Testimony of Clarissa Allega Mother of Tony with Epilepsy, Asthma and Hypospadias and Liam with Failure to Thrive, Dysphagia, GERD and Raynaud's Syndrome 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 Clarissa Allega. I live in Clinton, Ohio with my husband and our three children, all boys. My oldest son is a twin – the boys were born a little early at 33 weeks. Tony's identical twin passed away almost 7 years ago after living almost 2 years with significant developmental disabilities, as well as epilepsy. Tony has epilepsy and asthma – both of which are now well controlled with his current medications. My middle child, Liam, is an extremely busy preschooler who has a laundry list of developmental and medical concerns, none of which is his final diagnosis. We are waiting on private insurance approval for whole exome sequencing by his genetics doctor with hopes that we'll get a better picture of why he is the way he is. My youngest, Franklin, is a vibrantly healthy 9 month old.

I am here 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 sons. 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. My family is a cost-share family and the proposed change to move the program into Medicaid will mean that we may no longer meet the financial eligibility guidelines.

My husband works full time and carries our private insurance through his employer. Our family deductible is \$5200 this year (and goes up annually.) Our out of pocket maximum for insurance is \$8,000. We had met that figure before the end of February this year. There are items (such as Liam's formula) that our insurance doesn't cover at all, that we pay in addition to those amounts.

I used to work full time at a small general practice law firm, but was unable to maintain the facetime in the office that I needed to keep that position after my middle child was born and I started having to take him to therapy appointments twice a week. I am currently self-employed, and run my law practice primarily from home. My income changes dramatically from year to year. Having CMH as a safety net to help with making

the deductible expenses each year gives me the ability to work the reduced hours that are needed for me to take the boys to their various doctors and therapy appointments.

I am very concerned that when my children have their CMH renewals processed next January, we'll be left out in the cold, as our family gets a new cost share amount every year. Even with my reduced income, with me working less hours from home, we are over the proposed 225% of poverty level for our household size.

We spent six months with no CMH coverage between June 2015 and January 2016 while I compiled the paid medical bills to prove we'd met our cost share for that year of \$8833.40. For our renewal in 2017, we met our cost-share of just over \$2000 in the twelve month look back, so there was no break in our coverage this year.

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.

Even for a solidly middle class family, after paying the mortgage, utilities, student loans, and putting food on the table, there aren't unlimited dollars available for healthcare expenses. For our family, CMH coverage means help with paying the \$373.25 copay every 21 days for Liam's medication to treat his delayed gastric emptying. It means not having to choose between filling the prescription for his formula to help him gain weight (that our insurance doesn't cover at all) or filling the prescription for thickener so he doesn't aspirate that formula and end up with pneumonia. It means not deciding if I get Liam's other medications for the month or filling Tony's two asthma medications.

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 and I would be happy to answer any questions.