANCASTER BRANCH

Lorie & Brian
Kerstetter
717-626-9679

MOUNT CARMEL BRANCH

Jolene & Sam
Scicchitano
570-339-4137

READING/POTTSTOWN BRANCH

Tina & Jeff McMullen
610-582-1731

Pennsylvania Bleeding Disorders Premium Assistance Program



Program Objective

The Pennsylvania Bleeding Disorders Premium Assistance Program was established in 2009 to provide assistance to residents of the Commonwealth with Hemophilia and von Willebrand Disease. This program offers financial assistance to subsidize private health insurance premiums and insurance case management services.

This Program May Help

- Patients in need of financial assistance to cover health insurance premium costs (even premiums deducted from payroll).
- Those who need assistance identifying individual health insurance options to make informed choices.
- Patients that have either lost or are at risk of losing Medicaid benefits due to age.
- Patients who are terminated from their employment and qualify for COBRA benefits.
- Patients who have hit the lifetime maximum on their policy.

Referral Process

This program will receive referrals from **The Delaware Valley Chapter of the National Hemophilia Foundation, the Western PA Chapter of the National Hemophilia Foundation and other community partners like Hemophilia Treatment Centers, State Agencies, Patient Organizations, Home Care Companies, etc.** Patients can also contact PSI directly. If approved, patients will transition into private insurance or continue with their current private insurance policy and PSI will subsidize the premium cost. The amount of financial assistance offered by PSI to approved clients is determined on a sliding scale* based on a client's total household income, dependants, the cost of living for the state of residence, and pre-determined extenuating circumstances.

Program eligibility will be determined by the following guidelines:

- Diagnosis: Hemophilia/von Willebrand Disease
- Hemophilia Severity: Moderate or Severe
- Von Willebrand: Actively treating with a factor product
- Resident of Pennsylvania
- Household Income at or below 200% of the Federal Poverty Level (FPL%)
- This pilot program will assist as many patients as funding permits.
- Per the PSI Choice Policy, the patient will be responsible for the choice of product, provider, vendor, and prophylactic treatment.
- Approved patients:
 - Will be required to provide updated financial documentation for review on an annual basis.
 - May have a cost share of 5% to 7% of their health insurance premium.
 - May be able to utilize up to \$11,000 of assistance annually.

How can PSI help me?

I already have a private insurance policy. PSI may be able to provide financial assistance with your insurance premium.

I don't have a private insurance policy. PSI can provide resources for private insurance policies offered in your state that might work for you. Once you select and enroll in a private plan, PSI may be able to provide financial assistance with your insurance premium.

I and/or my child are currently enrolled in Medicaid or I will soon age out of Medicaid eligibility. PSI can provide resources for private insurance policies offered in your state that might work for you. Once you select and enroll in a private plan, PSI may be able to provide financial assistance with your insurance premium.

Contact PSI at 1.800.366.7741 to request an application.

A Client Service Representative will guide you through the enrollment process.