Ohio Bleeding
Disorders Council
Advocacy is in our blood

Interested Party Testimony- Senate Finance Committee
HB 96 — FY26-27 State Operating Budget
May 28th, 2025

Chair Cirino, Vice Chair Chavez, Ranking Member Hicks-Hudson, and members of the Senate Finance Committee — Thank you for the opportunity to provide written testimony on the FY26-27 State Operating Budget.

My name is Randi Clites, and I am the State Policy Director for the Ohio Bleeding Disorders Council.

As you consider the operating budget, we ask you to please support the expanded eligibility for the **Children and Youth with Special Health Care Needs** through the age of 26 beginning July 1, 2025, granted in the House version and add $500,000 in FY27 to the program (Ohio Department of Health - GRF appropriation item 440505).

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 to support our young adults.**

I would like to share a bit about the bleeding disorders community so you can understand why this is so important. 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.**

I respectfully ask that you maintain the House version of our amendment that expanded eligibility for the **Children and Youth with Special Health Care Needs** program by increasing the maximum age of participants from 25 to 26 and add $500,000 in FY27 to the program.

Sincerely,
Randi Clites
State Policy Director
Ohio Bleeding Disorders Council