



## HEMOPHILIA COUNCIL OF CALIFORNIA

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*Hemophilia Council of California 1507 21<sup>st</sup> Street, Suite 103 Sacramento, CA 95811 (916) 498-3780*

January 26, 2012

Peter Lee, Executive Director  
CA Health Benefits Exchange

Dear Mr. Lee, Board Members & Staff:

The Hemophilia Council of CA (HCC) appreciates the opportunity to provide feedback on health care benefits. HCC represents the 4,000 people in California with hemophilia, as well as the over 360,000 people living in California who have Von Willebrand Disease.

Until the 1970s, 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 has provided people with hemophilia and other bleeding disorders the opportunity to lead normal lives, free of pain and crippling arthritis. The preferred method of treatment of hemophilia today is intravenous injection, or infusion, of prescription blood clotting products several times per week, along with case management and specialized medical care at a federally designated regional hemophilia treatment center.

### **Access to Hemophilia Treatment Centers for Medical Care**

The Hemophilia Council of CA supports people with Hemophilia having, at a minimum, an annual evaluation at a federally qualified hemophilia treatment center (HTC) in order to maintain positive health outcomes for these patients. The CDC has determined that mortality and morbidity rates have a 40% reduction associated with care provided through the hemophilia treatment centers. Patients in California with Hemophilia and other severe bleeding disorders have this direct access under the public programs such as the California Children's Services (CCS) and the Genetically Handicapped Persons Program (GHPP). Most standard insurance plan models also provide for this direct access to Hemophilia Treatment Centers. The Hemophilia Council of California seeks to ensure that this is maintained as a health care benefit under the plans in CA that roll out in 2014 for newly insured patients.

### **Access to Broad Range of Clotting Factor Products**

There are currently no generics for clotting factor. Patients have different reactions to different products. HCC believes it is critical to maintain access to a full range of clotting factor products for patients with Hemophilia and other bleeding disorders, as these pharmaceutical products are not interchangeable.

### **Limit Barriers to Patient Compliance**

Pharmacy benefits are cited as an essential benefit by the federal government. However, co-payment barriers exist today in many private insurance plans. If the co-payments are not equivalent to a typical brand name pharmaceutical product, patient compliance could be at risk. Poor patient compliance historically has produced some of the most disabled individuals in the hemophilia and bleeding disorders community. Therefore, the Hemophilia Council of California seeks to eliminate co-payments for clotting factor, as is done in many other countries.

Respectfully,

*Yvette Bryant*

Yvette Bryant, Chair  
HCC Board of Directors and Mother of Son with Hemophilia

