

For the purpose of ensuring medically necessary care for persons in Maryland with Hemophilia and von Willebrand disease, the Hemophilia Foundation of Maryland (HFM) Advocacy Committee has come up with these discussion points for making the case for standards of care bill to state legislators. You can use this list as a model or starting point to develop other talking points for relaying the importance of adequate care for patients in Maryland with a bleeding disorder. The purpose of meeting with your legislators should be to find a sponsor or supporter for the standards of care bill.

TALKING POINTS

HEMOPHILIA FOUNDATION OF MARYLAND

ADVOCACY EFFORTS FOR FALL 2009

The following discussion points may be useful in stressing the importance of ensuring medically necessary care for persons with Hemophilia and von Willebrand (vWD) disease:

- Hemophilia and von Willebrand disease are bleeding disorders affecting hundreds of individuals in the State of Maryland. There are approximately 300 individuals have Hemophilia A and B combined, and 1% of the population lives with vWD around 56,000 in Maryland. They are chronic, lifelong, and incurable diseases.
- Most people with von Willebrand disease are undiagnosed at this point in time and this leads to increased medical costs as the symptoms are treated but not the underlying disease state.
- Without proper management, bleeding disorders like hemophilia and von Willebrand disease can be crippling, life-constraining, and even fatal. In younger and older sufferers alike, uncontrolled bleeding causes pain, destroys joints, and damages muscles and organs.
- Promptly administered therapies – clotting factors dispensed through specialty pharmacies and given intravenously in the patient's home – enable most persons with bleeding disorders to avoid lifelong impairments and to lead normal, productive lives free of pain and crippling arthritis.
- Access to and qualified administration of clotting therapies can be costly, but they save lives, prevent disabilities, and produce cost-effective health outcomes. It is critical that the care available to sufferers of bleeding disorders meet medically-endorsed treatment standards and not be delayed or curtailed by shortsighted cost-reduction measures.
- The purpose of a standards of care act for the bleeding community is to establish qualifications and standards for specialty pharmacies, hospitals and physicians by which persons with bleeding disorders receive care.