



Hi I am Joe Pugliese, President of the Hemophilia Alliance (“The Alliance”). The Alliance represents 95 comprehensive hemophilia treatment centers (HTCs) across the country. HTC’s take care of children and adults with severe bleeding and clotting disorders through a “comprehensive care” model. Hemophilia impacts the quality of life, can cause disability, and major healthcare issues throughout a patients lifespan. For over 30 years we’ve known that it is a comprehensive care team that results in the best outcomes for patients with hemophilia. The team includes the physician, the nurse practitioner, genetic counselor, physical therapist and importantly our health psychologist. This program is the most successful managed health care idea and the model by which todays medical home concept has been created from. Through this program, HTC;s have been able to maintain a very high quality of care, manage complications, keep patients out of the hospital, and do this all in a very cost effective manner. The HTCs providing clotting factor to their patients through their participation in the 340B program are able to sustain their comprehensive care model through the revenue derived from factor sales to this very small patient population.

The importance of the comprehensive care team for hemophilia and other rare disorders was recognized by our Congress approximately 37years ago when they enacted and funded the comprehensive care model. The Congressional intent was reinforced in 1992 when HTCs were made covered entities under the Veteran Health Care. . It allows HTCs to sell product to providers like yourself at very competitive rates. The 86 HTCs who are Alliance members participate in the 340B Drug Purchasing Program. They coordinate the provision of pharmacy services as part of their comprehensive care program, providing constant monitoring of bleeds and clotting factor utilization to allow for a quick response to needed changes in treatment. They are also cost effective providers of pharmacy services, tracking dosing, compliance with medication orders, and providing assay inventory management and maintaining a stat inventory of product necessary to distribute to urgent situations that prevent unnecessary usage of costly emergency room care.

The income from these pharmacy programs is reinvested into the HTC to help support these health care teams. At a recent summit meeting held in Washington D.C. the key finding of the meeting was that the comprehensive care model for hemophilia is completely dependent on the revenue stream available to the HTCs through their factor programs. The funding provided by the HRSA grant is not nearly adequate for maintaining these centers of clinical excellence.

The most expensive part of care for a hemophilia patient is the cost of factor itself. The average hemophilia patient costs about \$100,000-\$150,000 per year in just providing factor in the outpatient setting to prevent bleeding. In fact the average adult patient that has a severe or high titer inhibitor costs somewhere in the order of a half a million to a million dollars per year. The HTCs are centers of excellence in hemophilia care and have a long history of producing markedly superior clinical outcomes, reducing healthcare costs while improving health outcomes. Superior clinical services save money by reducing complications, the number of Emergency Room visits and hospital inpatient stays, and have the added benefit of producing healthier, happier, more productive patients. We are your partner in better outcomes both clinically and fiscally. Email us at [info@hemoalliance.org](mailto:info@hemoalliance.org) or call 215-279-9236.

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