

October 5, 2011

The Honorable Jon Leibowitz
Chairman- Federal Trade Commission
600 Pennsylvania Avenue, NW
Washington, D.C. 20580

Dear Chairman Leibowitz:

The Hemophilia Federation of America (HFA) is a national 501(c) (3) organization, consisting of 36 member organizations and independent members across the country. Based in Washington, DC and established in 1994, HFA provides community support programs and grassroots advocacy on behalf of individuals with bleeding disorders and their families.

We are writing in regards to the impact of consolidation in the health care delivery marketplace, and most recently the proposed merger between Express Scripts and Medco. As you evaluate this merger and its impact on consumers, we encourage you to examine the needs of the patients who will be affected, especially those with rare and chronic diseases.

Bleeding disorders are a genetic condition which there is a problem with the blood clotting process. These disorders are serious conditions that can be painful, disabling and life threatening. The two most common bleeding disorders are hemophilia and von Willebrand disease. In the United States, hemophilia affects 1 in 5,000 male births. The CDC currently estimates that 20,000 people in the U.S. have hemophilia in the U.S. von Willebrand disease is estimated to occur in 1-2% (or over 4.5 million) of the U.S. population. For both disorders all races and economic groups are affected equally. Individuals with bleeding disorders lead productive lives when regular and ongoing access to needed treatments, therapies and specialized medical professionals are available.

Living with a bleeding disorder requires a continuum of constant and comprehensive care. The cost of clotting factor for a person with hemophilia averages in the hundreds of thousands annually, and can be higher depending on the type of bleeding disorder, its severity, needed medical procedures, and/ or if an immune complication develops.

Health outcomes associated with the delivery of health care for individuals with bleeding disorders are critically dependent on highly qualified and specialized pharmacies for the dispensing of their treatment. Treatment for a bleeding disorder is typically known as factor replacement therapy (Factor), and must be transfused intravenously at home by the patient, a family member or infusion therapy specialist. It is extremely important that patients have a choice when selecting a specialty pharmacy health care provider to ensure their provider has experience in dispensing these therapies; clinically relevant customer service to respond to questions and concerns; and any adverse events a patient may experience.

HFA encourages the examination of the bleeding disorder specific Standard of Care/Service developed by the Medical and Science Advisory Committee (MASAC) of the National Hemophilia Foundation (NHF) regarding pharmacy providers. This standard was developed as a minimum level of care a patient should expect from a pharmacy dispensing Factor for home use by patients with bleeding disorders. This established standard recommends: health care delivery providers have staff with knowledge of clotting factor concentrates and ancillary supplies; maintain a full range of products and additional supplies; ensure the timely processing of prescription orders (within 48 hrs); offer access to pharmacy staff (24 hours per day; guarantee timely delivery of factor concentrate; and establish a robust recall notification.

The HFA would like to thank you for your work on behalf of patients and consumers in the health care marketplace. We look forward to any additional discussion of the needs of patients.

Sincerely,



Kimberly Haugstad
Executive Director
Hemophilia Federation of America