

House Bill 383 - Bleeding Disorders Awareness Month Proponent Testimony

December 10th, 2019

Chairman Lipps, Vice-Chair Manning, Ranking Member West, and members of the House Health Committee, thank you for the opportunity to testify in support of House Bill 383, sponsored by State Representative Randi Clites. My name is Leslie Witkoff and I am here today on behalf of the parents, patients, and providers who are members of the Ohio Bleeding Disorders Council.

As you know, HB 383 would designate March as Bleeding Disorders Awareness Month. 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.

By way of background, I am the Nurse Coordinator at the Ohio State University Hemostasis and Thrombosis Center. At the OSU HTC, we see adult patients typically have around 650 patients for whom we provide support, treatment, and case management services. One of my primary roles is to prevent unnecessary emergency room admissions for our patients. Awareness of bleeding disorders, especially in emergency situations, is critical to the overall health and wellbeing of these patients.

I would like to provide a quick example of how greater awareness can help save lives. A patient who has received care at our HTC in the past fell from a roof. When EMS personnel arrived, he was conscious and told them he needed factor to control his bleeding. Factor was administered and the patient was transported to a trauma facility. Once admitted, the trauma surgeon remarked that he was lucky to have not broken his neck and that he did not require factor to control his bleeding since he was only bruised. The surgeon did not contact a hematologist at OSU to discuss the situation further.

Later at night, the patient's wife noticed his bruising was spreading down his back and chest. She quickly informed the nurses on call who reached out to the trauma surgeon. Again, the surgeon did not believe factor was needed for the patient. Ultimately, the wife had factor brought to her from home and administered it to her husband directly. She also contacted the OSU HTC and was able to take her husband home the next day and subsequently bring him to OSU for further treatment. When I visited her husband, he had some of the worst bruising I have ever seen. Thankfully, his wife was aware of his condition and was able to respond when others would not.

To me, this situation illustrates the need for greater awareness of bleeding disorders. In many cases, it's not just everyday citizens who benefit from these types of bills, but clinicians and others involved in the care of patients. Education is a key component of what we do at OSU and other HTC's across the state. Our focus is not only on patients and family members, but on physicians, nurses, EMT's, and other healthcare providers who may not encounter patients with a bleeding disorder often in their practice.

I want to thank the committee for their support of this important legislation and for bringing awareness and support to individuals living with a bleeding disorder in Ohio. Thank you for your time and I would be happy to answer any questions you may have.