



Hemophilia Association of the Capital Area (HACA) 6412 Brandon Avenue, #412 Springfield, VA 22150 Tel: 703-352-7641 admin@HACAcares.org | www.hacacares.org Virginia Hemophilia Foundation (VHF) 9702 Gayton Rd., Suite 277 Richmond, VA 23238 Tel: 804-740-8643 info@vahemophilia.org | www.vahemophilia.org

Prescription Drug Affordability Boards (PDABs) - HB 1724

What is in the best interest of patients, and how will HB 1724 protect their access to essential care and treatments?

Some of the things that we hope you will consider include:

- **Protect Access to Essential Treatments:** Patients with bleeding disorders face high out-of-pocket costs and significant challenges in accessing the treatments they need. Many of these challenges come from insurance plans that exclude certain medications from their formularies, limiting treatment options. We are concerned that the proposed Upper Payment Limit (UPL) could make it even harder for patients to access life-saving therapies, especially since there are no generic alternatives or pharmacologically equivalent therapies for bleeding disorders treatments.
- Include Patient Voices in Decision-Making: In states that have established PDABs, patient organizations are often left out of discussions with key decision-makers and excluded from working with relevant board stakeholders to alleviate potential concerns. This exclusion prevents them from addressing potential access challenges and ensuring that patients' needs are considered.
- To date, no PDAB has successfully implemented an UPL in any state. However, in 2024, Colorado's PDAB selected a treatment for review that is one of the few available options for patients with Hemophilia A with inhibitors.
- **Potential Impact on Covered Entities:** Hemophilia Treatment Centers (HTCs) rely on the 340B program to sustain the comprehensive care model that provides specialized, cost-effective treatment for patients. Any changes or restrictions to the 340B program could jeopardize their ability to deliver critical services and support, ultimately affecting patient access to necessary care.
- **Potential Unintended Consequences:** Rare disease patients, including those with bleeding disorders, may face significant challenges when they are not included in decision-making processes. Excluding patients from these discussions can lead to policies that do not fully address their unique healthcare needs, potentially resulting in reduced access to essential treatments and quality of care.