Ohio Bleeding Disorders Council

# Randi Clites
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Chairman Hackett, and members of the Finance Subcommittee on Health and Medicaid, my name is Randi Clites. I am the Advocacy Coordinator for the Ohio Bleeding Disorders Council, the chair of the Parent Advisory Committee for the Ohio Department of Health's Children with Medical Handicaps Program, and a parent of a 15 year old who has been served by the program since his birth. Thank you for the opportunity to provide testimony today.

OBDC's mission is to ensure and enhance the quality and accessibility of comprehensive care and services for children and adults with hemophilia and related bleeding disorders through information sharing, public education and advocacy. OBDC is comprised of representatives of Ohio's eight hemophilia treatment centers and local chapters of the National Hemophilia Foundation. We represent the more than 3,000 Ohioans who have bleeding disorders.

I would like to testify in support of the House-passed version of the budget related to the Children with Medical Handicaps program and the Hemophilia Premium Payment Program.

**<u>Children with Medical Handicaps Program Overview</u>**

The Children with Medical Handicaps Program (CMH) is a health care program operating under the Ohio Department of Health (ODH). CMH links families of children with special health care needs to a network of quality providers and helps families obtain payment for the services their children need that is not covered by their current health insurance policy. CMH's mission is to assure, through the development and support of high quality, coordinated systems, that children with special health care needs and their families obtain comprehensive care and services that are family centered, community based and culturally sensitive.

The program funds services for the diagnosis and treatment of medically eligible conditions; collaborates with public health nurses and local health departments to assist in increasing access to care; supports service coordination for children with a qualifying diagnoses; and assists families to access and utilize appropriate sources of payment for services for their child. CMH promotes early identification of children with handicapping conditions and treatment of those children by appropriate health care providers.

CMH is a payer of last resort. It helps families pay for needed care, medicine, or equipment that is not covered by private insurance or Medicaid. CMH children only receive assistance for their qualifying condition. As important to families with medically fragile children, CMH helps to coordinate care which saves time and money for the families and the health care system. CMH helps to pay for social workers in Ohio's eight Hemophilia Treatment Centers to assist with this coordination of care.

CMH also is the umbrella for the Hemophilia Premium Payment Program (HIPP). This modest program has a budget of just $100,000 and assists approximately 15 adults with hemophilia. HIPP helps with payment of health insurance premiums for persons over 21 years of age, with hemophilia or a related bleeding disorder, who meet the income eligibility criteria.

CMH serves approximately 40,000 children; half are Medicaid eligible and half are on private insurance. CMH is a safety net that allows many families to maintain private insurance coverage and not have to enroll in, or qualify for, Medicaid.

## Treating Bleeding Disorders

While there are many bleeding disorders, I want to spend a few minutes educating you on Hemophilia A, also called factor VIII (FVIII) deficiency or classic hemophilia. It is a genetic disorder caused by missing or defective factor VIII, a clotting protein. Although it is passed down from parents to children, about one-third of cases are caused by a spontaneous mutation, a change in a gene.

According to the US Centers for Disease Control and Prevention, hemophilia occurs in approximately 1 in 5,000 live births. There are about 20,000 people with hemophilia in the US. All races and ethnic groups are affected.

The main medication to treat hemophilia A is concentrated FVIII product, called clotting factor or simply factor. Recombinant factor products, which are developed in a lab through the use of DNA technology, preclude the use of human-derived pools of donor-sourced plasma. And while plasma-derived FVIII products are still available, approximately 75% of the hemophilia community takes a recombinant FVIII product.

These factor therapies are infused intravenously through a vein in the arm or a port in the chest. Patients with severe hemophilia may be on a routine treatment regimen, called prophylaxis, to maintain enough clotting factor in their bloodstream to prevent bleeds.

The cost of prophylaxis can be up to $1 million annually. Most patients meet their insurance out-of-pocket maximums early in the plan year. They reach the maximum every year.

## Success of the HIPP program

With the cost of treating hemophilia being so high, maintaining insurance coverage is critical to access factor to prevent bleeding episodes. For one gentleman who is enrolled in HIPP, the program is doing just that.

He is 40 years old with moderate hemophilia A and treats on a prophylaxis regimen due to a history of frequent bleeds.  The patient is married and has two children. Due to an unforeseen job change last fall, he had to purchase insurance through the market place while his wife and children remain on a separate policy. He found a policy that would cover his treatment (which runs approximately $1.2 million annually) at a premium cost of $340 per month. This is in addition to the family's premium of $350 per month and out of pocket health care costs. The family struggled to meet financial needs and acquired debt for several month before an HTC social worker helped him enroll in HIPP.

Since the patient has had HIPP help cover the cost of his insurance premium, he has been able to treat twice per week as prescribed by his physician. This regimen has kept the patient bleed-free and relatively pain-free. He is able to maintain his full-time employment. Failure to treat per doctor recommendations, which he was doing before HIPP assistance, could results in crippling arthritis and subsequent need for surgical intervention. HIPP has been a life-line for this family.

## Proposed Changes in HB49

Governor Kasich proposed a number of changes to the program including:

- Eliminating new enrollment in the Hemophilia Premium Payment Program that assists adults with hemophilia afford private insurance premiums costs
- Requiring income eligibility for diagnostic and service coordination services
- Significantly reducing income eligibility for new enrollees in a newly established treatment program
- Moving the program from ODH to the Department of Medicaid

The changes will restrict the program for many middle-income families who need the program's support to care for their medically fragile children. While the administration states that current enrolled families will be grandfathered in, it is unclear if families who are eligible because of an income spend down or cost-share and have to apply annually for the program, will maintain eligibility. The result could be a disincentive for parents to continue working. You likely have received letters over the past week from concerned families who wanted to make sure you understand the importance of the program to their family.

My family has been on and off the CMH program because of financial eligibility and meeting cost-shares over the past 15 years and know how critical the program is to help us make ends meet when facing thousands of dollars in out-of-pockets costs with our private insurance. A recent audit of the CMH program shows that in SFY2014, 1,175 families did not meet financial eligibility requirements and were offered a cost share. Of those families, 361 met the cost share and only 210 ended up receiving services paid for by the CMH program. The average taxable income for these families was $56,651. **The average cost share of medical expenses was $4,352**. And, the average CMH benefit was $1,268.

I am honored to be the current Chair of the CMH Parent Advisory Committee. In this role, over the past 4 years, I have been able to learn much more about this program including the internal working of the Department and the CMH Program as a parent advisor. The CMH staff, our approved providers and county health departments are true heroes to our families. They are always just a phone call away to help us, and when it feels like there are no other options, they find us options and resources. They answer the phone when we call, return calls in a timely manner after making promises to get back to us, and make much needed home visits, especially during the initial diagnosis or when a family experiences a change in financial eligibility. They do this because they understand and care about children's health issues.

In 2012, I was selected as only the second Ohioan to represent our CMH program nationally through the AMCHP Family Scholars Program. This training program was more than a year-long training where I was able to learn about other state's Title V programs and learn how to be a family advocate. We finished our training in Washington DC where we were able to meet with our federal lawmakers about the importance of Title V and State Health Departments. It changed my life in ways I never imagined. I was very proud to share how efficiently our program is operating. It truly is a safety net program in many ways and not just as a payer of last resort. The program is successfully helping low and middle-income families get access to needed medical care without causing them to face detrimental financial losses.

The House of Representatives rejected the proposed changes as part of the budget and modestly increased the appropriation. We ask you to support the House recommendation to remove the changes and provide additional funding to provide sustainability for the program.

I appreciate the opportunity to testify and I would be happy to answer any questions.