Testimony of Jenni Meyers WRITTEN ONLY

Mother of Balian Meyers with Cystic Fibrosis 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 "BCMH" program.

My name is Jenni Meyers, my son, Balian Meyers benefits from the CMH program. My husband and I reside in Oak Harbor, Ohio with our three children including Balian. Balian is three years old and living with cystic fibrosis. He has an older brother, Noah who is four years old and a younger sister, Lila who is one year old. Neither of his siblings have cystic fibrosis but it affects all our lives. Cystic fibrosis is a genetic disease that affects the lungs, digestive track, and other organs with thick, sticky, mucous. Cystic fibrosis is a chronic and terminal disease. There is currently no cure but advancements are being made in the treatment of care of cystic fibrosis patients allowing for longer lives and better quality of life.

Balian is just one of 40,000 children aided by the CMH program in the Department of Health. I am urging you to maintain the CMH program as it is, serving those with medical handicaps throughout the state of Ohio. The proposed changes would greatly impact the level of medical care received by many of the current children being served under CMH.

Although, my child will be "grandfathered" into the CMH program I worry about his future and the future of other children living with medical handicaps in the state of Ohio. As our family income increases, we may no longer meet the financial guidelines for the CMH program if it is placed under Medicaid. This could leave us with large medical expenses that we will have difficultly covering on our own, even with private insurance.

Currently my son has coverage under private insurance through my husband's employer, secondary coverage through a Medicaid managed care plan, and then CMH as payor of last resort. CMH helps cover cost that are not covered by the other two. For my child, that includes supplement drinks and nutrition consults. It may not seem like much, but a month worth of supplement drinks can cost near \$400. When you are living paycheck to paycheck, that is unobtainable. My husband will be making a career change in the next two years as he finishes school and with that change will come an income increase. This increase will most likely make my children ineligible for Medicaid. Therefore, as soon as our income changes so too will out of pocket expenses for my son's medical care. We know this from experience, for my son's first year of life we had private insurance and CMH as secondary for diagnosis related expenses.

CMH helps the families in the in-between the most. When your family is making just above the guidelines for Medicaid a severe diagnosis can be financially devastating. The first two weeks after my son's official diagnosis we had to pay for all our copays fully and upfront.

This quickly added up to several hundred dollars as we paid for several specialist appointments and life-long medications. We were fortune enough to have the help of family and friends during that time but the burden was not one any of us could continue to carry alone. CMH made it possible for my family to focus on care, rather than the cost at a crucial moment in our lives.

If the CMH program was no longer available, families could be in severe financial ruin very quickly. The cost of medications, medical equipment, therapies, doctors' appointments, and procedures with a medical handicap is staggering and ongoing. These financial costs can cause families more emotional and physical stress as they try to cope not only with a diagnosis but how to pay for the best care for their children. They may be forced to work more hours, several jobs, and then be unable to provide the emotional stability that is extremely important for their children. CMH helps families spend time together and obtain the best medical treatments.

CMH is a unique program for our unique children, it provides much-needed services to the middle- and low-income families that are unable to provide the best care for their children with private insurance and/or Medicaid. I urge you to allow it to continue to do so. Thank you for your time and consideration.