



**NATIONAL HEMOPHILIA FOUNDATION**  
*for all bleeding disorders*

June 15, 2012

Oregon Health Policy Board  
Oregon Health Insurance Exchange Board  
General Services Building  
1225 Ferry Street SE, 1st Floor  
Salem, OR 97301

**RE: Selection of the State's Essential Health Benefits (EHB)**

The National Hemophilia Foundation (NHF) is the nation's leading advocacy organization working to ensure that individuals affected by hemophilia and related bleeding disorders have timely access to high quality medical care and services, regardless of financial circumstances or place of residence. We appreciate the opportunity to provide comments on the selection of PacificSource as Oregon's benchmark plan and possible supplemental benefits to consider as part of the final recommendation.

Hemophilia and related bleeding disorders are rare, complex genetic conditions for which there are no known cures. Individuals often experience spontaneous and prolonged internal bleeding in the joints and tissues. To effectively manage these disorders, patients often require life-long infusions of clotting factor therapies that replace the missing or deficient blood proteins, thus preventing debilitating and life threatening internal bleeding. While therapies are safer and more effective than ever, they are also more costly than other types of medication. For example, cost of treatment for a person with severe hemophilia can be \$250,000 a year or more. Developing an inhibitor (i.e., an immune response to treatment), complications such as HIV/AIDS, hepatitis and joint diseases, or bleeding as a result of trauma or surgery can increase those costs to over \$1 million.

We commend the Oregon Health Insurance Exchange (ORHIX) Board and Oregon Health Policy Board (OHBP) for taking the first step of creating a health benefit exchange and soliciting input from stakeholders. However, we have some concerns that by choosing a small group plan that requires riders (i.e., vision, dental, and prescription drugs) to meet the requirements under the Affordable Care Act (ACA) may not adequately address the needs of individuals with bleeding disorders.

Traditionally, small group plans have more restrictive networks and offer less generous benefits making it more difficult to access recommended healthcare providers and adhere to the prescribed treatment. We are concerned that once all of the ACA-related federal and state mandated benefits are incorporated the plan may be simply be unaffordable and not offer adequate benefits for the very people the Exchange was setup to help find affordable coverage. As the state considers supplemental benefits to incorporate into the benchmark plans it is important that the unique needs of the bleeding disorder community are being addressed, thus ensuring that individuals have access to necessary treatment and healthcare providers. More specifically, plans should guarantee the following:



## **1. Access to specialists at federally recognized hemophilia treatment centers (HTCs)**

Since 1974, Congress has authorized and funded a national network of HTCs to provide comprehensive, specialized care for individuals with hemophilia and other bleeding disorders. These centers are staffed with healthcare professionals across multiple disciplines including hematologists, physical therapists, nurses, dentists and social workers that work as a team to provide coordinated care for this complex patient population. In addition to disease and case management, HTCs monitor blood safety and offer numerous educational programs for individuals and their families.

Numerous U.S. Centers for Disease Control and Prevention (CDC) studies show that individuals receiving care at HTCs have a 40 percent reduction in morbidity and mortality, despite the fact that more severe patients are seen at an HTC. Moreover, studies show that patients who use HTCs experience fewer long-term complications and hospitalizations, increasing quality of life and reducing total healthcare care costs over a patient's lifetime.<sup>1,2</sup>

The ACA specifies that entities covered under section 340B(a)(4) of the Public Health Service Act (which includes federally recognized HTCs) be designated as essential community providers. This designation helps ensure that HTCs are included in qualified health plans and that individuals have access to these specialized healthcare providers.

## **2. Access to the full range of FDA approved clotting factor products**

Clotting factor therapies are biological products (derived from human blood plasma or using recombinant technology) for which there are no generic equivalents. Moreover, because of the nature of bleeding disorders, an individual's response and tolerability for a specific product is unique. For these reasons, NHF's Medical and Scientific Advisory Council (MASAC) recommends that individuals have access to the full range available clotting factor products.<sup>3</sup> Limiting access, through the use of restrictive drug formularies, such as requiring prior authorization and preferred drug lists, will negatively impact patient care. Therefore, benefit designs employing these methods should be avoided and which product an individual uses should be a decision of between patient and physician.<sup>4</sup>

## **3. Access to a range of specialty pharmacy providers**

Unlike other types of medication typically bought at a retail pharmacy, clotting factor therapies require special handling, shipping and refrigeration. Additionally, patients often require other products (i.e., syringes, saline), nursing services, and intensive education to

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<sup>1</sup> Soucie JM et al. Mortality among males with hemophilia: relations with source of medical care. *Blood* 2000; 96:437-442.

<sup>2</sup> Soucie JM et al. Home-based factor infusion therapy and hospitalization for bleeding complications among males with hemophilia. *Haemophilia* 2001; 7:198-206.

<sup>3</sup> MASAC Document #132. (2002). Standards and Criteria for the Care of Persons with Congenital Bleeding Disorders. [www.hemophilia.org](http://www.hemophilia.org).

<sup>4</sup> MASAC Document #159. (2005). Recommendation Regarding Factor Concentrate Prescriptions and Formulary Development and Restrictions. [www.hemophilia.org](http://www.hemophilia.org).



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manage their complex health condition. These requirements are beyond the ability of a traditional retail pharmacy and are only available through specialty pharmacy providers. These providers are specially trained to handle the unique needs of the bleeding disorder community and are expected to adhere to the standards outline by MASAC.<sup>5</sup> Considering the variability of patient needs and provider services, patients need access to a network of pharmacy providers to properly manage their conditions allowing patients to live longer, healthier lives.

We thank you for taking the time to review our comments and for giving them your careful consideration. If you have questions, please contact Michelle Rice, Director of Public Policy, at (317) 517-3032 or [mrice@hemophilia.org](mailto:mrice@hemophilia.org); or Ruthlyn Noel, Senior Manager of Public Policy, at (212) 328-3730 or [mnoel@hemophilia.org](mailto:mnoel@hemophilia.org).

Sincerely,

A handwritten signature in black ink that reads "Michelle M. Rice".

Michelle Rice  
Director of Public Policy

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<sup>5</sup> MASAC Document #188. (2008). Recommendation Regarding Standards of Service for Pharmacy Providers of Clotting Factor Concentrates for Home Use to Patients with Bleeding Disorders. [www.hemophilia.org](http://www.hemophilia.org).