

## Bleeding Disorders Facts & Figures

- The average cost of treatment for a person with severe hemophilia is approximately \$300,000 per year and can surpass \$1,000,000 if complications occur.
- Approximately 3,000 patients with bleeding disorders receive care at one of the 7 Hemophilia Treatment Centers (HTC) located in the Commonwealth.
- The 7 treatment centers are:
  - The Children’s Hospital of Philadelphia
  - The Hemophilia Center of Western Pennsylvania
  - Thomas Jefferson University Hospital
  - Lehigh Valley Hospital
  - Hospital of the University of Pennsylvania
  - Penn State Hershey Medical Center
  - St. Christopher’s Hospital for Children
- **CDC studies demonstrate a 40% reduction in mortality and medical complications in patients who receive their care at an HTC compared with those followed by hematologists outside of this network. The overall costs of care are reduced as well.**

### What is hemophilia?

Hemophilia is an inherited blood disorder. It is due to a deficiency or lack of a specific protein in the blood necessary for proper clotting. The primary symptom of the disorder is chronic, uncontrolled, and often spontaneous bleeding into the joints, muscles, and soft tissue areas of the body. There are three levels of severity – severe, moderate and mild.

### What is von Willebrand Disease?

Von Willebrand disease (VWD) is the most common bleeding disorder, affecting between 1% or 2% of the U.S. population. The condition occurs when the von Willebrand factor, a protein that works in unison with factor VIII, is missing or defective. VWD affects both men and women. Symptoms often include frequent nosebleeds, easy bruising and excessive bleeding, particularly following surgery. Like hemophilia, there are three different levels of severity—severe, moderate and mild.

### How are bleeding disorders treated?

Hemophilia and related bleeding disorders patients require life-long infusions of expensive clotting factor therapies to replace the missing or deficient proteins in order to prevent life-threatening bleeding.

### Where do bleeding disorders patients receive care?

Hemophilia and related bleeding disorders patients need access to hematologists and other health care professionals and specialists knowledgeable about hemophilia. The majority of patients receive care at a federally-funded hemophilia treatment center (HTC).

HTCs provide comprehensive care via specially-trained multi-disciplinary teams that include hematologists, pediatricians, nurses, social workers, physical therapists, orthopedists, and dentists, among others.

### Hemophilia Program Line Item

In 1974, Pennsylvania became one of the first states in the U.S. to establish a state hemophilia program to improve patient medical outcomes, providing annual state funds to support comprehensive hemophilia treatment centers in Pennsylvania.

The Governor's proposed 2019-20 budget combined the line item funding for four separate patient programs currently managed through the Department of Health into a single line item now titled Disease Management and Education Programs.

### Our Request

**Reinstate the Hemophilia Program as a separate line item that is at least level funded at \$959,000.**