Testimony of Matthew and Allison Dolan — WRITTEN ONLY
Parents of Eóin Dolan, child with cerebral palsy, sensory processing disorder, cortical visual impairment and global developmental delay
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.

We are Matthew and Allison Dolan of Cincinnati, proud parents of a 10-year-old daughter and a four-year-old son. Our son, Eóin, has cerebral palsy, sensory processing disorder, cortical visual impairment and global developmental delay as a result of a neonatal brain injury.

We are writing to you 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 our son. The proposed changes dramatically reduce services and eligibility for this critical program.

When we learned of Eóin's brain injury and the medical challenges ahead of him, we were devastated but determined to do whatever it took for Eóin to realize his full potential. The prognosis was scary — he might never eat, talk or walk on his own — but we were hopeful: Because the brain damage occurred so early, with appropriate therapies and treatments, Eóin's brain could form different pathways to develop skills and milestones. Matt took on the full-time job of caring for Eóin and coordinating his numerous doctor appointments, therapies, and insurance claims.

From the very beginning of our journey, BCMH has been a lifeline for Eóin and our family. The BCMH diagnosis program covered the portion of Eóin's 3-week NICU stay that our insurance didn't cover. Since then, BCMH has made it possible for Eóin to get the care he needs to thrive. Eóin requires weekly physical therapy, occupational therapy and speech therapy to develop basic motor skills and communication skills. He needs vision care from doctors and therapists who understand the nuances of cortical visual impairment (a neurological rather than anatomical eye disorder). He also sees a behavioral psychologist to successfully manage his communication and sensory challenges.

These therapies are having tremendous results: At age 2, Eóin was able to sit up on his own and self-feed with his hands. At age 3, thanks to behavioral intervention, he transformed from melting down whenever he was placed in a walker to walking down the hallway smiling and laughing to favorite songs. Today, at age 4, he is beginning to walk on his own, learning to eat with utensils and saying over 100 words with increasing clarity. His visual function and curiosity have increased; he can now look at favorite objects and identify them by name.

Without BCMH, our family simply could not afford this care. The therapies and specialist appointments cost thousands of dollars each month; we literally do not earn enough after taxes and private insurance costs to pay for all of Eóin's medical care, even though Allison has a good, stable job in the publishing industry. The premiums for our private insurance cost \$900 per month — more than our mortgage — and our plan requires us to pay another \$6,000 each year out of pocket. Eóin exceeds the therapy visits allowed by our private insurance by April of each year; the rest of the visits are covered by BCMH. Our private insurance does not cover vision or speech therapy at all; we would have to pay for those entirely out of pocket without BCMH.

Yet under the proposal to roll CMH into Medicaid, children like Eóin will no longer qualify. Our annual income of \$70,000 before taxes exceeds the proposed \$54,000 cap for a family of four. While the language of the proposal seems to indicate that Eóin would be "grandfathered" into the program, we do not feel confident this is actually the case, as families must reapply every year. If BCMH were not available to us, we would be left with choices that are unthinkable to us, such as having to reduce our income in order for Eóin to qualify for Medicaid. As hardworking, taxpaying Ohioans, we are saddened and disturbed at the fact that this proposal could force us to make such a choice. We also worry deeply about the children born after July 1 who will never qualify for the crucial benefits BCMH has provided to Eóin, and the terrible position those parents will be put in — on top of the strain of coping with their children's medical conditions.

For more than a century, the CMH program has successfully enabled families like ours to manage our children's illnesses while keeping us privately insured, contributing to the state's economy and paying taxes. We are deeply concerned that if the CMH program moves into Medicaid, sick and disabled kids will not receive the help they desperately need to live and thrive.

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 our family's story. We would be happy to answer any questions; you may contact us at 513-967-0240 or at this email address.