



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

May 17, 2011

The Honorable Jay Nixon
Governor of Missouri
P.O. Box 720
Jefferson City, MO 65102

Re: HB 552, Standards of Care for Persons with Bleeding Disorders

Dear Governor Nixon:

The National Hemophilia Foundation (NHF) is the leading advocacy organization working to improve the lives of individuals with bleeding disorders throughout the United States. **We are writing to ask you to sign into law HB 552**, which establishes crucial standards for pharmacies that dispense blood clotting factor products to individuals with bleeding disorders on Missouri's HealthNet program.

Hemophilia and other bleeding disorders are complex conditions requiring individuals to undergo lifelong infusions of clotting factor therapies to prevent and control bleeding. These are unique biological products which require specialized handling, making it vital that specialty pharmacy providers are knowledgeable about the products and have experience working with the patient population whose needs vary depending on severity of the condition, age, and the existence of other complications.

The key provisions outlined in HB 552 are firmly rooted in the standards of service guidelines established by NHF's Medical and Scientific Advisory Council (MASAC). This group is composed of the leading experts on bleeding disorders in the United States, including physicians, researchers, and other healthcare providers. Taken together, MASAC's recommendations represent the medical standard of care for the treatment of bleeding disorders throughout the United States, and are equally respected around the world.

Again, we respectfully encourage you to support individuals with bleeding disorders by signing HB522 into law. Enshrining in law these medically established standards helps ensure that low-income and vulnerable Missourians with bleeding disorders have access to the quality care and treatment they so greatly need.

Thank you for allowing us to convey our support of HB552 and for giving them your careful consideration. If you have any questions, please do not hesitate to contact Ruthlyn Noel, Manager of Public Policy, at (212) 328-3730 or rnoel@hemophilia.org.

Respectfully,

Val Bias
Chief Executive Officer