



Western Pennsylvania Chapter of the National Hemophilia Foundation

May 2, 2012

The Honorable Robert Casey
United States Senate
393 Russell Senate Office Building
Washington, DC 20510

Dear Senator Casey:

Thank you for your leadership on behalf of families with chronic and catastrophic illnesses residing in the Commonwealth of Pennsylvania. It has been a pleasure working with your staff, particularly Sara Mabry. As the Executive Director of the Western Pennsylvania Chapter of the National Hemophilia Foundation (WPCNHF) located in Cranberry Township, Pennsylvania; I respectfully request that you become the lead sponsor in the Senate for companion legislation to *H.R. 4209: The Patients' Access to Treatments Act (PATA)*. This legislation was introduced in the House of Representatives by Congressman David McKinley (R-WV) and Congresswoman Lois Capps (D-CA).

WPCNHF serves over 450 families in Western Pennsylvania affected by bleeding disorders (Hemophilia & von Willebrands Disease). Our organization has advocated strongly for access to needed treatments for our patients for many years. Anti-hemophilia factor replacement treatments are very expensive, typically costing patients anywhere from \$40,000 to \$200,000 a year. As health insurance providers look for ways to shift costs back to consumers and patients, many are moving treatments for bleeding disorders to specialty tiers (proposed Tier IV). The result is patients will be required to pay 25% to 33% of the coinsurance for this life sustaining treatment. This is particularly concerning to the bleeding disorders community as these are resources that our patients simply do not have. Many of the families we service are independent and contributing members to the Commonwealth, yet they still struggle to make ends meet due to treatment costs. To add the cost of coinsurance to their list of bills would prove detrimental to our community.

The Patients Access to Treatments Act (PATA) would limit cost-sharing requirements applicable to medications in a specialty drug tier to the dollar amount applicable to treatments in a non-preferred brand drug tier. This legislation would enable patients to continue to access much-needed treatments and therapies which would reduce the need for disability benefits and uncompensated care in the hospital setting which reduces overall health care costs. While this will not solve the challenges the families we serve face, this legislation will allow many patients to remain covered by insurance, rather than utilizing government resources such as Medicare. It is imperative that we work together to ensure that the families residing in Western Pennsylvania are not crippled by specialty tier drug pricing.

If you have any additional questions, please feel free to contact me directly at 724.741.6160 or by email at jennifer@westpennhemophilia.org. Thank you for your time and consideration of this legislation.

Sincerely,

Jennifer Wahlen Pegher
Executive Director