

To Whom it May Concern:

My name is Lauryn Tubesing and I live in Lebanon, Ohio. I have three children, two of which have Cystic Fibrosis. I'm here today to urge you to not approve Governor Kasich's proposed budget as it currently stands, and to refund BCMH to it's current state.

My story begins at LA AFB in California. My husband and I were both in the Air Force; I was a Finance Officer and my husband was an ICBM Combat Crew Commander transitioning into Satellite Acquisitions when we received the phone call that our newborn daughter had failed her newborn screening and most likely had Cystic Fibrosis. After lots of test, tears and doctors appointments we were told that our daughter fell into a new grey-zone diagnosis: Cystic Fibrosis Related Metabolic Syndrome (CRMS). What this means is that my daughter had the genetics for Cystic Fibrosis but she did not fail the diagnostic sweat test they utilize to diagnosis the disease.

This diagnosis meant that my daughter had to have test after test for years of her life to make sure that the diseases wasn't progressing without our knowledge. My husband and I chose to leave the AF and move to Ohio so AJ would have continuity of care, great doctors and BCMH. BCMH covered the slew of tests our daughter was subjected to. When you're daughter is constantly undergoing testing for a terminal disease not having to worry about the finances truly allows you to focus on whats important: your child.

In December 2016 our daughters pulmonologist told us that our daughter needed to have procedure done to look inside her lungs and see what was going on. I was 37 weeks pregnant when we were told that our daughters lungs were classic CF lungs and her diagnosis would change immediately. After AJ was released from the hospital, and our last child (Carson Rose) was born, we headed back to the CF clinic. Carson had failed her new born screening as well and was diagnosed with Cystic Fibrosis. Our doctor gave us the rundown: life expectancy is 40, daily time-consuming treatments, no guarantees of her health. He then asked if we had any questions and I said "yes! BCMH coverage". The doctor sighed and said "sure, but its probably not going to be around". My heart sank.

My husband and I both work and do not qualify for medicade but our out of pocket expenses for one child with CRMS was around six thousand dollars. That will increase quite a bit with two children with Cystic Fibrosis. The financial stress this puts on family directly impacts our daughters health. Its the kind of stress that you can't shake and it permeates your entire life, and the life of those around you. Please don't give up on my family, and do not defund BCMH. My girls, and all other children, are worth your investment and I know that they will not let you down.

Thank You,

Lauryn Tubesing