



May 19, 2023

RE: Memo of Support for SB 6521

On behalf of over 1,000 adults 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 by supporting senate bill 6521. We were grateful to see ACFAP rollover funds from SFY 2022 and SFY 2023 in the One-House budget; however, it is now critical that this program is authorized with statutory language and funding to meet the needs of adult New Yorkers living with CF. We urge you to support senate bill 6521.

The SFY 2020-2021 budget eliminated the ACFAP and repealed statutory language authorizing the program from Article 27-G of the Public Health Law.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 funding for services 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, funding and language reinstating the ACFAP in statute are critically needed.

About cystic fibrosis and the Adult Cystic Fibrosis Assistance Program

Cystic fibrosis is a rare genetic disease that affects more than 1,600 people in New York, including over 1,000 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.

ACFAP, 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 – helping them 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, and some are delaying or forgoing care entirely.

ACFAP Helps People with CF Afford Their Care and Maintain Private Insurance

Cystic fibrosis requires intensive care and treatments, and many people with CF forgo 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 additional 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). For people with cystic fibrosis, consistent care and access to specialized therapies are a necessity, and any loss or gap in care—even for as little as

seven days—puts them at increased risk of pulmonary exacerbations, hospitalizations, and potentially irreversible lung damage.¹

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 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 program, we know that some New Yorkers with CF have had to make difficult financial decisions related to their care. For instance, Melissa, an adult with CF who needed to forgo the use of Advair, an inhaled Bronchodilator that is typically administered every 3 to 4 hours. Without Advair, Melissa experienced an exacerbation of her CF symptoms and concern about the long-term impact on her health. Unfortunately, Melissa's story is not uncommon. The Foundation has heard from many New Yorkers with CF that reported needing to forgo paying for food, car, or electricity bills in order to afford their co-copay costs. People with CF are now living longer and healthier lives than ever, which makes dependable, affordable, and accessible CF care a lifelong necessity. While non-profit organizations are sometimes able to help offset costs, their funding can run out and not all patients are eligible—making state programs like ACFAP an invaluable safety net for adults in New York.

Reinstate the ACFAP

The elimination of this vital program has made it more difficult for adults with CF to remain on commercial insurance and access the care they need. Please reinstate this program by supporting SB 6521 and adding the ACFAP back into statute and appropriating roughly \$375,000 of funding per year.

Thank you for keeping in mind the needs of people with CF when considering this bill. We look forward to working with the state to improve the lives of New Yorkers living with cystic fibrosis.

¹ Trimble AT, Donaldson SH. Ivacaftor withdrawal syndrome in cystic fibrosis patients with the G551D mutation. *J Cyst Fibros.* 2018 Mar;17(2): e13-e16. doi: 10.1016/j.jcf.2017.09.006. Epub 2017 Oct 24. PMID: 29079142.