



## Ohio Bleeding Disorders Council

### Interested Party Testimony- House Health Committee HB 96 — FY26-27 State Operating Budget March 5, 2025

Chair Schmidt, Vice Chair Deeter, Ranking Member Somani, and members of the House Health Committee — Thank you for allowing us to submit written testimony for the FY26-27 State Operating Budget.

As you consider the operating budget, we ask you to please expand eligibility for the **Children and Youth with Special Health Care Needs** by extending the age limit by one year beginning July 1, 2025, increasing the maximum age of participants from 25 to 26 and add \$500,000 in FY26 to the program (Ohio Department of Health - GRF appropriation item 440505).

We would like to share more information on our community and why this legislative priority is so critical to our patients and their loved ones.

#### **Program for Children and Youth with Special Health Care Needs**

Formerly known as the Children with Medical Handicaps, Children and Youth with Special Health Care Needs is a health care program in the Ohio Department of Health (ODH) that links individuals with special health care needs to a network of quality providers and helps individuals and their families obtain payment for needed services. Major components of the program include: conducting quality assurance activities to establish standards of care and to determine unmet needs of individuals with special health care needs and their families; funding services for the diagnosis and treatment of medically eligible conditions; collaborating with public health nurses and local health departments to assist in increasing access to care; supporting service coordination for individuals with selected diagnoses; and assisting individuals and their families to access and utilize appropriate sources of payments for services. **OBDC supports continued funding and expansion of the treatment program up to age 26.**

#### **Background on Bleeding Disorders**

Approximately 4,000 Ohioans have a bleeding disorder. 1,300 of those 4,000 have a form of hemophilia, a genetic bleeding disorder that prevents blood from properly clotting. Unless expertly treated, this condition can result in excessive bleeding that threatens life and limb. Most commonly bleeding occurs within joints, and this leads to crippling arthritis at young ages. **There is no cure for hemophilia** and individuals affected by it need lifelong infusions of clotting therapies, injectional mimetics or re-balancing agents which, on average, can cost \$250,000-500,000 per year. The National Institute of Health found that studies of economic burden on people with bleeding disorder often underestimate the total burden due to the difficulty of defining indirect costs.

Von Willebrand disease is another lifelong bleeding disorder and is due to insufficiency or dysfunction of a protein that helps small blood cells (platelets) stick together properly. When platelets cannot stick together,

the clotting process is unable to take place, and a person can have uncontrolled bleeding. Symptoms include excessive bruising, nosebleeds, heavy menstrual bleeding, bleeding with surgeries, procedures, and childbirth. **The cost of care can range anywhere from \$40,000 to \$150,000, not including indirect costs.**

#### **About the Ohio Bleeding Disorders Council**

In 1988, the Ohio Hemophilia Action Coalition came together to promote the interests of Ohioans with hemophilia. One major accomplishment made by this group was restoration of the state budget line item and the creation of the Hemophilia Insurance Pilot Program. This program provided state assistance for individuals with hemophilia who had access to private insurance but could not afford premiums. In 2002, the state eliminated the program and direct funding of \$1 million, which caused the dissolution of the Coalition. Two years went by before the group knew they needed to start meeting again to advocate for issues affecting those in the bleeding disorders community. This revitalized group began meeting on a regular basis and called itself the Ohio Bleeding Disorders Council.

I encourage you to support our amendment to please expand eligibility for the **Children and Youth with Special Health Care Needs** program by extending the age limit by one year beginning July 1, 2025, increasing the maximum age of participants from 25 to 26 and adding \$500,000 in FY26 to the program.

Sincerely,  
Lisa Raterman  
Ohio Bleeding Disorders Council Chair