



April 14, 2021

Governor Mike Parson  
Office of the Governor  
P.O. Box 720  
Jefferson City, MO 65102

Dear Governor Parson,

On behalf of those living with cystic fibrosis (CF) in Missouri, we thank you for all that you and the state of Missouri are doing to ensure the health and safety of state residents in the midst of the COVID-19 pandemic. While we understand that these are unprecedented times, adequate funding for Medicaid is more important than ever for people living with CF and the providers who treat them. We urge you to preserve funding for MO HealthNet, including for enrollees newly eligible under Medicaid expansion, and the Adult Cystic Fibrosis Treatment Program in the FY 2022 budget and reject any proposed reductions to eligibility or benefits.

#### **About Cystic Fibrosis & the CF Foundation**

Cystic fibrosis is a life-threatening genetic disease that affects 30,000 children and adults in the United States, including over 700 in Missouri. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. While great strides have been made in the treatment of the disease, the lives of young people with cystic fibrosis are still cut far too short; half of young adults with this disease still die before age 30.

The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with CF the opportunity to lead long, fulfilling lives by funding research and drug development, partnering with the CF community, and advancing high-quality, specialized care. The Cystic Fibrosis Foundation accredits the more than 130 care centers in the United States—including seven programs in Missouri—and supports the development of CF clinical practice guidelines. Because cystic fibrosis requires targeted, specialized care and treatment, most people with CF receive care at one of these accredited CF care centers, which provide multidisciplinary care in accordance with systematically reviewed, data-driven clinical practice guidelines.

#### **Adult Cystic Fibrosis Treatment Program**

The Adult Cystic Fibrosis Treatment Program is a state program run by the Missouri Department of Health and Senior Services that serves as a safety net for adults with special health care needs who meet medical and financial eligibility requirements. The program fills gaps in coverage related to the adult's special health condition and acts as a payer of last resort to help meet the individual's needs. The Adult Cystic Fibrosis Treatment Program provides services for people over age 21 with CF, which includes including prescription medications, medical supplies, nutritional counseling and physical therapy.

## **MO HealthNet**

Medicaid is a crucial source of coverage for people living with CF and we urge you to ensure the FY 2022 preserves MO HealthNet funding, eligibility, and benefits. Half of children and a quarter of adults with CF in Missouri depend on the program for some or all of their health care coverage. Medicaid plays an important role in helping patients afford the specialized care they need to stay healthy—for many people with cystic fibrosis, it fills coverage gaps left by private insurance that would otherwise leave patients with unmanageable out-of-pocket costs. For people with CF, adequate coverage is not a luxury; it is a necessity. Without access to expert CF care and treatments, the risk of lung exacerbations, irreversible lung damage, and decreased quality of life increases drastically.

We were pleased to see that Missouri will expand Medicaid eligibility to an estimated 275,000 Missourians beginning July 2021 and urge you to ensure that the budget includes adequate funding to implement these changes. We commend Missouri for extending MO HealthNet eligibility to childless adults with incomes less than 138 percent of the Federal Poverty Level. In doing so, the state will be able to draw down much-needed federal dollars and strengthen a vital safety net for Missouri's most vulnerable residents, including those with cystic fibrosis.

Cystic fibrosis care and treatment is expensive, even for those with comprehensive coverage, and reducing funding for Medicaid could disrupt access to care for vulnerable Missourians at a time when they can least afford it. According to a survey conducted by George Washington University of over 1,800 people living with CF and their families, over 70 percent indicated that paying for health care has caused financial problems such as being contacted by a collection agency, having to file for bankruptcy, experiencing difficulties paying for basics like rent and utilities, or having to take a second job to make ends meet. The same study found that nearly half of people with CF delayed or skipped treatment in the preceding year due to cost. Medicaid helps to ease the cost burden of care for the 740 people in Missouri with CF who rely on the program for some or all of their health care coverage.

Additionally, we are concerned that any cuts to Medicaid would further stress hospitals and providers already in a weakened financial state. CF care centers are often housed within academic medical centers, which serve a disproportionate number of low-income patients. These medical centers rely on Medicaid reimbursement for a large portion of their revenue, and many are already in financially precarious positions due to reduced volume in certain procedures during the COVID-19 pandemic. Some CF care centers have been forced to furlough or lay off staff; additional cuts to provider reimbursement could further exacerbate these issues and result in centers losing critical staff.

## **Policy Recommendation**

We understand that Missouri is facing budget constraints as it continues to address the economic and public health effects of the COVID-19 pandemic. However, we urge you to protect people with CF and preserve MO HealthNet funding and Adult Cystic Fibrosis Treatment Program in the upcoming budget. We stand ready to serve as a resource as you address the current public health emergency. If you have any questions about CF or would like to discuss this request further, please contact Sage Rosenthal, State Policy Senior Coordinator at [srosenthal@cff.org](mailto:srosenthal@cff.org) at (301) 841-2632.

Thank you for your attention to this important issue.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with a large initial "M" and "D".

**Mary B. Dwight**

Chief Policy & Advocacy Officer  
Senior VP of Policy and Advocacy

CC: Randall W. Williams, MD, FACOG, Director Missouri Department of Health and Senior Services