



February 28, 2023

New York Assembly Health Committee
LOB 823
Albany, NY 12248

Dear Chairwoman Paulin and Members of the Health Committee:

On behalf of those living with cystic fibrosis (CF) in New York, we urge you to support reinstatement of the Adult Cystic Fibrosis Assistance Program (ACFAP) and its funding in the SFY 2023-2024 budget. It is also critical that funds appropriated for people with CF in the SFY 2021-2022 and SFY 2022-2023 budgets are rolled over to allow for their intended use.

The SFY 2020-2021 budget eliminated the ACFAP and repealed statutory language authorizing the program from Article 27-G of the Public Health Law. While SFY 2020-2021 and SFY 2022-2023 budgets both appropriated one-time funding for services that the ACFAP previously provided, the program has not been restored in statute and none of the \$800,000 in allocated funds have been disbursed. The past three years have shown that an appropriation alone is not enough – in order for adults with CF to receive benefits from this program, the SFY 2023-2024 budget must include both funding and language reinstating the ACFAP in statute.

This critical program, which had operated in the state since 1987 prior to its elimination, helped adults with cystic fibrosis afford the high 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 manage the disease. Without the support of the ACFAP, adults with CF are struggling to afford their premiums and care; some are delaying or forgoing care entirely.

About cystic fibrosis and the Adult Cystic Fibrosis Assistance Program

Cystic fibrosis is a rare 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. No one insurance type, even commercial plans, adequately protects people from the high cost of CF care so three-quarters of people with CF receive some financial assistance to help pay for

their care. Even so, nearly half reported skipping or delaying care because of cost and adults with CF were twice as likely (60 percent) to delay their care as children (30 percent).

The 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. The 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, 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 program served an average of 83 adults with CF between FY 2018 and FY 2020 (the last three fiscal years prior to elimination). Average expenditure over the same period was just shy of \$350,000.

Without the ACFAP, New Yorkers with CF have been struggling for nearly three years to afford their premiums and care.

2020 National Health Expenditure data reflects that average growth in per capita personal health care spending was highest in New York State at 6.1 % per year.¹ As insurance premiums continue to rise, having fewer options for assistance has placed additional financial strain on adults with CF. For example, we know that some in New York have had to make difficult financial trade-offs, such as having to choose between paying for rent or their health insurance premiums for months at a time. While non-profit organizations are a vital resource for people with cystic fibrosis, they are not an adequate substitute for state programs and nothing has been able to fully fill the gap left by the elimination of the ACFAP.

Reinstate the ACFAP

The elimination of this vital program in the midst of the COVID-19 pandemic came at a time when our community could least afford it and has since made it more difficult for adults to remain on commercial insurance and access the care they need. Please reinstate the ACFAP by adding it back into statute and appropriating roughly \$375,000 per year, in addition to any unused funds from FY 2021-2022 and FY 2022-2023.

Thank you for keeping in mind the needs of people with CF when forming the SFY 2023-2024 budget. We look forward to working with the state to improve the lives of New Yorkers living with cystic fibrosis.

Sincerely,

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¹ National Health Expenditure (NHE) Fact Sheet (HHS.gov)
<https://www.hhs.gov/guidance/document/national-health-expenditure-nhe-fact-sheet-0>

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