



February 4, 2021

Senator Liz Krueger
Chair, Senate Finance Committee
172 State Street, Capitol Building
Room 416 CAP
Albany, NY 12247

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

Dear Chairwoman Krueger and Chairwoman Weinstein,

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 2022 budget.

The SFY 2021 budget eliminated ACFAP's \$800,000 annual appropriation and repealed language authorizing the program from Article 29G of the Public Health Law. This program helped adults with cystic fibrosis to afford the 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 stay healthy.

Cystic fibrosis (CF) 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.

Without ACFAP, New Yorkers with CF are struggling to afford their premiums and care. For instance, Robert, an adult with CF who lives in New York City, relied on ACFAP for more than 17 years to help afford his insurance premiums and medications. He is self-employed, works full-time, and purchases his insurance through the marketplace; he estimates that ACFAP previously contributed \$9,000 towards his premium costs each year. Since the program was eliminated last year, Robert has worried about his ability to afford comprehensive insurance that meets his healthcare needs. While Robert, like many other New Yorkers with CF, has been able to find temporary private assistance, nothing has been able to fill the gap left by the elimination of this program.

The elimination of this vital program in the midst of the economic and public health crises caused by COVID-19 has made it more difficult for adults to remain on commercial insurance and access the care they need. Please reinstate ACFAP by adding it back into statute and appropriating roughly \$800,000 per year for this program.

Thank you for keeping in mind the needs of people with CF when forming the SFY 2022 budget. We look forward to working with the state to improve the lives of New Yorkers living with cystic fibrosis.

Sincerely,

Mary B. Dwight

Chief Policy & Advocacy Officer
Senior Vice President, Policy & Advocacy
Cystic Fibrosis Foundation
Bethesda, MD

Andrei Constantinescu, MD, PhD

Associate Director, Pediatric CF Care Center
Children's Hospital of New York
New York, NY

Barry L. Diener, MD

Associate Director, Pediatric CF Care Center
Stony Brook Children's Hospital
Stony Brook, NY

Allen Dozor, MD, FCCP, FAAP

Associate CF Center Director
Associate Pediatric CF Program Director
NY Medical College at Westchester Medical Center
Valhalla, NY

Rany Condos, MD

Director, Adult CF Care Center
New York University School of Medicine
New York, NY

Joan DeCelle-Germana, MD, CPI

Director, Pediatric CF Care Center
Cohen Children's Medical Center of New York
New Hyde Park, NY

Emily DiMango, MD

Director, Adult CF Care Center
Columbia University Cystic Fibrosis Program
New York, NY

Jeffrey Fahl, MD

Associate Director, Pediatric CF Care Center
Albany Medical Center
Albany, NY

Chris Fortner, MD, PhD

Director, Pediatric CF Care Center
SUNY Upstate Medical University
Syracuse, NY

Suzette Gjonaj, MD

Director, Associate CF Care Center
Vassar Brothers Medical Center
Poughkeepsie, NY

Catherine Kier, MD, FAAP, FCCP, DABSM, AE-C

Director, Pediatric CF Care Center
Stony Brook Children's Hospital
Stony Brook, NY

Alison Lennox, MD

Director, Adult CF Care Center
NY Medical College at Westchester Medical Center
Valhalla, NY

Steven Scofield, MD

Director, Adult CF Care Center
University of Rochester, Strong Memorial
Rochester, NY

Zafer Sultant, MD

Associate Director, Pediatric CF Care Center
SUNY Upstate Medical University
Syracuse, NY

Patricia A. Walker, MD

Co-Director, Cystic Fibrosis Center
Director, Adult CF Program
Mount Sinai Beth Israel
New York, NY

John Welter, MD

Director, CF Care Center
NY Medical College at Westchester Medical Center
Valhalla, NY

Carla Frederick, MD

Director, Adult CF Care Center
The Cystic Fibrosis Center of Western New York
Buffalo, NY

Danielle Goetz, MD

Director, Pediatric CF Care Center
The Cystic Fibrosis Center of Western New York
Buffalo, NY

Robert Kaslovsky, MD

Director, Pediatric CF Care Center
Albany Medical College
Albany, NY

Hossein Sadeghi, MD

Director, Pediatric CF Care Center
Columbia University Cystic Fibrosis Program
New York, NY

Boris Shkolnik, MD

Associate Director, Adult CF Care Center
Albany Medical College
Albany, NY

Karen Z. Voter, MD

Director, Pediatric CF Care Center
University of Rochester, Strong Memorial
Rochester, NY

Janice Wang, MD

Director, Adult CF Care Center
Long Island Jewish Medical Center
New Hyde Park, NY