



NATIONAL HEMOPHILIA FOUNDATION

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NHF Policy Statement Hemophilia Treatment Center Participation in the 340B Drug Discount Program

The National Hemophilia Foundation (NHF) is committed to ensuring the bleeding disorders community has access to high quality care services and treatment at affordable prices. NHF fully supports the participation of the national network of hemophilia treatment centers (HTCs) in the 340B drug discount program. The provision of pharmacy services furthers the comprehensive care mission of HTCs and benefits all patients seen at HTCs.

Background on Bleeding Disorders

Hemophilia is a rare, chronic bleeding disorder affecting approximately 20,000 people in the US, who infuse high-cost clotting factor therapies to replace missing or deficient blood proteins. These therapies are safer and more effective than ever, but are also very expensive. Drug costs for a person with severe hemophilia can be \$250,000 a year or more. Developing an inhibitor (an immune response to treatment) can increase those costs to \$1 million. In addition, complications such as HIV/AIDS, hepatitis and joint diseases, or bleeding as a result of trauma or surgery have the potential to impact clotting factor utilization and costs. Due to the high costs of treatment and the volatile nature of hemophilia and its complications and comorbidities, the hemophilia community is extremely medically vulnerable. There are also similar bleeding disorders, like von Willebrand Disease, that affect up to 1 million Americans.

Most individuals with bleeding disorders receive care at HTCs, which provide comprehensive, multi-disciplinary, patient-centered care for bleeding disorders and their long-term complications, including inhibitors, liver disease and HIV/AIDS. Studies have shown that mortality and hospitalization rates are 40% lower for people who use HTCs than in those who do not, despite the fact that more severely affected patients are more likely to be seen in HTCs.

Background on HTC Participation in 340B

The Veterans Health Care Act of 1992 designated federally-funded Hemophilia Diagnostic and Treatment Centers as covered entities eligible to participate in the 340B Drug Pricing Program. HTCs were included as covered entities to stretch their federal grant funding to provide comprehensive services to all patients served by the center. Before the passage of the Affordable Care Act, access to discounted drugs also prevented patients from exceeding their insurance plans' lifetime and annual limits.

Today, approximately 100 of the 140 HTCs have elected to participate in the 340B program. HTCs treat a mix of patients with private and public insurance, as well as the uninsured. As a condition of their federal grant, HTCs must invest all revenues from the 340B program back into patient services, care coordination, research and other programs that directly benefit patients. In order to dispense 340B drugs to a patient, the individual must receive services at the center.

Federal funding for HTCs was flat for many years and has declined in recent years due to budget cuts and the effects of sequestration. Today, average federal funding per center is approximately \$35,000, which does not cover the many uncompensated services provided by HTCs, including social work, physical therapy assessments, care coordination, and patient

education. In this era of fiscal constraint, HTC participation in the 340B program has provided a critical means of financial support for HTC services and maintaining comprehensive care for all patients seen at the center.

NHF Policies on the 340B Program and Patient Choice

NHF believes that the bleeding disorders community should have a choice in healthcare provider, treatments, and supplier of health care services. NHF believes that HTCs with 340B drug programs are an important option that should be available to all patients, regardless of their health insurance coverage – private or public (Medicaid, Medicare). NHF strongly supports the HTC policy that all 340B savings from hemophilia treatments be used to support HTC services and programs that benefit all patients served by the HTC.

Depending on their healthcare coverage, consumers may have a variety of pharmacy options from which to choose, including HTC 340B pharmacy programs. NHF supports programs that include comprehensive coordinated clinical services and an integrated pharmacy program. NHF opposes any system that limits patient choice or fragments care. Moreover, NHF opposes any policies that would limit the ability of an HTC to participate in the 340B program based on the percentage of the patient population that is indigent or that would allow only uninsured patients to access 340B drugs. Due to the high cost of care and complexity of their condition, all patients served by HTCs are medically vulnerable.

In order for consumers to make an informed choice, they must have adequate information as to the various options, services and their price. NHF affirms the right of consumers to know the unit price of the products they are purchasing.

NHF encourages HTCs to incorporate the following elements in their pharmacy programs:

- Meet all requirements of MASAC Recommendation #188, which sets minimum standards of service for all specialty pharmacy providers that serve people with bleeding disorders.
- Allow patients choice of product, supplier and the delivery of health care services. This requires HTCs to provide complete information on its pharmacy services and inform patients that other pharmacy provider options are available.
- Create no disincentive or conflict of interest in the prescribing of a specific product. Product choice must be based on medical treatment decisions.
- Ensure that any savings realized through 340B pricing support HTC services and programs that benefit all HTC patients.