



June 2, 2021

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

Dear Chairwoman Weinstein and Members of the Assembly Ways and Means Committee:

On behalf of those living with cystic fibrosis (CF) in New York, we write to express our enthusiastic support for AB 5432, which would reinstate the Adult Cystic Fibrosis Assistance Program (ACFAP) in statute.

Before its funding was eliminated and its authorizing language repealed by the SFY 2021 budget, this critical program helped adults with cystic fibrosis afford the high cost of the medical care and insurance premiums, enabling them to maintain their private health insurance coverage and access the care and treatments they need to manage this complex disease.

Cystic fibrosis is a rare, life-threatening genetic disease that affects approximately 1,600 people in New York, including 970 adults. 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.

Cystic fibrosis requires intensive care and treatments, and many people with CF have forgone care due to cost. According to a recent survey of the CF community conducted by George Washington University, over 70 percent of people with CF and their families reported that paying for health care has caused financial problems such as being contacted by a collection agency, having to file for bankruptcy, experiencing difficulty paying for basic needs like rent and utilities, or having to take a second job to make ends meet. The vast majority of people with CF receive some financial assistance to help pay for their care but even so, nearly half reported skipping or delaying care because of cost.

ACFAP helped alleviate the financial burden of cystic fibrosis care by reimbursing patients for CF-related services such as insurance premiums, prescription drugs, inpatient and outpatient care, and vitamins ordered by a medical provider. ACFAP was not an insurance program. Instead, it defrayed some of the out-of-pocket costs for people with CF enrolled in commercial plans, allowing them to continue to work and keeping them off of public health insurance. To participate, adults with CF had to 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.

The SFY 2022 budget includes a one-time appropriation of \$375k for ACFAP. It is our understanding that the Department of Health can stand up and administer the program absent the reinstatement of

the statutory language authorizing the program. That said, the needs of those who utilize ACFAP will not end after this year so the passage of AB 5432 will be critical in our efforts to secure funding for this program again next year and going forward.

The elimination of ACFAP came at a time when our community could least afford it: during the economic and public health crisis caused by COVID-19. Without it, many in our community struggled to afford their health insurance premiums and needed care. AB 5432 is an important step toward ensuring this program remains in place and available to New Yorkers with CF for years to come.

Thank you for your attention to this important issue. We look forward to working with the state to improve the lives of New Yorkers living with cystic fibrosis.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with a large initial "M" and "D".

Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President, Policy & Advocacy