

March 24, 2008  
Reference No.: SAS08030

The Honorable Sheila Kuehl  
Chair, Senate Health Committee  
State Capitol  
Sacramento, CA 95814

Dear Senator Kuehl:

The Plasma Protein Therapeutics Association (PPTA) strongly supports the enactment of SB 1594 the "Hemophilia Standards of Care Act," currently under consideration by the Senate Health Committee at its upcoming April 2, 2008 hearing. People with bleeding disorders require access to high quality care in order to live long, productive lives. This bill would ensure that Californians affected by these disorders have unimpeded access to such care. We urge you to support SB 1594 in your Committee.

PPTA is the primary advocate for the world's leading producers of plasma-derived and recombinant analog therapies, including blood clotting factor therapies. These therapies are used by more than 1 million people worldwide to treat a variety of diseases and serious medical conditions, including hemophilia and other bleeding disorders. PPTA member companies include: Baxter BioScience, CSL Behring, Grifols, Octapharma, and Talecris Biotherapeutics.

It is crucial as a matter of public policy that the participants in California health insurance plans are not denied timely access to the treatments they need to keep them functioning as productive members of society. Delayed access to clotting factor can cause painful and crippling injury to a hemophiliac's joints and organs. Such complications often lead to increased costs for hospital, skilled nursing and other specialty services.

A landmark peer reviewed study published in *Blood* (the Journal of the American Society of Hematology) in 2000 documents the relative advantages of treating hemophilia patients in Hemophilia Treatment Centers (HTCs). Specifically, a study of more than 3000 hemophilic males funded by the Centers for Disease Control and Prevention found a 40% decrease in mortality and a 40% reduction in blood related hospitalizations among men who used an HTC at least once in the three year study period. This study was also highlighted in a November 2005 article published in the American Journal of Public Health. SB 1594 would require that patients have access to such recognized hemophilia programs.

SB 1594 also would ensure that individuals with bleeding disorders have unrestricted access to the full range of blood clotting factor therapies. Access to the full range of therapies is essential to optimal treatment. These therapies are distinct sole source products that have no generic biological equivalents. They are not interchangeable. Furthermore, individual patients will react differently to therapies depending upon their unique health care needs. Insisting on preferred brands and other formulary restrictions places the bleeding disorders population at increased risk. The decision about which therapy should be used should be made in close consultation between the patient and the physician, respecting the sanctity of the physician-patient relationship.

SB 1594 would also require that individuals are able to select providers that are familiar with the treatment of bleeding disorders. For example, many consumers self-infuse hemophilia factor concentrates in their homes. The type(s) of home supportive services that a patient requires is a decision best made by the patient in consultation with his physician. Individuals need options in choosing such services to ensure that patients are receiving the highest possible level of service and care.

On behalf of Californians and all Americans with bleeding disorders, we would like to express our gratitude for your consideration of this legislation aimed at preserving access to a broad array of therapies. Thank you for your work on this important issue. Should you have any questions or need additional information, please do not hesitate to contact me at (202) 789-3100 x2102.

Sincerely,



Ryan M. Faden, J.D., M.P.H.  
Assistant Director, State Affairs