



February 18th, 2025

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 Eastern Pennsylvania Bleeding Disorders Foundation supports medical research and provides financial assistance, education, family programming, and advocacy at the state and federal level to benefit patients with hemophilia, von Willebrand disease and other factor deficiencies. We proudly represent 41 counties, which stretch from Philadelphia to Potter, Clinton, Centre, Huntingdon, and Fulton. It is the Foundation's responsibility to serve our community with the highest level of service while always displaying compassion, respect and understanding.

The Eastern Chapter works closely with six hemophilia treatment centers (HTCs) in Pennsylvania:

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

The seventh HTC, the Hemophilia Center of Western Pennsylvania, services the remainder of the state and partners with our sister chapter, the Western Pennsylvania Bleeding Disorders Foundation.

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

We wanted to express our appreciation for maintaining the line item (\$1,017,000) for the HTCs last year. We 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 in previous years, to all seven HTCs.

As we begin the FY 2025-26 budget process, we respectfully make the following requests:

- **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 HTC's.**

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). 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 Lehigh Valley Health Network HTC utilizes their grant funding 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 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 population-based barriers to care and improving health outcomes for patients. The goal of the UCPs is to increase communication and collaboration within health systems and between health systems and external partners to address population health concerns while acknowledging the complexities involved in managing bleeding disorders. The UCPs are designed to support the HTC in developing, establishing, and maintaining public health infrastructure that improve system performance and service delivery; and
- **Supporting the Patient and Family Advocacy Council**, which convenes six times a year to provide a platform for patients and families to voice their concerns and suggestions. This direct engagement fosters a sense of community and ensures that patient perspectives inform our HTC's initiatives and strategies, including the ongoing refinement of the UCP.

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 bleeding disorders community, thank you for your continued support and understanding of our issues. If you need any additional information, please feel free to contact me at sarah@epbdf.org.

Very truly yours,

A handwritten signature in cursive script that reads "Sarah Pilacik".

Sarah Ross Pilacik
Executive Director
Eastern Pennsylvania Bleeding Disorders Foundation

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The official registration and financial information of the Eastern Pennsylvania Bleeding Disorders Foundation may be obtained from the Pennsylvania Department of State by calling toll-free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.