



National Hemophilia Foundation  
Delaware Valley Chapter

*Helping People With Bleeding Disorders*

**We make**

**a living by**

**what we get,**

**but we make**

**a life by what**

**we give.**

Winston Churchill



# ABOUT US

Established in 1950, the Delaware Valley Chapter has served local families with bleeding disorders for more than fifty years! **OUR GOAL:** to enhance the quality of life for local families affected by hemophilia and related bleeding disorders. We serve more than 1,700 patients in central Pennsylvania and the metropolitan area surrounding Philadelphia and Delaware. The DVC fulfills its goals by raising funds for:

- Research
- Patient Services
- Program Support
- Education and Information
- Advocacy
- Special Events

## *Our Mission...*

The Delaware Valley Chapter of the National Hemophilia Foundation is dedicated to focusing and channeling resources available at the local level to help people affected by hemophilia and related bleeding disorders.

**“We can’t thank you enough for providing funding that helped Matt get to camp in Lake Luzerne, New York this summer. He came back a different kid, although he still had his hemophilia! He met other kids just like him and he actually learned to infuse his medicine at camp! He is more self confident in every way. He actually didn’t really want to come home! We don’t know what we would do without your help and want you to know how much we appreciate your constant help and guidance. It has made a real difference in Matt’s life and ours too!”**

–Family, Willow Grove, PA



**“Just knowing that the Delaware Valley Chapter provides more scholarships than any other NHF Chapter in the United States, makes me feel very lucky to have this resource behind me in my life. I wouldn’t have been able to do this without you. I have been helped by your great organization for the last four years. It meant a lot to me and my family.”**

–Student, Hatboro, PA



# WE BELIEVE

**We believe** in helping local families network with each other, by providing opportunities for shared experiences. We sponsor family-oriented special events and family support groups, camp opportunities for children, a family camp, holiday party and family dinner every year to bring families together.

**We believe** in promoting legislative support for government-sponsored programs beneficial to the community. We support The Hemophilia Standards of Care Act that will provide assurance to patients in Pennsylvania that their quality of life will be maintained, as well as their access to essential medicine and treatment.

**We believe** in providing information and education to families affected by bleeding disorders and social opportunities that help them support each other. We provide an informative newsletter, scholarships and camp opportunities and need-based short term financial support to members of our local community.

**We believe** in supporting local medical researchers and medical programs dedicated to serving the bleeding disorders community. We help in this area through direct financial support of local medical researchers and hemophilia programs, including seed funding for promising research on gene therapy, our hope for the future.

**We believe** in providing resources for local patients with bleeding disorders to help them identify appropriate, accessible medical treatment. We refer families to local hemophilia treatment centers that specialize in the care of patients with hemophilia and von Willebrand disease. We can provide information on options in home supportive care.

More than 18,000 people in the United States have hemophilia A or hemophilia B. A person with hemophilia has a missing or diminished amount of one of the blood factors needed for normal blood clotting. Depending on severity, people with hemophilia may be at risk for bleeding after dental work, surgery and trauma. They may also suffer internal bleeding, especially into the joints, with no trauma or injury and without apparent cause. While hemophilia A and hemophilia B are almost always found in males, another inherited bleeding disorder, von Willebrand disease, affects males and females equally.

**“It is with grateful hearts that we thank you for helping us network with other families who share our challenges. The newsletter, the family events and the support you have provided to our family this year meant so much to us. You have been a great resource to us this year.”**

—Family, Blue Bell, PA



**“When COBRA coverage ran out for our son with hemophilia, we turned to the Delaware Valley Chapter for help and help is truly what we got! With your help, we were able to continue his healthcare coverage through your Health Insurance Premium Assistance Program and it was truly a lifesaver. If he had lost his coverage, we would have been in financial ruin, with his medicine costing nearly \$35,000 per month! What would we do without you? We send our love and sincere gratitude. We are glad to know you are always there.”**

–Family, Norristown, PA



**“The DVC scholarship was a great help in making my dreams a reality. I have always wanted to go to college and major in Communications/Media. Now I’m actually doing it at Indiana University of Pennsylvania. My goal is to be a part of a major movie production company and make hundreds of movies for the public to enjoy. With your help, my college education will be the catapult that gives me the knowledge, confidence and industry connections to bring my work to the highest level. I am eternally appreciative!”**

–Student, Chalfont, PA

**“We had a great time at camp this year. Our three boys just loved it. Having the lake right there and the high and low ropes course open all weekend was a hit for sure! Having the nurses and doctors there all weekend allowed us time to talk with them and learn so much. Thank you for providing this great time for all of us.”**

–Parent, Folcroft, PA



**National Hemophilia Foundation, Delaware Valley Chapter**  
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The official registration and financial information of the National Hemophilia Foundation, Delaware Valley Chapter may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, 1 (800) 732-0999. Registration does not imply endorsement.

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We are proud of what we have accomplished in our most recent fiscal year. We provided \$600,000+ for local patient programs and services, including:

- \$78,000+ in educational stipends, including scholarships, camperships and sponsorships to regional and national conferences.
- \$91,000+ to help local families deal with short term financial difficulties.
- \$16,000 for research support.
- Social and referral support for families in our area, including more than 5,000 one-on-one phone calls.
- Camp opportunities for children and family social and educational events.
- Direct support to hemophilia medical programs in Pennsylvania and Delaware.
- State initiatives to ensure access to care for local patients with bleeding disorders.
- \$134,000 for health insurance premium assistance to local patients.
- \$22,500 in support of the World Federation of Hemophilia and Patient Services, Inc.

## 2011 FINANCIAL REPORT

- 90 cents of every dollar contributed to the Delaware Valley Chapter was used to support programs and services for local patients with bleeding disorders.
- The Delaware Valley Chapter provided financial support to the following Hemophilia Programs:
  - Cardeza Foundation Hemophilia Center  
Thomas Jefferson University Hospital,  
Philadelphia, PA
  - Children's Hospital of Philadelphia  
Hemophilia Programs  
Philadelphia, PA and Voorhees, NJ
  - St. Christopher's Hospital for Children  
Hemophilia Program, Philadelphia, PA
  - Christiana Hospital  
Hemophilia Program, Newark Delaware
  - Hemophilia Center of Central PA  
Hershey Medical Center, Hershey, PA
  - Lehigh Valley Hospital  
Hemophilia Program, Allentown, PA
  - Penn Comprehensive Hemophilia Program  
Hospital of the University of PA  
Philadelphia, PA
- The Delaware Valley Chapter implemented a Pennsylvania State grant to assist with health insurance premiums for patients with bleeding disorders in Pennsylvania.
- The Delaware Valley Chapter was a partner with and strong supporter of the National Hemophilia Foundation's *Research Is Our Future Campaign* supporting important research paving the way to a cure.
- Provided more than \$600,000 in direct patient aid.
- Added to an endowment established with the Philadelphia Foundation.

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