

Protect Americans with Bleeding Disorders - Extend the Enhanced Premium Tax Credit

Congress' Commitment to Bleeding Disorders

Since the Hemophilia Act of 1973, the United States Congress has made a continuing commitment to treating Americans with hemophilia and other bleeding disorders like Von Willebrand's Disease, ensuring that they are healthy and productive members of society.

Without treatment made available through affordable health coverage, patients face loss of critical specialized medication and care that can lead to severe internal bleeding, joint damage, permanent disability, and death.

With treatment and through Congress' continued support, patients are able to full lives, have families, and contribute to the American economy, just as all citizens should be able to.

As Congress has understood for over 50 years, **healthcare is critical for Americans with bleeding disorders.**

The Enhanced Premium Tax Credit

In 2021, Congress authorized an extension of the existing premium tax credit (PTC) to make Marketplace health plans more affordable, keeping more Americans like bleeding disorders patients on private health coverage instead of utilizing government health coverage like Medicaid.

The enhancement not only made sliding-scale PTCs available to higher-income groups at amounts that limited their premiums to 8.5% of their annual income, but also allowed those earning only 100 to 150% of FPL to enroll in benchmark plans for zero premiums.

These enhancements helped a record 92 percent of Marketplace enrollees, nearly 20 million Americans, receive PTCs, including 9.6 million who were not previously eligible. According to the Centers for Medicare and Medicaid Services (CMS), they reduced average monthly premiums for Marketplace enrollees by 32% since 2021 and saved the average enrollee \$800 per year.

Given that the average cost per year to treat hemophilia is over \$300,000, patients are often forced to choose the highest cost gold and platinum tier coverage that limits their total out-of-pocket costs and ensures access to life-saving treatment, rather than risk disability or death. Through the enhanced premium tax credit (ePTC), bleeding disorders patients have been able to maintain affordable coverage without financial ruin.

Despite the benefits to millions of Americans, including those with bleeding disorders, the ePTCs will expire at the end of 2025 if Congress does not take action. If not extended, the Congressional Budget Office predicts that premiums will spike for nearly all Marketplace enrollees and at least 3.8 million enrollees will become uninsured.

With an estimated one-third of Americans with bleeding disorders already utilizing Medicaid due to disability or poverty and under the new changes implemented through the OBBA, **the impacts to bleeding disorder patients will be catastrophic.**

Our Request to Lawmakers

Please extend the ePTCs beyond 2025, and **continue your half-century-long commitment** to ensuring bleeding disorders patients can access healthcare, especially for many of whom care is least affordable.

The ePTCs are a lifeline by which many bleeding disorders patients can afford a plan that ensures the prompt access to the specialized care they need, preventing severe injury, disability, or death.

With your support of affordable coverage, Americans with bleeding disorders can stay employed, avoid turning to emergency care or taxpayer-funded safety nets, and lead healthy and productive lives with their families.

At least 30,000 people in the United States have hemophilia, and **up to 3.4 Million** people have Von Willebrand's Disease



Treatment options vary depending on diagnosis; most patients have to take intravenous injections to replace the missing clotting protein their body

lacks. It costs an average of

\$300,000

per year to treat hemophilia.

In 1973, Congress passed The Hemophilia Act, creating a nationwide network of Hemophilia Treatment Centers, providing comprehensive care and medical experts for bleeding disorders patients.



www.hemophiliafed.org