



## Ohio Bleeding Disorders Council

*Proponent Testimony – House Bill 291*

**Lisa Raterman, Chair**

**Ohio Bleeding Disorders Council**

*House Insurance Committee*

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Chairman Lampton, Vice Chair Barhorst, Ranking Member Miranda, and members of the House Insurance Committee, thank you for the opportunity to submit testimony in support of House Bill 291, sponsored by Representatives Liston and Carruthers. My name is Lisa Raterman, and I am the Chair of the Ohio Bleeding Disorders Council.

Bleeding disorders are characterized by the inability of the patient to form a proper blood clot. These patients will often experience extended bleeding after injury, surgery, trauma or other health issue. Sometimes the bleeding is spontaneous, without a known or identifiable cause. The two main types of bleeding disorders are Hemophilia and von Willebrand Disease. In one-third of cases, there is no family history of hemophilia. In Ohio, there are more than 1,200 individuals living with hemophilia and 1,500 living with von Willebrand Disease. This is one of the largest populations nationwide.

As you know, House Bill 291 would prohibit ‘non-medical’ switching of drugs during a benefit plan year. These types of changes impact how drugs are classified on a health plan formulary. For patients with a rare disease like hemophilia, these changes that can impact a patient’s access to clotting factor and other medications can have profoundly serious consequences. The hallmark of severe hemophilia is the occurrence of repeated episodes of bleeding into muscles and joints that until recently, inevitably lead to permanent crippling arthritis frequently requiring hospitalizations and surgical procedures to help correct these problems.

Today there are several highly effective clotting factor medications for the treatment and prevention of bleeding in hemophilia and von Willebrand disease. These medications require patient-administered intravenous infusions, which may require that infusions be done every other day to once every 4 to 6 weeks, depending on the choice or brand of clotting medication. These medications may differ from each other by their mechanism of action or length of time they remain in the blood stream. However, with the proper medication, bleeding and its toll on muscles and joints can now be prevented in most

patients. The problem is that not every brand of clotting factor concentrate is appropriate for individual patients. Medications display individual differences between patients meaning that the choice of medication must in the end be based on the response of each individual patient to that brand of medication.

The goal of the treating hematologist is to find the appropriate medication for each individual patient. These highly specialized medications may cost thousands or hundreds of thousands of dollars per year, a cost very few families can afford without adequate insurance coverage. However, the inability to access the appropriate medication for a patient may be the difference between a relatively normal life and one burdened by repetitive bleeds into muscles and joints leading to both short term and long-term disability. Therefore, to change access to the appropriate medication a patient is on in the middle of an annual insurance contract can have serious consequences.

HB 291 would prohibit these mid-plan year changes and ensure that patients have access to necessary prescription drugs. Health plans would still be able to make changes to their formularies prior to the start of a new benefit year, but a family should be aware of these changes before selecting their individual annual health plan. Please support this important legislation, thank you.