

The Honorable Keith Faber 77 S. High St 13th Floor Columbus, OH 43215

March 16, 2017

Dear Representative Faber,

On behalf of the 1,519 individuals living with cystic fibrosis (CF) in Ohio, the Cystic Fibrosis Foundation writes in opposition to the Governor's budget proposal (H.B. 49) which would severely limit eligibility and available services for the Bureau for Children with Medical Handicaps (BCMH) program. This program serves as a vital safety-net for families with children who have serious medical conditions, including cystic fibrosis, and promotes access to the high quality, specialized care and treatments that people with CF depend upon for optimal health.

Cystic fibrosis is a life-threatening genetic disease that affects 30,000 children and adults in the United States. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to serious, life-threatening infections. Cystic fibrosis is both serious and progressive; lung damage caused by infection is irreversible and can have a lasting impact on length and quality of life. For this reason, it is vitally important that all people with CF are able to access CF treatments and care by CF experts at accredited care centers.

For people with CF, adequate health coverage is not a luxury, it is a necessity. Without access to expert CF care and treatments, the risk of lung exacerbations, irreversible lung damage, costly hospitalizations and decreased quality of life increases drastically. Our research shows one-quarter of people with CF already delay or skip care due to cost concerns. For people living with CF in Ohio, BCMH acts as supplemental insurance, offering critical supports that include filling coverage gaps and providing cost-sharing assistance that ensure access to essential services for this population.

The Cystic Fibrosis Foundation seeks to ensure that the same number of individuals with cystic fibrosis who would be served or have been served by the Ohio Department of Health's BCMH program are able to access the same level of services, without delay, that they currently receive through the program. Should this proposal be enacted, it will result in a reduction of covered services and delays in accessing care that this population depends on. Within this budget proposal, we have identified several areas of concern, outlined below:

Cuts in services for individuals with private insurance

The proposal specifies that the new medical assistance program administered by Medicaid shall cover only the health care services that Healthchek covers. The Cystic Fibrosis Foundation is concerned that this new program will not provide the same seamless coverage of critical services that the Department of Health administered BCMH program currently provides, such as nutritional supplements and help with copays, deductibles and premiums (see appendix for full list of services).

TEL: 800.FIGHT.CF

FAX: 301.951.6378

Elimination of services for individuals with Medicaid

As of January 1, 2017, those with CF enrolled in BCMH and Medicaid were transitioned from fee for service Medicaid to Medicaid managed care. Although we understand one objective of that transition was to provide additional services through Medicaid for individuals enrolled in both programs, these individuals still rely on BCMH for seamless access to certain services. For instance, BCMH pays upfront for health services that are inconsistently or not fully covered by Medicaid and for services that require prior authorizations (e.g. catheter care supplies, durable medical equipment, enzymes, insulin pump monitoring systems and nutritional formulas). BCMH also provides care coordination and support services beyond what is covered by Medicaid.

Reduced eligibility for the new medical assistance program

Currently, individuals with a family income up to 185% of the federal poverty level (FPL) or those who spend a significant portion of their income on medical care are eligible for BCMH. We understand that the effective financial eligibility cap for BCMH is 500% FPL and are concerned that the establishment of a 225% FPL cap for the new medical assistance program will eliminate a vital safety-net for some families. Additionally, the CF Foundation is concerned about applicants who apply after July 1, 2017 and under the proposal, would not be eligible for any services.

We support Ohio's intentions to streamline its coverage programs and promote efficient, effective delivery of health care. However, this should not be done at the expense of Ohioans with CF who greatly benefit from BCMH services. The CF Foundation stands ready to assist you as you prepare for the 2018-2019 fiscal years. Please do not hesitate to contact Meghan Pudeler, State Policy Specialist at mpudeler@cff.org. We thank you in advance for considering the needs of people with cystic fibrosis.

Sincerely,

Mary B. Dwight Senior Vice President for Policy & Patient Assistance Programs Lisa Feng, MPH Senior Director, Access Policy & Innovation

TEL: 800.FIGHT.CF

FAX: 301.951.6378

CC: Governor John Kasich

Representative Cliff Rosenberger, Speaker of the House Representative Kirk Schuring, House Speaker Pro Tempore Representative Ryan Smith, Chair, House Finance Committee House Finance Health and Human Services Subcommittee House Finance Committee