



NATIONAL HEMOPHILIA FOUNDATION

www.hemophilia.org

September 6, 2013

Vivianne Chaumont
Director, Division of Medicaid & Long Term Care
State of Nebraska, Department of Health and Human Services
301 Centennial Mall South, 3rd Floor
PO Box 95026
Lincoln, NE 68509-5026

RE: Provider Synergies L.L.C., TOP\$SM – Product Review

Dear Ms. Chaumont,

The National Hemophilia Foundation (NHF) is the nation's leading advocacy organization for individuals with bleeding disorders. Our mission is to ensure that individuals affected by hemophilia and related bleeding disorders have timely access to quality medical care, therapies and services, regardless of financial circumstances or place of residence.

We recently learned of a request for proposal notification that was sent to several blood clotting factor manufacturers by Provider Synergies L.L.C. The RFP is seeking supplemental rebates for factor products and by-passing agents. Subsequent communications with Provider Synergies raised concerns that through this process, patients may encounter barriers to access care. These therapeutic classes have previously been excluded from the standard preferred drug list (PDL) process. We recognize that the complexities involved in treating hemophilia and related bleeding disorders can result in high medical expenses for patients and their health insurance plans. While the need to identify cost containment strategies is necessary, it is critical that such strategies not compromise continuity of care for those with complex medical conditions.

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 into the joints and soft 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 today's 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 reach \$250,000 per year or more. Developing an inhibitor (i.e., an immune response to treatment) or other complications such as HIV/AIDS, hepatitis, chronic joint disease, or bleeding as a result of trauma or surgery can increase those costs to over \$1 million.



NATIONAL HEMOPHILIA FOUNDATION

www.hemophilia.org

Clotting factor therapies are biological products derived from human blood plasma or by 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 retain access to the full range of FDA-approved clotting factor products.¹ Limiting access through the use of restrictive drug formularies such as those requiring prior authorization, preferred drug lists, and fail first/step therapy, could have a negative impact on patient care and ultimately result in higher drug spends. Therefore, drug benefit designs employing these methods should be avoided, and the choice of product used by an individual should remain a decision between patient and physician.²

On behalf of individuals in the State of Nebraska affected by bleeding disorders, we urge you to continue the practice of allowing patient access to all FDA-approved therapies available to treat hemophilia and related bleeding disorders. If you would like additional information or have questions, please feel free to contact Michelle Rice, NHF Director of Public Policy, at 317-517-3032 or via email at mrice@hemophilia.org. Thank you for your consideration of our request.

Sincerely,

Val D. Bias
Chief Executive Officer
National Hemophilia Foundation

Marion A. Koerper MD
Medical Advisor, NHF
Vice Chair, MASAC, NHF

¹ MASAC Document #217 (2013) Recommendation Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders. www.hemophilia.org

MASAC Document #166 (2005) MASAC Resolution Regarding Preferred Drug Lists. www.hemophilia.org