Testimony of Randi Clites Mother of Colton Clites 15 year old CMH Child and Chair of CMH PAC HB49 as Introduced by the Governor House Finance - Health and Human Services Subcommittee March 23, 2017

Chairman Romanchuk and 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 Randi Clites. My family lives in Ravenna, in Northeast Ohio. My husband Matt and I have one child. Colton is a survivor. He has severe hemophilia and has also survived leukemia and a brain bleed. We have been on and off the CMH program because of financial eligibility and meeting cost-shares over the past 15 years. However, today I'm not here to share my family situation with you specifically, because you will hear from others first hand how this program impacts them and also in written testimony provided by families whose children are too medically fragile to make the trip here. I am here to represent the parent voice for those who need our protection from the impacts this proposed change will have on their lives.

First, I would like to thank you from the bottom of my heart for your support already provided to us and your willingness to allow our families to have a voice in this process during public testimony. It is extremely important that their voices be heard and hopefully we can be part of the steps to take actions to protect this program for our future children.

We are all here today to put a face to the success of those served by the CMH Program in the Department of Health. The program has a long history of almost 100 years providing stability to families like ours. Because of this, there is a strong group of dedicated parents and community members who have become the face of this program around the state and in the media. Since the beginning of February, when PAC started a Facebook group to educate our state about the proposed changes, we have been able to connect with about 1,200 families and concerned citizens. Some are here in blue wearing a button that says #SaveOhioCMH to show their support of our families. I'd like to also thank them for their ongoing and unwavering support.

I am honored to be the current Chair of the PAC. In this role, over the past 4 years, I have been able to learn much more about this program including the internal working of the Department and the CMH Program as a parent advisor. The CMH staff, our approved providers and county health departments are true heroes to our families. They are always just a phone call away to help us, and when it feels like there are no other options, they find us options and resources. They answer the phone when we call, return calls in a timely manner after making promises to get back to us, and make much needed home visits, especially during the initial diagnosis or when a family experiences a change in financial eligibility. They do this because they understand and care about children's health issues. I fear if this program is moved to Medicaid where the bottom line is always about the financial savings to the state and the Managed Care Plans; our children will suffer, our families will suffer.

In 2012, I was selected as only the second Ohioan to represent our CMH program nationally through the AMCHP Family Scholars Program. This training program was more than a yearlong training where I was able to learn about other state's Title V programs and learn how to be a family advocate. We finished our training in Washington DC where we got to meet with our federal lawmakers about the importance of Title V and State Health Departments. It changed my life in ways I never imagined. I was very proud to share how our program is run in Ohio. It truly is a safety net program in many ways and not just as a payer of last resort. We are successfully helping low & middle-income families get access to medical care needed without causing them to face detrimental financial losses. This program does not remove all financial burdens from the family, and we are okay with that, families accept their share of the costs as determined by the CMH program financial guidelines.

Mr. Chairman and committee members, here is my major concern. I have been part of the PAC since 2005. The program has been growing constantly over those years due to meeting the CMH mission statement and making sure the program helps families navigate a cumbersome system of care and remain somewhat financially stable. It is not because there are more children diagnosed with chronic illness, it is because the out of pocket costs are being increased on families like ours and the provider networks are narrowing, so those of us dependent on both commercial and state health insurance, will have no place to turn when our payers won't give us access to the care our children so desperately need to survive or that will greatly increase their quality of life, if this program is moved to Medicaid.

In 2005, when I testified about the program, CMH was serving 24,000 from a state budget of 12.5 mil, now it is serving 40,000 children on 7.5 mil state support. Through JMOC reports (pages 27-37) and audits (total of 5), this program is proven to be a program that is needed and running well, however the financial support that this program needs to be sustainable has not been requested in the Governors budget for the past 3 budget cycles. I urge this committee to not only remove the language to protect this program from the changes in the proposed budget but I also urge you to help us protect this program from further cuts or actions to dismantle it.

In closing, Mr. Chairman and committee members, please protect Ohio's children, we urge you to strike the proposed language in the Governors Budget and allow the CMH program to continue providing services through the Department of Health where our medically fragile children belong. Thank you for the opportunity to testify today and I would be happy to answer any questions.