

Katie Barbato, Written Only Testimony
Mother of Avery Barbato, Tyrosinemia Type 1
Mother of Leighton Barbato, Tyrosinemia Type 1
HB49 as Introduced by the Governor
House Finance - Health and Human Services Subcommittee
March 23, 2017

Chairman Romanchuk, members of the HHS Subcommittee, thank you for the opportunity to provide testimony on the CMH - Children with Medicals Handicaps, also known as the "BCMHS" program.

My name is Katie Barbato. I am currently a single, working mother of two, living in Dublin, Ohio. I have two little girls, Avery age 7 and Leighton age 4, that were diagnosed with Tyrosinemia Type 1, at birth.

I am writing today to put a face to the 40,000 children served by the CMH Program in the Department of Health and ask that you Save the CMH Program by protecting it from proposed changes in the Governor's budget. Please allow the program to continue to provide an important safety-net for chronically ill children like my two daughters. The proposed changes dramatically reduce services and eligibility for this critical program.

Although the proposed language seems to "grandfather" our family into the CMH Health program, I'm concerned about future generations and my future eligibility when my income changes. The thought of living in poverty, as a hardworking, educated, single mom to be able to afford my children's medication is frightening. My family is a cost-share family and the proposed change to move the program into Medicaid will mean that I may no longer meet the financial eligibility guidelines. CMH program has helped me as a single mom, pay for treatments and medication I couldn't afford. My girls are on a special diet, as they cannot break down Tyrosine, which is an amino acid that comes from protein. Tyrosinemia is a very rare genetic, metabolic, disease that effects 1 in every 100,000 babies in the United States. Just one of their medications that saves their lives, and they take daily, is close to \$4 Million dollars a year. Their diet is very costly as well, along with the medical drink they must have to grow properly and thrive as young children. CMH program has greatly been a major resource in other areas as well. I am very grateful to have access to this program and how its helped my family, along with thousands of other families in my similar situation. I fear my future and my children's future if I don't have access to this program or we are put on Medicaid.

The CMH Program has had great success providing assistance through the medical home model for almost 100 years and keeping families like ours privately insured, contributing to the Ohio economy, paying taxes and owning homes; I am concerned that the CMH children will fall through the cracks if the program is moved to the Department of Medicaid.

In closing, Mr. Chairman, thank you for protecting Ohio's children by allowing the CMH program to continue providing services to middle- and low-income families. Thank you for the opportunity to share my family's story.

