

Testimony of Katie Jones “WRITTEN ONLY”
Mother of Mason Jones with Malformation of Coronary Vessels
HB49 as Introduced by the Governor
House Finance- Health and Human Services Subcommittee
March 23, 2017

Chairman Romanchuk, members of the HHS Subcommittee, thank for you the opportunity to provide testimony on the CMH- Children with Medical Handicaps, also known as the “BCMh” program.

I am Katie Jones. I live in Lisbon, Ohio. Mason is my active child and has been since birth. We had signed Mason up for soccer since he loved t-ball so much. It was a hot fall evening, and he was playing the best game he had ever played when all of a sudden, our lives were flipped upside down. He came over to me and told me that he had pain in his heart. He was red and sweating, so I told him to go sit down, take a drink, and he would be fine but of course since he is so active, he got right back out there and started again. Again, he complained of his chest hurting, so that evening I drove him to Akron Children's. They did an EKG and told us absolutely nothing other than the fact that they thought that he was dehydrated and to follow up with a cardiologist, said the ER doctor. We did not think anything of it until six weeks later when the appointment came. Unfortunately, I was very ill so my husband had to take him. He called me and told me that our son was going to need open heart surgery. They had never seen anything like this before and were assuming that would be the only measure to be able to fix him. Of course, I wanted my child fixed, but then in the back of my head I was wondering how we were going to be able to afford it. It's not just a \$20 copay or hitting the deductible, but it's that percentage after our private insurance that adds up extremely quick. We had more testing done and so far at the age of seven, a year-and-a-half after his diagnosis, he is able to play some sports. BCMH has given us this invaluable opportunity to be able to make his appointments for his tests, that are quite costly, and be able to keep me at home as a stay-at-home mom, and for us to be able to continue to pay our bills without hesitation. Our son still has a coronary artery anomaly and will for the rest of his life, but with the assistance of BCMH, it takes that burden off of us that we will fully be able to continue to pay on our house, buy groceries, and be able to give our children the life that they deserve. There is no reason in this world why we should have to continue to produce Narcan to every drug addict when they want to have a great weekend, yet be able to tell these families that they are unable to get the proper treatment, testing, medicine, supplies for their child, and basically a right hand with the nurses that go right alongside of BCMH. We will never be approved for Medicaid for our son due to the fact that we make too much money being a working-class family.

Thank you for taking your time to listen to our child's story. These children of BCMH have grown to become a community that do not see their medical handicaps as being different but all the same in God's eyes. They deserve everything under the sun to give them the best quality of life that they deserve. Thank you for the opportunity to share my family's story and I would be happy to answer any questions.

Katie Jones