



The Honorable Bob Hackett
1 Capitol Square, Ground Floor, N.
Room 040
Columbus, OH 43215

May 16, 2017

Dear Senator Hackett,

On behalf of the 1,519 individuals in Ohio living with cystic fibrosis (CF), we write to urge you to adopt the language in H.B. 49, which maintains eligibility and available services for the Bureau for Children with Medical Handicaps (BCMh) program and increases funding for the Medically Handicapped Children's line item. We also request that you increase the Targeted Health Services over 21 line item appropriation to \$1,620,058 per fiscal year to align the appropriation with program costs.

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. 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 that although 99 percent of people with CF in the U.S. have health insurance, one-quarter 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.

Specifically, for individuals with private insurance, BCMh helps with cost-sharing and covers goods and services that may not be covered by private payers, such as certain medications, life sustaining nutritional formulas and durable medical equipment. Similarly, for BCMh recipients with Medicaid, BCMh fills in coverage gaps and pays upfront for health care goods and services that require prior authorizations (e.g. catheter care supplies, durable medical equipment, enzymes, insulin pump monitoring systems and nutritional formulas), so patients do not experience a delay in care.

We are grateful that the House recognized the importance of this program by removing language from the original bill that would have reduced eligibility and covered services and by increasing the Medically Handicapped Children's line item (440505) to align with program costs, allowing BCMh to continue to provide services to medically needy children in the state. We ask that the Senate adopts the language, passed by the House, which maintains the eligibility and services for the BCMh program and increases funding for the Medically Handicapped Children's line item.

While we understand tough choices must be made as a result of Ohio's budget situation, we also ask that the Senate increase the Targeted Health Services over 21 line item (440507) to align with program costs. The Targeted Services over 21 line item appropriation, which covers adults with cystic fibrosis and hemophilia, is \$1.074 million in the House budget; however, according to the Joint Medicaid Oversight

Committee report on the Ohio Department of Health Treatment Program Review report, the Adult line item cost \$1.62 million in SFY15. An increase to the Adult line item would cover program costs, in order to avoid cutting eligibility and services.

We thank you for your help in preserving this critical program and stand ready to assist you as you finalize the state's budget 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 of Policy
& Patient Assistance Programs



Lisa Feng, DrPH
Senior Director of Access Policy & Innovation

CC: Senate Finance Committee
Senate Finance – Health and Medicaid Subcommittee