



January 11, 2017

The Honorable Nikki Haley  
1205 Pendleton Street  
Columbia, SC 29201

Dear Governor Haley,

On behalf of the people living with cystic fibrosis (CF) in South Carolina, the Cystic Fibrosis Foundation urges you to protect CF-related health care programs as you begin to work on the state budget for FY 2018. These programs ensure 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 develop 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, private insurers are passing on more costs for essential CF care to patients and families, making it more difficult for them to access the care and treatments they need. Given the role that Medicaid and other state health care programs have in assisting patients with cost sharing, it is vitally important that you consider the needs of the CF community when developing your state health care budget.

In order to help people with cystic fibrosis retain access to lifesaving therapies and accredited care centers, the CF Foundation urges you to maintain funding for Medicaid and CF-related health care programs in FY 2018 and to consider the following policies:

***Protect Vital CF Care Programs in the FY 2018 Budget***

For people with cystic fibrosis, adequate health coverage is not a luxury, it is a necessity. Without access to expert CF care and treatments, the risk of lung infections, irreversible lung damage, costly hospitalizations, and decreased quality of life increases drastically. Our research shows that one-quarter of people with CF already delay or skip care due to cost concerns. The CF Foundation urges you to maintain funding for key public programs, like Medicaid, that serves a third of adults and half of children living with cystic fibrosis, Children's Rehabilitative Services and other state health care programs. These programs help people living with this disease to afford the increasingly costly co-pays and co-insurance rates for prescription medications and inpatient and outpatient care, making adequate funding for these programs a primary concern for people with cystic fibrosis in South Carolina.

***Ensure Access to High-Quality Specialized Care***

Maintaining lung function and nutritional status as well as preventing lung infections and treating them when such prevention fails requires access to a number of different therapies delivered according to evidence-based standards of care. Availability of FDA-approved treatments and high quality CF care is crucial to management of this disease and the achievement of the best possible health status.

People with CF must be able to get coverage for CF treatments and care at an accredited cystic fibrosis care center. The CF care model exemplifies the delivery of high-quality, specialized care for a complex disease. CF clinicians apply evidence and expertise to deliver coordinated care that is centered on patients' unique needs. South Carolina should take all necessary steps to help people with CF access the high quality, specialized care available in the state's accredited care centers. This includes ensuring Medicaid and other health insurance plans provide adequate coverage for cystic fibrosis care, including access to CFF-accredited care centers and CF therapies.

We recognize that the next few years may bring significant changes to the health care system, which is why funding for Medicaid and other critical safety nets is more important than ever. The CF Foundation stands ready to assist you and your administration as you develop your FY 2018 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 Finance Committee, House Ways and Means Committee