

Testimony of Rev. David Hoffman
House Finance: Health and Human Services Sub-Committee
Wednesday, April 10, 2019

Chairman Romanchuk, Ranking Member West and Members of the Finance Sub-Committee on Health and Human Services, my name is Rev. David Hoffman. I live in Marion, Ohio in Marion County and my wife and I are the parents of identical twins, Alyson and Andrea, who are living with the genetic disease cystic fibrosis (CF). I have the privilege of co-chairing the Ohio Cystic Fibrosis Legislative Task Force and serving as a member of the Parent Advisory Committee of the Children with Medical Handicap Program (CMH formerly BCMH) at the Ohio Department of Health.

CF is a life-limiting condition that mainly affects the lungs and the digestive system. CF care requires daily medications, aerosol treatments, and chest therapy to add both quality and quantity to their lives. Currently there is no cure for CF only ways to treat the symptoms of this disease. The medications, treatments, and therapies are time consuming and costly. With continual access to quality care and treatment, those with CF can lead longer and stronger lives.

Currently, Alyson and Andrea, are adequately insured with two large private health insurance group plans provided by our employers and rely heavily upon the benefits of the CMH program of the ODH. We know that as they transition into adulthood, the adequacy of their health insurance is in question, especially as they hit the transition ages of 21 (at age 21 Alyson and Andrea will lose the benefits provided by the CMH treatment program) and 26 years of age (at age 26 Alyson and Andrea will not have access to parental health insurance coverage). Alyson and Andrea are 18 years old and will be attending the Ohio Northern University in Ada, Ohio this coming fall.

Fortunately, the CMH program recognizes the unique needs of the CF population including the high cost of caring for this disease and has a supplemental adult CF program that covers limited benefits for adults age 21 and over. In the past, CF was considered only a childhood disease as many children did not survive past their adolescence. Because of advances in research with the discovery of new medications and therapies, persons with CF are now living into their adulthood and surviving into their mid-forties. As a disease community, we now have more adults living with this disease than children.

As a parent and advocate for children with special health care needs, I urge your continued support of the CMH program and the increase of line 440505 and 440507 (CMH Medically Handicapped Children/CMH -Targeted Health Care Assistance-Over 21) included in the Governor's budget proposal. We truly appreciate the meaningful attention and investment that the Governor's office has given these two line items.

The Governor's proposal for the over 21 line item (440507) allows for many services to be partially restored that were cut over a decade ago. I am requesting today, **as a parent and advocate for those living with CF, for your support in providing additional funds beyond what is proposed in line 440507. An additional increase in this line item recognizes the reality that adults with CF are living longer and are requiring the same safety nets that they experienced as children in the CMH program. An increase in this line item will restore back necessary benefits that were lost in previous budget cycles and will improve the lives of adults living with CF providing them with access to affordable care and treatment. An amendment is currently being offered in the House that will add \$659,586 in FY 20/21. Currently there are 280+ adults living with CF covered under this program.**

Thank you for hearing my concerns and for making a difference in the lives of Ohioans who are living with CF.

Sincerely,
Rev. David Hoffman

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