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House of Representatives  
COMMONWEALTH OF PENNSYLVANIA  
HARRISBURG

COMMITTEES

HEALTH - MAJORITY CHAIRMAN  
POLICY  
RULES

JEWISH LEGISLATIVE CAUCUS - CO-CHAIR  
PA SAFE - CO-CHAIR

April 15, 2026

The Honorable Jordan Harris  
Chairman  
House Appropriations Committee  
512E Main Capitol Building  
PO Box 202186  
Harrisburg, PA 17120-2094

The Honorable Scott Martin  
Chairman  
Senate Appropriations Committee  
281 Main Capitol  
Senate Box 203013  
Harrisburg, PA 17120-3016

The Honorable James Struzzi  
Chairman  
House Appropriations Committee  
245 Main Capitol Building  
PO Box 202062  
Harrisburg, PA 17120-2070

The Honorable Vincent Hughes  
Chairman  
Senate Appropriations Committee  
545 Main Capitol  
Senate Box 203007  
Harrisburg, PA 17120-3007

**RE: PENNSYLVANIA STATE SUPPORT FOR HEMOPHILIA TREATMENT  
CENTERS**

Dear Chairmen:

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 their 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.

The western chapter 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

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4. Penn State Hershey Medical Center
5. Thomas Jefferson University Hospital
6. Lehigh Valley Hospital

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

I wanted to express my sincere appreciation for maintaining the line item (\$1,017,00) for Hemophilia Treatment Centers (HTCs) last year. I am 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 in previous years, to all seven HTCs.

**As we continue the 2026-27 budget process, they would like to note their support for the Governor's budget proposal to fund the hemophilia line item. Myself and the WPBDF also request to**

- **Include language in the fiscal code to maintain the existing distribution of funding to the HTCs; 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). A portion is also used as an emergency fund to help patients in financial hardship due to their bleeding disorder. For the past few years, there have been an unprecedented number of requests.**

As an example, the Hemophilia Center of Western PA received \$204,406 for the 2024-25 fiscal year and they utilized these dollars for some of the following initiatives:

- Supporting patients with transportation costs, allowing patients to attend necessary appointments. They have also been vital for **accessing rare medications that are often costly and inadequately covered by insurance;**
- **Supporting routine screenings** for conditions like anxiety, depression, and PTSD are critical for identifying and addressing behavioral health issues that often accompany chronic illnesses. While these screenings are conducted regularly, the significant shortage of providers who accept Medical Assistance complicates timely access to care for our

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- most vulnerable patients. The funding helps facilitate referrals and overcome some of these systemic barriers, although the need for expanded resources remains urgent;
- Supporting the **Unified Care Protocol (UCP)**, a transformative framework aimed at eliminating barriers to care and improving health outcomes for patients. The UCP is essential for developing a comprehensive, patient-centered approach that acknowledges the complexities involved in managing bleeding disorders. It not only focuses on medical treatments but also emphasizes the vital need for psychosocial support and assistance in navigating healthcare systems. By ensuring that everyone receives holistic care tailored to their unique circumstances, the UCP significantly enhances the quality of life for patients of all ages and backgrounds; and
  - Supporting the **Consumer Advocacy Council**, which convenes three times a year to provide a platform for patients and families to voice their concerns and suggestions.

There are approximately 20,000 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 HTC's**, all of which have been recognized as centers of excellence by the Commonwealth.

The HTC's 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.**

**Again, on behalf of Pennsylvania's hemophilia community, thank you for your continued support and understanding of their issues.** Please reach out to Executive Director Kara Dornish at 724-741-6160 or [kara@wpbdf.org](mailto:kara@wpbdf.org) with any questions.

Very truly yours,

A handwritten signature in black ink, appearing to read "Dan Frankel".

Rep. Dan Frankel