

**Testimony of Shandon Mackall- "WRITTEN ONLY"**  
**Mother of Brendon Mackall with Muscular Dystrophy**  
**HB49 as Introduced by the Governor**  
**House Finance- Health and Human Services Subcommittee**  
**March 23, 2017**

Hello and good day. My name is Shandon Mackall. I am one of the many families that have received and continue to receive help through BCMH. Our son Brendon has been diagnosed with MUSCULAR DYSTROPHY.

We as many families started out on our own trying to get answers seeing specialist after specialist as the bills piled up. See we so many others are your average middle class working family, the usual ones that get lost in the middle. We are a family of four, mom, dad, and two kids. My husband works 55-60 hours a week to provide for our family due to its complicated for me to work outside the home and still be available for our son. We have private insurance, we are not rich enough to pay for everything on our own, but we are not financially eligible for any kind of government assistance because my husband works his butt off pulling overtime to provide for us, but if he was willing to settle for the simple 40hrs a week we may qualify but he being the hard working husband and father he is wants the best for his family and tries to do it without sucking the system dry like so many do.

Our journey down this stressful, tiring and many times sleepless road started about four years ago. Knowing that something was different and off with our son and seeking the help, as we got deeper and deeper into trying to figure out our sons diagnoses, the doctors wanting to do this test and that test, but me having to explain that we needed to only do the necessary because we were doing it alone. The financial burden becoming more and more, racking up medical bills to turn around and hopefully be able to pay that year's medical debt off at income tax time.

We then had a doctor refer us to the Bureau of Children with Medical Handicaps also known as BCMH. I never thought there was any assistance we could get to help us, but low and behold we were eligible and this was absolutely amazing!

Our current insurance only covers so much and some treatments or test not at all, and because of deductibles and such we pay a large sum out of pocket. Therefore, on our own without any help form a program such as BCMH, our son wouldn't be able to receive testing and therapies and devices such as his braces, which cost thousands of dollars because we just couldn't afford to pay for it.

Since we have been blessed with BCMH as a secondary insurance for our son, he has been able to everything he has needed and needs to determine what he had, such as specialist, muscle biopsy, nerve biopsy, physical therapy, occupation therapy, braces yearly, and the most recent has been a genetic test to determine what strand of muscular dystrophy he has. We never could have afforded this on our own and finding this out is crucial to our son's future, and for us as parents to prepare for what the future may hold for our child, and for the doctors to be able to make a care plan for him.

**WE NEED TO BE ABLE TO CONTINUE TO TAKE OUR SON TO HIS SPECIALIST,**  
**which can range from every three to six months. HE NEEDS TO BE ABLE TO CONTINUE**  
**TO GO TO PHYSICAL AND OCCUPATIONAL THERAPIES EVERY SINGLE WEEK (our**  
**insurance only covers so many sessions per year) TO KEEP HIS INDEPENDANCE**  
**AND LORD WILLING KEEP HIM OUT OF A CHAIR. WITHOUT BCMH WE WOULD BE**  
**LIMITED TO HOW MANY TIMES HE WOULD BE ABLE TO DO THIS IN A YEAR. WE**

KNOW THESE SERVICES WORK, THE DOCTORS SEE HIM MAINTAINING AND NOT REGRESSION.

There are thousands of families in this same predicament, therefore its programs like BCMH that helps all families with children with disabilities regardless of their financial class.

If BCMH would be defunded or moved to the Ohio Dept. of Medicaid, thousands of families would be left with the terrifying decision of getting meds, care or devices for their child or paying the bills and putting food on the table etc. No family should ever have to fear if they can provide the needs for their child. Many are fearful for their child's life due to they know they are unable to do on their means alone.

Now I do understand the need to balance the budget for the state of Ohio, but not at the expense of the care for children with disabilities. BCMH has been implemented for almost 100 years and serves and helps alleviate the burden carried by families with these children. If this is moved to Medicaid and the criteria is moved to 225% FPL, I see you forcing people to divorce, separate, quit their jobs or simply take lower paying jobs just to be able to be qualified for their child to be able to get the care they need. I don't see how this will be productive for our state, or our economy in the end.

IF OUR GOVERNMENT IS WILLING TO DEFUND KIDS WITH MEDICAL HANDICAPS TO BALANCE THE BUDGET THEN WHERE DOES IT END? WHEN THE BOTTOM LINE IS MORE IMPORTANT THAN THE QUALITY AND CARE OF A CHILDS MEDICAL NEEDS OR LIFE I GET CONCERNED. WHEN A PERSON OR PERSONS IS COLD ENOUGH TO LOOK AT THESE CHILDREN WITH DISABILITIES AS JUST A NUMBER ON PAPER, I GET CONCERNED. THESE KIDS DID NOT HAVE A CHOICE TO THE WAY THEY WERE BORN, WE NEED TO HELP THEM AND NEED TO PROTECT THEM. WE NEED TO KEEP THEM THRIVING AND KEEP THEIR LIVES AS PRODUCTIVE AS POSSIBLE!

I am asking Governor Kasich and all Ohio's government to please vote NO to HB49 BCMH. We families are already dealing with the problems and financial cost of having a child with a disability. Please don't add to the financial and emotional burden that comes with it but cutting such a worthwhile program such as BCMH.

Thank you for your time.

Concerned Parent of BCMH Child,  
Shandon Mackall