

Testimony of Megan Strok, "WRITTEN ONLY"
**Mother of Ryan T. Strok with CDKL5, Epilepsy, Hypotonia, Developmental
Delays, Cortical Vision Impairment and Apraxia of Speech**
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 Children with Medical Handicaps (CMH or BCMH) program.

My name is Megan Strok, and I live in Cleveland, Ohio, with my husband, John, and our three young children: Lily (9), Jack (7) and Ryan (5). John works full-time for the Cuyahoga County Fiscal Office, and I work full-time for Cleveland Clinic Children's Hospital. Ryan was diagnosed with epilepsy at 8 months of age and with CDKL5 just after his second birthday. He suffers from intractable epilepsy, hypotonia, developmental delays, cortical vision impairment and apraxia of speech. We were told that Ryan would never walk or talk and would be dependent on others for his entire life. Ryan has learned to walk, however, and although he uses a wheelchair at times, he is defying the odds—thanks in large part to the services made possible to us through BCMH.

I am writing today to put a face to the 40,000 children served by the Department of Health's CMH program and ask that you save CMH by protecting it from the 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 son. The proposed changes dramatically reduce services and eligibility for this critical program.

Although the proposed language seems to “grandfather” our family into the CMH program, I'm concerned about future generations and our own future eligibility should our income change. My family is a cost-share family, and the proposed change to move the program into Medicaid may mean that we no longer meet the financial eligibility guidelines. (A cost-share is similar to a deductible: depending on a family's income, they may be assigned a dollar amount to meet for medical expenses for the entire family over a two-year period before BCMH is re-established for the child in need.)

I have excellent insurance through Cleveland Clinic, but having a child with needs as significant as Ryan's is still very expensive. There are out-of-pocket requirements, as well as limitations to our coverage. For example, each therapy discipline carries a \$10 copay and is limited to 20 visits per calendar year. Ryan has physical therapy, speech therapy and occupational therapy on average 40 times per year for each discipline (120 total therapy visits, of which 60 would be covered). At minimum, this comes with a cost of \$100 per month in copays. Additionally, we easily exhaust our therapy allowances long before December. Without BCMH, we would be forced to make a choice between paying out of pocket until the new year starts or forgoing Ryan's therapy altogether.

Ryan takes three anti-seizure medications daily and has one rescue medication in the event of cluster seizures or a seizure lasting longer than 4 minutes. The copays for these monthly refills under our primary insurance total approximately \$100.

Ryan sees a specialist (either neurology, gastroenterology, otolaryngology or ophthalmology) about twice per month. Our copay for specialty visits is \$35 each. Emergency room visits are far more common with Ryan than with our two typical children and require a \$100 copay for each visit. Inpatient admissions are also routine for us—Ryan is generally admitted at minimum twice per year for overnight EEG testing—and our copay under our primary insurance is \$100 for admission.

This is to say nothing of the medical equipment that Ryan requires. He has used AFOs (ankle and foot orthoses) since age 2 and requires a new pair each year. Our co-insurance amount for these is approximately \$265 annually. Ryan was approved for a wheelchair through our primary insurance, but the co-insurance was in the neighborhood of \$10,000.

All of these copays and out of pocket expenses—for therapy appointments, medications, specialty visits, ER visits, inpatient admissions, AFOs and his wheelchair—are covered for us through BCMH. Without BCMH, these high costs would put Ryan’s therapies, treatments and equipment out of our reach, limiting the mobility and independence in him that they have encouraged.

Simply put, we should not have to choose between paying our mortgage and paying for Ryan’s medical care. Every child deserves to be supported to reach his highest potential. My family is fortunate and blessed to have one of the best private insurance plans in the state through my employment at Cleveland Clinic. If *we* have significant concerns about making ends meet without the support of BCMH, I can only imagine the fear felt by other families, those who have large annual deductibles in addition to co-insurance and copay amounts.

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 deeply concerned that the children served by CMH 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. I would be happy to answer any questions you have.

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