



Senator Liz Krueger
Chair, Senate Finance Committee
172 State Street, Capitol Building
Room 416 CAP
Albany, NY 12247

Assemblywoman Helene Weinstein
Chair, Assembly Ways and Means Committee
Legislative Office Building 923
Albany, NY 12248

February 12, 2020

Dear Senator Krueger and Assemblywoman Weinstein,

On behalf of those living with cystic fibrosis (CF) in New York, we write urging you to protect the Adult Cystic Fibrosis Assistance Program (ACFAP), which the SFY 2021 Executive Budget proposes to eliminate entirely.

Cystic fibrosis (CF) is a rare, life-threatening genetic disease that affects approximately 1600 people in New York and over one-quarter of adults with CF rely on Medicaid or state programs for some or all of their health coverage. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Cystic fibrosis is both serious and progressive; lung damage caused by infection can be irreversible and have a lasting impact on length and quality of life. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications.

ACFAP helps adults with CF with the cost of their medical care and insurance premiums, enabling them to maintain their private insurance coverage and access the care and treatments they need to stay healthy. ACFAP is not an insurance program. Instead, it defrays some of the out-of-pocket costs for people with CF enrolled in commercial plans, allowing them to continue to work and keeping them out of public health insurance. To participate, adults with CF must be at least 21 years old, be ineligible for Medicaid, maintain private health insurance, and contribute seven percent of their annual income to the cost of their CF-related medical care and/or insurance premiums. Without the financial assistance of this program, adults with CF may be unable to afford critical health care.

Cystic fibrosis requires intensive care and treatments and the majority of people with CF have forgone care due to cost. According to a recent survey of the CF community conducted by George Washington University, one out of four people with CF and their families pay more than \$10,000 in out-of-pocket expenses every year, not



including premiums and deductibles. The vast majority of people with CF receive some sort of financial assistance to help pay for their care but even with assistance, 58 percent of people with CF reported skipping or delaying care because of cost.

Eliminating the ACFAP could make it more difficult for adults to remain on commercial insurance and access the care they need. Please protect this program by rejecting the proposed repeal of Article 29G of the Public Health Law and continue to appropriate roughly \$800,000 per year for this vital program.

Thank you for keeping in mind the needs of people with CF when forming the fiscal year 2021 budget. As the health care landscape continues to evolve, we look forward to working with the state of New York to improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward.

Sincerely,

Mary Dwight

Senior Vice President, Policy & Advocacy
Cystic Fibrosis Foundation

Lisa Feng, DrPH

Senior Director, Policy & Advocacy
Cystic Fibrosis Foundation

Maria Berdella, MD

Director, CF Care Center
Beth Israel Medical Center

Robert Giusti, MD

Director, Pediatric CF Care Center
New York University School of Medicine

Rany Condos, MD

Director, Adult CF Care Center
New York University School of Medicine

Robert Kaslovsky, MD

Director, Pediatric CF Care Center
Albany Medical College

Joan DeCelie-Germana, MD, CPI

Director, Pediatric CF Care Center
Cohen Children's Medical Center of New York

Hossein Sadeghi, MD

Director, Pediatric CF Care Center
Columbia University/Children's Hospital of New York

Emily DiMango, MD

Director, Adult Cystic Fibrosis Care Center
Columbia University

Steven Scofield MD

Director, Adult CF Care Center
University of Rochester School of Medicine

Allen Dozor, MD

Director, Pediatric CF Care Center
New York Medical College

Janice Wang, MD

Director, Adult CF Care Center
Long Island Jewish Medical Center