



January 21, 2016

The Honorable Jane Kitchel
115 State Street
Montpelier, VT 05633

Dear Senator Kitchel,

On behalf of the people living with cystic fibrosis (CF) in Vermont, the Cystic Fibrosis Foundation urges you to protect CF-related health care programs as you begin to work on the state budget for FY2017. These programs promote access to the high quality, specialized care and treatments that people with CF depend on for optimal health. We also offer the expertise and support of the CF Foundation as you undertake the challenge of developing the state's priorities for health care funding and operations in the upcoming year.

CF is a life-threatening genetic disease that affects approximately 30,000 children and adults in the United States, a significant portion of whom are served by Medicaid and other public programs. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. CF is both serious and progressive; lung damage caused by infection is irreversible and can have a lasting impact on length and quality of life.

As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. Increasingly, the cost of essential CF care is being passed on to patients and families, making it more difficult for them to access the care and treatments they need. For this reason, it is vitally important that you consider the needs of the CF community when discussing and implementing health related legislation, especially Green Mountain Care funding. In order to help people with cystic fibrosis retain access to lifesaving therapies and accredited care centers, the CF Foundation urges you to fully fund Green Mountain Care in FY2017 and to consider the following policies:

Protect Vital CF Care Programs in the FY2017 Budget

The CF Foundation urges you to maintain funding for key public programs, like Green Mountain Care, that serve a third of adults and half of children living with cystic fibrosis. Medicaid helps people living with this disease to better afford the increasingly costly co-pays and co-insurance rates for prescription medications and inpatient and outpatient care. As a result, adequate funding to sustain the program is a primary concern for people with cystic fibrosis in Vermont. We strongly urge you to provide the same level of services for patients and families that rely on this program.

Ensure Access to High-Quality Specialized Care

People with CF must be able to get coverage for CF treatments and care at an accredited cystic fibrosis care center. The clinicians at CF care centers are experts in the evidence-based, peer-reviewed clinical practice guidelines that form the standard of care for people with this rare disease. Vermont should take all necessary steps to ensure people with CF are able to access the high quality, specialized care available in the state's accredited care centers. This includes ensuring Green Mountain Care and health

insurance marketplace plans provide adequate coverage for cystic fibrosis care, including access to CFF-accredited care centers, therapies and CF specialty care physicians.

The CF Foundation stands ready to assist you and your administration as you complete in the development of the upcoming budget. We thank you in advance for considering the needs of people with cystic fibrosis in your state.

Sincerely,



Mary B. Dwight
Senior Vice President for Policy
& CF Community Affairs



Lisa Feng, MPH
Senior Director, Access Policy & Innovation

CC: Senate Appropriations Committee