Testimony of Kristen Armbrust, WRITTEN ONLY
Mother of Madelyn Armbrust with diagnosis, CDKL5
HB49 as Introduced by the Governor
House Finance - Health and Human Services Subcommittee
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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 Kristen Armbrust and I am a resident of Blacklick, Ohio. I am married and mother to one uniquely, wonderful child, Madelyn who is 2.5 years old. Madelyn was diagnosed with a rare genetic disorder, CDKL5 when she was just 4 months old. Her diagnosis results in early onset, difficult to control seizures, and severe neuro-developmental impairment. She has daily seizures, feeding difficulties, GI difficulties, low-muscle tone, is nonverbal and is immobile.

I am writing today to express significant concern regarding the proposed changes to the CMH Program in the Department of Health in Governor Kasich's budget. I am a voice for not only my daughter, but the 40,000 children served by the CMH Program in the Department of Health. I strongly urge you to prioritize these children and their health and Save the CMH Program. Of particular concern, services and eligibility for the CMH Program are at risk of being drastically reduced with the proposed changes. I ask that you please allow the CMH program to continue to prioritize the healthcare needs of chronically ill children like my daughter by providing a safety-net to their families.

The proposed changes to the CMH program suggests that our family would be "grandfathered" into the CMH Health program, however other families, who are in need of these same services but do not meet the deadline, would no longer be serviced. These families will face enormous financial burden which will affect their ability to function in the community as they otherwise could have with the assistance of the CMH Program and could affect their child's ability to develop into a functioning, contributing member of the community. Our family is lucky to have had this assistance for the past 2 years, particularly as a single-income family. Like many families with children with special needs, my husband stays home to take care of the many needs of our daughter.

I have great concern for my family's future eligibility in the program should our income change and we no longer meet the financial eligibility guidelines. So far, in the 2.5 months of 2017, our family would already have to pay about $4,000 out of pocket for my daughter's medical expenses if we didn't have assistance from the CMH treatment program. For the 2016 year, without the program, we would have met our out of pocket maximum of $8,000 for our primary insurance, and likely would meet that each and every year because of her diagnosis and high needs. That's $8,000 annually, or $144,000 over the 18 years of her life, that we would have to determine if we could afford. For our single income family this would be impossible to afford without building mounds of debt.

I would like to share with you some of the ways that the CMH program has provided our family assistance beyond what our primary insurance would cover. Since Madelyn's diagnosis, we have received support from both the diagnostic and treatment programs. CMH provided financial assistance with diagnostic testing to determine the cause of the seizures that were plaguing my 10 week old daughter, which was eventually determined through genetic testing. Other tests included MRI, spinal tap, EEG, etc. CMH covered all that our primary insurance did not which was a huge relief at a time of significant stress and devastation.

After diagnosis, we quickly learned how intense our medical journey would be after being referred to many specialists. Again, CMH provided assistance to allow Madelyn to be seen by these specialists and participate in ongoing therapies which we certainly credit for her ongoing progress. Our primary insurance limits the amount of therapies that our daughter can participate in each year, yet her condition does not work on limits. She needs repetitive, intensive treatment to make progress, which we know is not only effective but also provides us hope. Without CMH, we couldn't afford to provide therapies and therefore she would be even further behind developmentally. CMH has also paid for equipment like a bath chair, which our primary insurance deems as unnecessary. The bath chair keeps our child safe in the bath while allowing us to maintain our own physical health while bathing her. Most notably, our primary insurance denied the wheels to our daughter's wheelchair. We have deep gratitude for CMH for providing our daughter a source of mobility, covering the costs our primary insurance would not including the wheels. CMH also covered a specialized formula that our primary insurance denied. This formula was prescribed because my daughter is tube fed and the formula was being utilized as a treatment to control seizures as part of the Ketogenic Diet. CMH has helped us to provide her the care she NEEDS to live and maintain some quality of life. It has allowed for us to invest in her future, like any child deserves, so that she can have opportunities she may otherwise not have.

The CMH program has been an effective program in providing assistance through the medical home model for almost 100 years. It has allowed families like ours to remain privately insured, contributing to the Ohio economy, paying taxes and owning homes. The proposed changes to the CMH program could result in the CMH children falling through the cracks and not having their complex health needs prioritized and managed in the health sector.

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