

Representative Bride Rose Sweeney Sponsor Testimony: H.B. 185 (Designate Bleeding Awareness Month) House Health Committee April 13, 2021

Chairman Lipps, Vice-Chairman Holmes, Ranking Member Russo, and members of the House Health Committee, thank you for the opportunity to provide sponsor testimony on House Bill 185 and to bring awareness to bleeding disorders. This bill would designate the month of March as "Bleeding Disorders Awareness Month." It was originally brought forward by Rep. Randi Clites in the 133rd General Assembly and passed the House 95-0 as an amendment to House Bill 358.

A bleeding disorder is a condition that cause patients' blood not to form clots. The two main types of bleeding disorders are Hemophilia and von Willebrand Disease (vWd), there are also 7 other inherited coagulation protein deficiencies that may result in bleeding.

Hemophilia affects about 1,200 patients in Ohio, which is in the top three largest state populations in the country. Most people remember the period in our history where hemophilia treatment led to a tragic time where patients contracted HIV and AIDS in the 80's and 90's from tainted blood products. The hemophilia community lost over 10,000 patients. World Hemophilia Day is also April 17^{th} – making this bill very timely.

Von Willebrand Disease is estimated to affect 1% of the population, but can take up to 16 years to get a diagnosis. There are approximately 1,500 vWd patients receiving treatment in Ohio. The incidence of bleeding disorders is dramatically higher in Ohio than most states due to its genetic prevalence in the Amish community.

Some physical symptoms that those with a bleeding disorder face include bleeding in the joints or muscles, brain bleeds, prolonged bleeding from minor cuts, hematomas, excessive bleeding with dental work, easy bruising, and heavy periods. Health care costs of bleeding disorders are significant, with Express Scripts estimating the average annual cost per patient with hemophilia at over \$270,000.

I believe that bringing awareness to bleeding disorders is crucial for Ohio because of the high incidence rates in the state, the high cost of treatment, and the large number of patients with a bleeding disorder that go undiagnosed. We need to work towards better care, more treatment options, and greater awareness for bleeding disorders.

Thank you for the opportunity to provide sponsor testimony on House Bill 185. I would be happy to answer any questions from the committee.