



Please make the reinstatement of the ACFAP and its funding a priority in the SFY 2023 budget. The SFY 2021 budget repealed language authorizing the ACFAP, a program that has operated in the state since 1987, from Article 27G of the Public Health Law and eliminated its funding. While the current state budget set aside money for the program, that money has yet to be disbursed, leaving adults with CF unable to re-enroll in the program and benefit from its assistance.

## ABOUT CYSTIC FIBROSIS

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- Cystic fibrosis (CF) is a **progressive, genetic disease** that affects approximately **1,600 people in New York, including more than 970 adults.**
- As a complex, multi-system disease, CF requires targeted, specialized treatment and medications.
- While **84 percent of people with CF received some form of financial assistance in 2019, nearly half still reported delaying or forgoing care due to cost concerns.**
- More than **one-quarter of adults with CF rely on Medicaid or state programs** for some or all of their health care coverage.

## THE NEW YORK ADULT CYSTIC FIBROSIS ASSISTANCE PROGRAM

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- **The ACFAP is not an insurance program.**
- It helps adults with CF enrolled in commercial plans with their out-of-pocket costs, allowing them to continue to work and sometimes diverting them from public coverage.
- The ACFAP **reimburses CF patients and families** for CF-related care and services, such as **health insurance premiums, prescription drugs, and inpatient and outpatient care.**
- To participate, adults with CF have to:
  - Be ≥ 21 years old
  - Be ineligible for Medicaid
  - Maintain private health insurance
  - Contribute 7% of their annual income to the cost of their CF-related medical care and/or insurance premiums

## PRIORITIZE REINSTATEMENT OF THE ACFAP IN FY23

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- For over three decades the ACFAP provided steady assistance to eligible adults with CF. Enrollees and their families have relied on this modest yet critically important program to afford their care.
- **Without the program, its beneficiaries have had to make tradeoffs and compromises to address their healthcare costs,** including delaying needed treatments and medications. Due to the progressive nature of CF, delays in care and treatment can have lasting effects on health.
- While waiting for SFY 2022's funding to be disbursed, **New Yorkers with CF face increasing premiums and little information about enrollment or reimbursement.**