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The Honorable Fran Pavley
California Senate
State Capitol, Room 4035
Sacramento, CA 95814

RE: SUPPORT for SB 971 (Pavley)

Dear Senator Pavley:

Thank you for your leadership in carrying SB 971 for the Hemophilia Council of CA (HCC). SB 971 is an important measure that would establish crucial standards of service for health care entities that deliver blood clotting products to people with hemophilia and other life-threatening bleeding disorders in the home setting.

Just a few decades ago, people with severe hemophilia suffered from uncontrollable internal bleeding, crippling orthopedic deformities and a shortened lifespan. My father, a severe hemophiliac personally suffered from multiple orthopedic problems and when I was only 18 years old he lost his life to HIV/AIDS contracted through tainted blood clotting products.

While my father didn't have the opportunity to see these changes; more recently, the production of highly purified blood clotting factors have provided people with hemophilia and other bleeding disorders with the opportunity to lead normal lives, free of pain and crippling arthritis. Like my father, for most people with these bleeding disorders, this necessitates intravenous injection or infusion of prescription blood clotting products several times a week.

SB 971 would 1) establish standards of service for entities that deliver blood clotting products and related equipment, supplies, and services for home use; and would 2) promote access to a full range of essential, cost effective, life-saving, blood clotting products and related equipment, supplies, and high-quality services for home use for persons with hemophilia and other bleeding disorders.

The state has initiated contracts on July 1, 2010 with pharmacies wishing to provide clotting factor to patients on Medi-Cal, CA Children's Services (CCS), and Genetically Handicapped Persons Program (GHPP). Those contracts will contain similar (in fact even more stringent) standards as outlined in SB 971. It is critically important to ensure that standards are codified in statute for future generations so that private pay patients will have the same protections.

For all of these reasons, I am in strong support of SB 971 (Pavley).

Sincerely,

Lynne M. Carey
Carrier of Hemophilia B (Factor 9)
Board Member, Hemophilia Council of California
Board Member, Central California Hemophilia Foundation

