



August 17, 2012

Ms. Danielle Holahan  
New York State Health Benefit Exchange  
New York State Department of Health

***Subject: Comments on Benchmark Options for Essential Health Benefits in the Exchanges***

Dear Ms. Holahan:

We, the undersigned organizations of the New York State Bleeding Disorders Coalition (“NYSBDC”), are writing to submit comments regarding the selection of an Essential Health Benefits (“EHB”) benchmark plan for the state’s Health Benefit Exchange (“Exchange”). NYSBDC is a statewide coalition of patient associations and hemophilia treatment centers (“HTC”) serving over 2,000 individuals with hemophilia, von Willebrand’s disease and other bleeding disorders.

Bleeding disorders are genetic conditions where individuals are either missing or have too little of a protein needed for blood to clot, causing them to bleed longer. Many of these people experience spontaneous bleeding often in joints and other organs, which increases their risk for severe joint, neurological and organ damage – and premature death in rare cases. There is no cure. Patients will require lifelong infusions of clotting factor products – the medication used to treat and control bleeding episodes.

Management of bleeding disorders has come a long way in 50 years when patients had to go into hospitals for infusions of blood, plasma products or clotting factor. Today the vast majority of patients self-infuse at home, enabling them to go to work or school. Supporting patients is a diverse team of HTC specialists who provide a range of services for them and their families. Examples of services provided include diagnosis, disease monitoring, education and coordination with clotting factor manufacturers and pharmacy providers to ensure adherence to treatment regimen. **This unique model of care has been documented to improve quality of life for people with hemophilia and has largely freed younger generations from having to experience the crippling effects of joint diseases, severe arthritis and other health complications which have plagued previous generations.** Moreover, studies conducted by the U.S. Centers for Disease Control and Prevention (CDC) have linked this existing care structure to higher attendance among school-aged children and fewer emergency room visitations and hospitalizations.<sup>12</sup>

**We commend the State for moving ahead with implementation of the Exchange** and are hopeful that the establishment of individual and small group exchanges in New York will lead to more coverage options for our members who know firsthand what it means not to be able to find adequate and affordable health insurance coverage. For example, several health plans refused to grant their members access to: a) bleeding disorder specialists at HTCs, b) the full-range of FDA approved

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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.

clotting factor products, and/or c) a range of specialty pharmacy providers (including 340B pharmacies affiliated HTC). Patients have even had difficulty with state programs such Child Health Plus (“CHP”) and Healthy New York which do not cover “outpatient” clotting factor for eligible children and adults. These barriers prevent individuals with bleeding disorders from getting adequate care and treatment and thus cannot be allowed to happen in the Exchange.

Given our unique situation, we will not be commenting specifically on which plan should be selected as the benchmark for determining the EHBs offered by plans participating in Exchange. Instead, **we urge the Exchange’s board of directors to ensure that the benefit packages offered by participating plans are “comprehensive” and tailored to address the essential health care needs of all their members, including those with rare disorders.** For people with bleeding disorders this means ensuring that:

- 1) **New York’s seven HTCs are available as in-network providers under all plans participating in the Exchange.** HTCs are crucial to managing and improving patient health outcomes so having access to them is essential.
- 2) **All FDA-approved clotting factor products are available and accessible without restrictions.** Clotting factor therapies are quite expensive. They are also not “interchangeable” or “therapeutically equivalent, so it is thus important that treating physicians have the discretion to determine which product work best for their patients without formulary restrictions such as prior authorizations, preferred drug lists and step therapy.”<sup>3</sup> It is also **crucial that all participating plans in the Exchange be required to cover “outpatient” clotting factor products.** Having the ability to self-infuse is the preferred and medically-established standard of care – it saves time and money and helps patients to have more control over their own care.
- 3) **A network of specialty pharmacy providers is available to help patients navigate the healthcare system and manage their conditions.** While the mix of HTCs with 340B programs in the State is robust, other clotting factor suppliers deliver life-saving therapies to many New Yorkers. It is important that patients have access to both 340B pharmacy programs that are affiliated with HTCs and other homecare/pharmacy providers who have experience providing services to this community.
- 4) Plans participating in the Exchange **are prohibited from imposing cost sharing on members** that makes it unaffordable for them to get the care and treatment they need.

We thank you for the opportunity to provide comments on EHBs offered by participating plans in the Exchange. If you have questions, please feel free to contact Ruthlyn Noel at 212.328.3730 or [rnoel@hemophilia.org](mailto:rnoel@hemophilia.org).

Sincerely,

Bleeding Disorders Advocacy Network  
Bleeding Disorders Association of Northeastern New York (Albany)  
Bleeding Disorders Association of the Southern Tier (Binghamton)  
Camp High Hopes and Camp Little Oaks (Syracuse)  
Central New York Bleeding Disorders Association (Syracuse)  
Coalition for Hemophilia B (National)  
Hemophilia Association of New York (New York City)

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<sup>3</sup> MASAC Document #159. (2005). Recommendation Regarding Factor Concentrate Prescriptions and Formulary Development and Restrictions. [www.hemophilia.org](http://www.hemophilia.org).

Hemophilia Center of Western New York (Buffalo)  
Hemophilia Federation of America (National)  
Long Island Jewish Medical Center (Long Island)  
Mary M. Gooley Hemophilia Center (Rochester)  
Mount Sinai School of Medicine (New York City)  
National Hemophilia Foundation (National)  
New York City Hemophilia Chapter (New York City)  
Regional Comprehensive Hemophilia & von Willebrand Treatment Center (Albany)  
SUNY Upstate Medical University-Adult Program (Syracuse)  
SUNY Upstate Medical University-Pediatric Program (Syracuse)  
UHSB Blood Disorder Center (Johnson City)  
Weill Medical College of Cornell University (New York)