



*Proponent Testimony – House Bill 412 (Rare Disease Advisory Council)*

**Lisa Raterman, Chair**

**Ohio Bleeding Disorders Council**

*Senate Health, Human Services, and Medicaid Committee*

**June 3<sup>rd</sup>, 2020**

Chairman Burke, Vice-Chair Huffman, Ranking Member Antonio, and members of the Senate Health, Human Services, and Medicaid Committee, thank you for the opportunity to offer written testimony in support of House Bill 412, sponsored by State Representatives Randi Clites and Tim Ginter. I am submitting these comments on behalf of the parents, patients, and providers who are members 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, HB 412 would establish the Rare Disease Advisory Council under the Ohio Department of Health. This new council would be tasked with providing insight and advice to the General Assembly and Executive Agencies on research, diagnosis, and treatment efforts related to rare diseases. The council would be comprised of health care providers, patients, and advocates who would provide expertise and valuable information.

HB 412 also requires the Ohio Department of Health to publish reports regarding the incidence of rare diseases in Ohio. This will be invaluable to future General Assemblies considering legislation impacting persons with rare diseases. The work of the council and data compiled by ODH will set the stage for robust and comprehensive policymaking.

HB 412 is a positive and pro-patient piece of legislation. On behalf of OBDC, I strongly encourage its swift passage. Thank you for your time and attention to this important issue.