



HEMOPHILIA AND OTHER INHERITED BLEEDING DISORDERS is a rare, chronic, bleeding disorder. Many persons with hemophilia bleed internally into muscles and joints, and bleeds in the brain or other organs can be life-threatening. Persons with hemophilia require life-long infusions of clotting factor therapies that replace missing or deficient blood proteins. **There are approximately 1,800 people in Illinois with hemophilia, impacting all racial and economic groups.** There are at least 12 other known bleeding disorders similar to hemophilia, with von Willebrand disease –the most common bleeding disorder – affecting about 1% of the population. Due to the rareness of the disease and the unique manufacturing of clotting factor, the average cost of therapy for an individual with severe hemophilia can be \$300,000 and up to \$1million if complications occur.

HEMOPHILIA TREATMENT CENTERS – For over 40 years, Illinoisans with hemophilia have received optimal, cost effective, comprehensive care through a multidisciplinary health care professional medical home known as federally-funded Hemophilia Treatment Centers (HTCs). Illinois has five HTCs – **Rush Hemophilia & Thrombophilia Center, Bleeding & Clotting Disorder Institute in Peoria, Northwestern Center for Bleeding Disorders, Lurie’s Children’s Hospital, and Stroger – Cook County Hospital.**

THE BLEEDING DISORDERS ALLIANCE ILLINOIS (BDAI) – As Illinois moves forward to address the challenges that lay ahead, the state’s patient organization, **BDAI**, has had a great working relationship with state legislators and regulators and wants to continue to be an asset. We come here to assist and provide our expertise. As trusted partners, we have assisted the state with solid direction that serves our community well and recognizes the responsibility we all have to make our state a great one. An excellent example of our focus on the state’s fiscal health is language in the **2012 SMART Act** that reduced costs and maintained the high level of care for people with bleeding disorders deserve. As changes are being considered that impact people with bleeding disorders, we would appreciate a continued seat at the table. We have collaborated with policy makers to lead the way to an appropriate balance between cost and care.

ISSUES

1. Managed Medicaid - The State has been increasingly moving patients to **Managed Medicaid**. We are seeing people with hemophilia who have been moved by the state to Managed Medicaid having issues including cost and delivery of medication and care. The bleeding disorders community worked directly with Illinois government several years ago to create the **Hemophilia Care Management Program** as part of the **SMART Act**. This program has provided significant cost-savings while offering solid care management for our population. It is our desire to explore the possibility of moving the entire hemophilia population back to this program.

2. Out of Pocket Costs for Prescriptions – Medications for life threatening or debilitating diseases can cost a patient between 20-50% of the drug’s total cost each month, causing people living with hemophilia and other bleeding disorders the potential to need to pay thousands of dollars a month. Financial inaccessibility to medications can result in patients with chronic illnesses stopping their treatment, compromising their health and lives and increasing overall medical costs. We ask you to work with the Governor and the Department of Insurance to help us find an administrative compromise to address this problem.

3. HB 4576 - The Development of a Rare Disease Commission – Many important decisions related to rare diseases are made at the state level, and the implementation of the Affordable Care Act has highlighted the increasingly important role of state policies and programs in assuring that the healthcare needs of the American public are addressed. This Commission will allow for the appointment of a team of experts to advise state government on the challenges and triumphs of living with rare diseases in the Illinois.