

WITNESS INFORMATION FORM

PLEASE COMPLETE THE WITNESS INFORMATION FORM BEFORE TESTIFYING

DATE: 03-23-2017

NAME: Rev. David Hoffman

ORGANIZATION: _____
(IF APPLICABLE)

POSITION/TITLE: _____

ADDRESS: 344 Durfee Dr.

CITY: Marion STATE: OH ZIP: 43302

TELEPHONE: 614-949-7570

ARE YOU REPRESENTING: YOURSELF ORGANIZATION _____

DO YOU WISH TO TESTIFY ON
LEGISLATION (BILL NUMBER): _____

SPECIFIC ISSUE: _____

SUBJECT MATTER: Budget proposal to move BCMH from ODH to ODM

DO YOU FAVOR _____ OR OPPOSE THE ENACTMENT OF LEGISLATION REGARDING THIS ISSUE?

PLEASE GIVE A BRIEF STATEMENT OF THE GROUNDS ON WHICH YOU FAVOR OR OPPOSE SUCH ENACTMENT:

Our daughters are currently served by BCMH and rely upon the safety net of BCMH.

Proposed changes will affect families ability to receive medically necessary care, medications, and treatments

WILL YOU HAVE A WRITTEN STATEMENT, VISUAL AIDS, OR OTHER MATERIAL TO DISTRIBUTE?

YES NO _____

(IF YES, PLEASE PROVIDE COPIES TO THE CHAIRMAN OR SECRETARY)

HOW MUCH TIME WILL YOUR TESTIMONY REQUIRE? 5 minutes

***Testimony of the Rev. David L.Hoffman
Father of Andrea and Alyson Hoffman who are living with cystic fibrosis and are
covered under the Bureau of Children with Medical Handicaps
HB49 as Introduced by the Governor
House Finance - Health and Human Services Subcommittee
March 23, 2017***

Chairman Romachuk and members of the committee,

My name is Rev. David Hoffman, and I am a parent of identical twin daughters, Andrea and Alyson Hoffman, both of whom are living with the life-shortening disease of cystic fibrosis. I am a resident of Marion County and serve as a volunteer on the Ohio Department of Health's Bureau for Children with Medical Handicaps Parent Advisory Council.

As a father, I know what it is like to be jarred awake in the middle of the night, hearing one of our daughters cough uncontrollably and then spend the rest of the night worrying whether or not this is going to be the beginning of a hospitalization or a decline in lung function. This gnawing kind of worry is a constant in the lives of parents who have sick children.

As a father, I also know what it is like to sit in a state of frustration, while sifting through pages and pages of insurance plan documents and explanation of benefits, or while filling out appeals with insurance companies, or while spending endless hours on the phone educating insurance providers about our daughters' disease, cystic fibrosis, and the medically necessary care, medication, and treatment that our daughters need in order to thrive and survive. This never ending kind of frustration is a constant in the lives of parents who have sick children.

It is difficult to walk in our shoes -- let alone have someone from the outside try to put themselves in our place and determine what is best for our children. Our own experience has shown to us that we cannot walk this journey alone. We rely upon our patient-centered medical providers to help us to coordinate and manage our children's care. We rely upon our employer sponsored private health insurance benefits to keep our children healthy. But we know, by experience, that that is not enough. Dealing with children who have complex medical conditions is costly, complicated, and constant. Even with excellent insurance coverage, there are still gaps in coverage, costly high deductible plans, and numerous co-pays. We estimate that our own out-of-pocket expenses for the healthcare our daughters, which is not covered by private insurance, exceeds \$10,000.00 annually and doesn't begin to stop there. Although the Affordable Care Act currently caps out-of-pocket maximums for individuals and families, those maximums are only for services that your specific plan covers. Not everything that is medically necessary is always covered and it depends on who is determining medical necessity. There are also assumptions made by decision makers that insurance based care coordination is adequate, while in reality, there are very few trained in the insurance world to deal with cases of multifaceted pediatric conditions like cystic fibrosis. We know that we cannot do it alone, and we have come to rely upon the help and benefits of BCMH. BCMH meets families where they are and provides a level of care coordination that understands the context of their family and the communities in which we live. BCMH walks with patients and families and helps to take away some of the worry and frustration so that parents can concentrate on caring for their children, remain working to make ends meet, and receive the medically necessary care in which they need.

For almost one hundred years, the governor and administrative agencies, along with the state legislature and county commissioners, have sought to understand the dilemma of families who have children with complex special health care needs. They understood the need to support and provide a

safety net for Ohio's most vulnerable children and adults – but that support will be eroded away by the proposals contained in Governor Kasich's Executive Budget.

Moving BCMH from the Ohio Department of Health to the Ohio Department of Medicaid creates an entirely different system of care. After July 1, 2017 the program limits eligibility for those currently receiving benefits and essentially eliminates the program for those under and above 225% of the Federal Poverty Level. (Yes – I just said that! It doesn't make sense. If you don't believe me, read the white paper and the frequently asked questions.) Those who are currently on BCMH who are Medicaid eligible will completely lose their safety net. There will no longer be a program that comes behind their Medicaid managed care. The Governor's proposal makes it sound like those who are on Medicaid will be moving to a new level of care when in reality -- they will be losing a level of care. Those who are Medicaid eligible are already on Medicaid managed care; and that new system of care will no longer have the oversight and benefits that come behind Medicaid managed care.

For those who are privately insured, this proposed new level of care isn't much better either. After July 1, 2017 if your child is diagnosed with one of the devastating diseases covered by BCMH and you make over 225% of the Federal Poverty Level you will be on your own. For those who are currently receiving benefits and are not Medicaid eligible, they will remain in a grandfathered program at the Ohio Department of Health until their medical or financial situation changes and then they will be subject to the new eligibility criteria thus eliminating many -- if not all -- from the program. Throughout the Governor's proposal, BCMH is criticized for the complex system of financial eligibility determination that has developed over the years – but it works and recognizes that families are facing complex and devastating circumstances that require more than just simple answers. BCMH is a program that incentivizes folks to stay employed, care for their children, pay taxes, and remain privately insured while the new program encourages folks to qualify for Medicaid and hope to receive the medically necessary care and treatment that their children need to survive.

With the uncertainty of looming changes in health insurance coverage on a federal level and the growing uncertainty of Medicaid funding – now is not the time to widen the holes of the safety net, allowing Ohio's most vulnerable to slip through the cracks. Now is the time to strengthen our resolve to ensure that those like our daughters will have what they need in order to live long and productive lives.

I respectfully urge you to keep BCMH at the Ohio Department of Health and keep it funded at levels that benefit Ohio's most vulnerable.