

On behalf of people with cystic fibrosis (CF) in New York, we urge you to preserve funding for the Adult Cystic Fibrosis Assistance Program (ACFAP), which the SFY 2021 Executive Budget proposes to eliminate entirely.

Eliminating the ACFAP could make it more difficult for New Yorkers with CF to remain on commercial insurance and access their care. Please support the appropriation of \$800,000 per year for this vital program.

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. Lung damage caused by infections can be irreversible and have a lasting impact on length and quality of life. CF requires targeted, specialized treatment and medications.

ACFAP helps adults with CF maintain their private insurance coverage and, for some, avoid enrolling in public insurance programs. 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. ACFAP assists people with CF enrolled in commercial plans by defraying some of their out-of-pocket costs and allowing them to continue to work and stay off public health insurance.

ACFAP helps ensure people with cystic fibrosis can access critical, life-sustaining care. According to a survey of the CF community conducted by George Washington University, a quarter of CF families pay more than \$10,000 in out-of-pocket expenses every year, not including premiums and deductibles, and 58 percent of people with CF reported skipping or delaying care because of cost. ACFAP helps adults with CF access their care by reimbursing for services like health insurance premiums and prescription drugs.

Please safeguard the ACFAP and help ensure that New Yorkers with CF can maintain private health insurance and access the care they need.