



Bleeding Disorders

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Bleeding Disorders Facts & Figures

- Hemophilia is a rare inherited blood disorder affecting more than 20,000 people in the United States, and as many as **300 people** in Nevada. It is estimated that **1-2% of the U.S. population** is affected by von Willebrand disease while other bleeding or clotting disorders are more rare than hemophilia.
- 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.
- Many Nevadans with bleeding disorders receive care at the **Hemostasis and Thrombosis Center of Nevada** located in Reno and Las Vegas, with satellite offices in central and northeast Nevada
- Studies have shown that mortality and hospitalization rates are **40% lower** for people who use HTC's than in those who do not, despite that more severely affected patients are more likely to be seen in HTC's.

What is hemophilia?

Hemophilia 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 to prevent life-threatening internal bleeding.

Due to their biologic nature, clotting factor therapies require specialized storage and handling. Thus, patients cannot access their medications at your traditional neighborhood pharmacy. Instead, medication is provided through specialty pharmacies.

Specialty pharmacies (including hemophilia treatment centers participating in the federal 340B program) usually deliver life-saving clotting factors to patients via mail or other home delivery method and provide a range of support services not offered by traditional pharmacies.

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 (HTCs).

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

HTCs treat the whole person and the family, through continuous monitoring of all the medical and psychosocial aspects of bleeding disorders, including their physical, emotional, psychological, educational, financial and vocational factors.