



August 9, 2021

Mr. Eric Anderson
Division Director of Management and Administration
Department of Health
P.O. Box 360
Trenton, NJ 08625-0360

Dear Mr. Anderson,

On behalf of the 700 people living with cystic fibrosis (CF) in New Jersey, we write to thank the state for providing increased funding to the Pharmaceutical Services for Adults with Cystic Fibrosis program. Currently administered by the New Jersey State Organization of Cystic Fibrosis (NJSOCF), this program plays a critical role in promoting the health and well-being of adults living with CF in New Jersey. We urge you to ensure the full funding of \$439,068 is distributed to the program for Fiscal Year 2022 and are requesting a meeting with your office to discuss how the Cystic Fibrosis Foundation can be a resource as the Department undertakes the allocation process.

About Cystic Fibrosis

Cystic fibrosis is a life-threatening genetic disease that affects approximately 30,000 children and adults in the United States, including nearly 500 adults in New Jersey. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Because cystic fibrosis is a complex, multi-system condition and requires specialized treatment and medications, most people with CF receive care at one of the more than 130 accredited CF care centers in the United States, including eight in New Jersey, where clinicians use evidence-based guidelines to deliver multi-disciplinary care.

While advances in CF care are helping people live longer, healthier lives, we also know that the cost of care is a barrier to access for many people with the disease. According to a recent survey conducted by George Washington University of over 1,800 people living with CF and their families, nearly half reported delaying or forgoing care— including skipping medication doses, taking less medicine than prescribed, delaying filling a prescription, or skipping a treatment altogether—due to cost concerns. Because CF is a progressive disease, patients who delay or forgo treatment face increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.

Pharmaceutical Services for Adults with Cystic Fibrosis

The Pharmaceutical Services for Adults with Cystic Fibrosis program is a state-funded program administered by NJSOCF that fills gaps in coverage so people with CF in New Jersey have access to the care and treatments they need but may otherwise be unable to afford. This program offers direct support for nearly 200 people with cystic fibrosis by providing prescription medications, medical supplies, nutritional supplements, and nutritious foods to meet the unique needs of people with CF. The program also reimburses enrollees up to \$500 annually to help meet their health insurance deductibles. To qualify, individuals must be 18 years of age or older, have a diagnosis of cystic fibrosis verified by a CF doctor, must be a New Jersey resident, and have an individual annual income of less than \$51,116/year.

Allocation of program funds for FY 2022

We thank the state for dedicating \$200,000 for the adult CF program in the FY 2022 legislative budget under a new line item called the “Pharmaceutical Services for Adults with Cystic Fibrosis”, in addition to the \$239,068 previously approved for the program under the wider Maternal, Child and Chronic Health Services program. Full funding of \$439,068 in FY 2022 will ensure that the program is able to continue providing the complete range of services that people with CF depend on to access their care.

Thank you for your commitment to improving the lives of people living with CF. Please contact **Sage Rosenthal, State Policy Sr. Coordinator** at srosenthal@cff.org or **(301) 841-2631** with your availability for a meeting to further discuss this important issue and how the Cystic Fibrosis Foundation can be a resource to you and your staff in the disbursement process.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary B. Dwight', written in a cursive style.

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