
Testimony of Cheri Unkefer - Written Only
Mother of Elijah Unkefer who has Duchenne Muscular Dystrophy
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 Medical Handicaps, also known as the "BCMh" program.

My name is Cheri Unkefer. I live in Columbiana, Ohio with my husband and three children. My youngest son, Elijah (age 5), was diagnosed with Duchenne Muscular Dystrophy one year ago and what a roller coaster it has been since. My husband works full time as a builder with his father, and I am a part-time sonographer at an Ob-gyn office in Boardman, Ohio. We have our health coverage with a Christian cost-sharing ministry called Samaritan Ministries, which is a great alternative to traditional insurance that is too expensive for small businesses to provide. It has covered all of our emergency visits and childbirth, but it does not cover doctor's appointments, medication, and only covers 40 physical therapy visits per diagnosis.

I am writing this today to put a face to the 40,000 children who are served by the CMH program in the Department of Health, and I am asking that you save the CMH program by protecting it from the proposed changes in the Governor's budget. I am asking that you would allow the program to continue to provide an important safety-net for chronically ill children like my son, Elijah. The proposed changes dramatically reduce services and eligibility for this critical program.

Although the proposed language seems to "grandfather" our family into the CMH Health program, I'm concerned about future generations and about my son's future eligibility should our income change. My family is able to be on the CMH program due to the cost-share, and the proposed change to move the program into Medicaid will mean that we may no longer meet the financial eligibility guidelines. Now I have been informed that we will still be able to use a cost-share to qualify, but I have not seen this in writing yet. Regardless, we may be able to use the cost share, what about children in our financial situation who may have a child diagnosed with a horrible illness next year, or the year after that, and so on? When Elijah was diagnosed, we were in shock. First of all, we had just been told that our son had a fatal genetic disorder that will slowly rob him of his ability to walk, his fine motor skills, his ability to breathe unassisted, and finally of his heart's ability to pump. Now, we have hope that a cure will be found, or even a medication to make this a chronic rather than fatal condition, but that all comes at a cost. We went from being a

very healthy family who rarely went to the doctor's to a family who has their son at the doctor's every three months, either near home or in Columbus at Nationwide Children's Hospital in the MDA clinic. Our health coverage covers some, but not his medication, doctor's appointments, or physical therapy. The CMH program was a balm to our family as we stressed over how we were going to pay for everything he needed to keep him walking as long as possible. Because of BCMH, we were able to get Elijah the therapy he needed last summer to bridge the gap between the school years where he normally receives physical therapy with his IEP. We have been able to afford his care with the help of BCMH, we have had the nurse at the Health Department to help us whenever we needed it, and we have hope that if we can remain on the program, Elijah will be able to get all of the care he will need in the future without us having to decide whether we buy his medicine and other devices, or pay our bills and have food on the table. And I hope, that families in the future in our same position, who make greater than 225% of the federal poverty level, but are not rich by any means, will have access to this great program through the Department of Health with a cost-share so they may be able to provide for their child the way this program has allowed us to.

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.

Sincerely,

Cheri Unkefer

