



May 28, 2019

The «Mail\_Title» «First\_Name» «Last\_Name»  
«Capital\_Address\_1»  
«Capital\_Address\_2»  
«City», «State» «Zip»

RE: Funding for the Adult Cystic Fibrosis & Other Chronic Respiratory Illnesses Program

«Title» «Last\_Name»,

On behalf of the nearly 1,500 people in Pennsylvania with cystic fibrosis (CF), we write to express our concern regarding the proposal to cut funding for the cystic fibrosis program and consolidate it with specialty care programs in Governor Wolf's proposed FY2019-2020 budget. The Adult Cystic Fibrosis & Other Chronic Respiratory Illnesses program is critical to ensuring access to the high-quality, specialized care and treatments that people with CF need. **We ask lawmakers to fully fund the Adult Cystic Fibrosis & Other Chronic Respiratory Illnesses program and keep it as a separate line item in the final 2019-2020 budget.**

Cystic fibrosis is a life-threatening genetic disease that affects approximately 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 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. Because of the complexity of the disease, people with CF must be able to get their care at accredited CF care centers, where CF clinicians apply evidence and expertise to deliver coordinated care centered on patients' unique needs (see attached handout for more information on the CF care center model).

This year, Governor Wolf proposed a substantial cut to the Adult Cystic Fibrosis & Other Chronic Respiratory Illnesses budget, reducing program funding from \$750,000 to \$350,000. This program provides essential funding to the 12 specialized adult and pediatric cystic fibrosis care centers in the Commonwealth, allowing them to deliver high-quality, specialized care and treatment. The proposed funding cut would put care centers at risk of losing care team members, compromise their ability to provide quality care to patients, and potentially cause disruptions in access to care for people with CF.

Furthermore, the Governor's budget integrates the Adult Cystic Fibrosis & Other Chronic Respiratory Illnesses program into a new line item, "Disease Management and Education Programs," along with appropriations for other chronic disease programs. While some of these programs exist for public education purposes, the Adult CF program provides direct funding to support CF care and quality improvement activities. As the CF program is significantly different from other programs in the consolidated line item, it should remain a distinct line item within the FY2019-2020 budget.

The current version of the House budget has fully funded this program in its own distinct line item. As you work to finalize the legislative budget, **we urge you to ensure the Adult Cystic Fibrosis & Other Chronic Respiratory Illnesses program maintains full funding and a distinct line item in the final version of this year's budget.**

If you have any questions about CF or the Adult Cystic Fibrosis program, please contact Lauren Ryan, Senior Specialist of State Policy, at [lryan@cff.org](mailto:lryan@cff.org) or (301) 841-2632.

Thank you for your attention to this important issue.

Sincerely,



**Mary B. Dwight**  
Senior VP of Policy & Advocacy  
Cystic Fibrosis Foundation



**Lisa Feng, DrPH**  
Senior Director of Policy & Advocacy  
Cystic Fibrosis Foundation