



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

Support Private Insurance Reforms in Health Reform

Request: Support the strongest possible patient protections in the final health reform bill, including the immediate elimination of lifetime and annual limits.

Support Private Insurance Market Reforms

NHF fully supports the many private insurance market reforms included in the health reform bills, which will benefit individuals with bleeding disorders and other high-cost, chronic and rare conditions. We ask that the final health reform legislation have the strongest possible patient protections and ensure access to health insurance plans for individuals with high medical costs. Specifically, we respectfully request that the final health reform legislation:

- Eliminate lifetime limits immediately;
- Remove annual limits;
- Establish guaranteed issue and renewal;
- Implement modified community rating;
- Prohibit rescissions except in cases of fraud;
- Eliminate pre-existing conditions exclusions;
- Limit out-of-pocket expenses; and
- Extend coverage for dependents.

Oppose Grandfathering of Existing Insurance Plans

NHF opposes exempting or grandfathering existing private insurance plans from the private insurance market reforms. If enacted, this would mean that these critical reforms will not benefit the majority of Americans, who currently receive health insurance through their employers. Private insurance reforms must apply to all health insurance plans.

Facts about Bleeding and Clotting Disorders

- Hemophilia is a rare chronic bleeding disorder affecting about 20,000 people in the United States. Related bleeding disorders include von Willebrand disease (VWD), which is estimated to affect up to 2% of the population. Many individuals with hemophilia are co-infected with HIV and hepatitis C as a result of receiving contaminated blood products in the 1980s.
- People with hemophilia require life-long treatment with high-cost clotting factor therapies, which replace missing or deficient blood proteins that allow blood to clot and prevent debilitating and life-threatening internal bleeding episodes.
- Costs for clotting factor are typically \$250,000 a year or more for a person with severe hemophilia. However, the development of an inhibitor (immune response to treatment), bleeding from a trauma, surgery or a variety of other complications can elevate the cost in a given year to \$1 million or more.