



Hemophilia Council of California • 1507 21st Street, Suite 206 • Sacramento, CA 95811

FACT SHEET -- SB 971/PAVLEY

Standards for Blood Clotting Products for Home Use

Background:

Just a few decades ago, people with severe hemophilia suffered from uncontrollable internal bleeding, crippling orthopedic deformities and a shortened lifespan. 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. For most people with these bleeding disorders, this necessitates intravenous injection or infusion of prescription blood clotting products several times a week. Many of these patients infuse at home.

SB 971 would:

Establish standards of service for pharmacies that deliver blood clotting products and related equipment, supplies, and services for home use and would promote access to a full range of essential, cost effective, life-saving, blood clotting products and related equipment, supplies for home use for persons with hemophilia and other bleeding disorders.

Need for Bill:

The state will be initiating 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 standards as outlined in SB 971. We believe it is critical to ensure that standards are codified in statute for future generations for both the public and private pay patients in CA. The State contracts will only apply to public pay patients.

Have There Been Problems?

We have had instances where pharmacies have left clotting factor on patient's doorsteps to spoil in the heat. Clotting Factor is an expensive biologic. It makes good sense for the patients and from a fiscal standpoint to have standards in place. It is also important for patients to be able to obtain, in a timely fashion, the clotting factor prescribed by their physician, as there are no generics for clotting factor to date, and patients metabolize clotting factor differently.

Who Supports SB 971?:

Hemophilia Council of CA (sponsor), National Hemophilia Foundation, Region IX Hemophilia Treatment Centers, CA Medical Association, Plasma Protein Therapeutic Assoc, several clotting factor manufacturers and individual pharmacies.

Do The Latest Amendments Remove Opposition From Advocacy Groups?

The Hemophilia Council of CA took amendments from the hospital industry and the pharmacists which are reflected in the June 15th version of SB 971/Pavley. The latest amendments further clarify that the bill **only applies to pharmacies and hospital pharmacies that dispense clotting factor for home use.**

CA Hospital Association, CA Children's Hospital Association and CA Pharmacist Association have all removed their opposition to the bill.

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