



August 3, 2022

The Honorable Charles Schumer  
Leader  
United States Senate  
Washington, DC 20510

The Honorable Mitch McConnell  
Republican Leader  
United States Senate  
Washington, DC 20510

Dear Senator Schumer and Senator McConnell:

The Cystic Fibrosis Foundation supports the provisions of the Inflation Reduction Act (IRA) to make health care more affordable for people with cystic fibrosis and urge its swift passage.

### **Cystic Fibrosis and the Foundation**

The Cystic Fibrosis Foundation is a national organization dedicated to curing cystic fibrosis (CF). We invest in research and development of new CF therapies, advocate for the needs of people with CF including access to high-quality specialized care, and fund and accredit a network of specialized CF care centers.

Cystic fibrosis is a life-threatening genetic disease that affects nearly 40,000 children and adults in the United States. Through careful, aggressive, and continuously improving disease management, the average life expectancy for people with cystic fibrosis has risen steadily over the last few decades. In addition to advances in care, recently approved genetically-targeted drugs that address the underlying cause of CF are available for patients with specific genetic profiles and have contributed to the increases in life expectancy. This milestone reflects over 50 years of hard work to improve CF treatments, develop evidence-based standards of care, and encourage adherence to a lifetime of chronic care. This system of care and the improvements in length and quality of life for those with CF can only be realized if patients have affordable insurance that ensures their ability to receive specialized care.

### **Medicare**

With recent advancements in treatment options, more people with CF are aging onto Medicare than ever before. This development highlights the extraordinary advancements in care; however, current Medicare coverage policies and the corresponding cost of care continue to be a barrier to accessing needed treatments and prescription drugs for people with CF. One in ten people with CF enrolled in Medicare pays over \$10,000 in cost-sharing annually, not including their premiums or deductible. This extraordinary cost leads people to forgo or delay essential care and treatments. In the era of personalized medicine, this is an untenable and unsustainable model.

The CF Foundation is grateful to see Congress finally address this issue in the IRA by enacting an annual out-of-pocket cap and smoothing those costs throughout the plan year. While an out-of-pocket cap is important, patients may continue to face significant costs for prescriptions within the first few months

of the calendar year. The Foundation believes that beneficiaries should be able to spread out the cap over the course of the year by allowing a monthly payment option for the annual cap.

**We strongly support the IRA Part D out-of-pocket provisions to create a \$2,000 annual out-of-pocket cap and spread those costs across the plan year, as this will provide substantial savings for Medicare beneficiaries with CF.**

#### **Enhanced Advanced Premium Tax Credits**

Despite gains made by the Affordable Care Act (ACA), many people remain unable to afford health insurance due to high premiums. The American Rescue Plan Act took an important first step by expanding eligibility of advanced premium tax credits (APTCs) to those over 400 percent of the federal poverty level and reducing the level of income an individual must contribute to their premiums. People with CF often struggle with the cost of their coverage and care, and this policy is critical to ensuring those who purchase marketplace coverage—and often have no other coverage option—have access to an affordable insurance plan. **The CF Foundation strongly supports the three-year extension of the enhanced APTCs so people with CF who are enrolled in the ACA marketplace can continue to benefit from affordable and high-quality insurance options.**

#### **Medicaid Coverage Gap**

The American Rescue Plan Act took important steps to expand Medicaid coverage, particularly for individuals in non-expansion states. Medicaid provides a vital source of coverage for half of children and one-third of adults with CF. For many individuals with CF, Medicaid helps them afford the treatments, medications, and inpatient and outpatient care they need. A crucial component of efforts to maintain and increase health coverage enrollment will be uninterrupted coverage in the Medicaid program through closing the Medicaid coverage gap. **We are disappointed the IRA does not address the Medicaid coverage gap and ask Congress to protect individuals in the states that have failed to expand Medicaid eligibility.**

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We are ready to work with you on efforts that improve coverage and care for people with cystic fibrosis. If you have any questions, or would like to discuss any of the priorities listed above further, please direct your staff to contact David Elin at [delin@cff.org](mailto:delin@cff.org). Thank you for your consideration.

Sincerely,



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