August 17, 2018

The Honorable Alex Azar  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Dear Secretary Azar:

Re: State of Kentucky 1115 Waiver Application and Operational Modification Request

The Cystic Fibrosis Foundation appreciates the opportunity to submit additional comments on the Kentucky HEALTH Waiver Application and Operational Modification Request. We have serious concerns that this waiver, specifically the proposed employment and community engagement requirements and six month lock out period, could jeopardize access to coverage and life-sustaining care for thousands of Kentuckians, including people living with cystic fibrosis (CF). Given these concerns, which are supported by the state’s own internal estimates, we strongly urge you to deny Kentucky’s waiver application.

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 581 people in Kentucky and 30,000 children and adults in the United States. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. Given the role that Medicaid plays in helping this patient population access the high-quality care and treatment they need to maintain or improve their health, we urge you to consider the needs of CF patients as you review the state’s request to make changes to its Medicaid program. Within Kentucky’s 1115 Waiver Application and Operational Modification Request, we are concerned particularly with the following provisions:

Employment and community engagement requirements

The Cystic Fibrosis Foundation has serious concerns regarding the impact of the proposed community engagement requirements on coverage for people living with cystic fibrosis. Some individuals with cystic fibrosis may not qualify for disability but their ability to work may vary over their lifetimes. While many are able to work full or part-time, others are not able to maintain employment due to their health status or the amount of time they need to spend on their treatments. For instance, variations in health status due to pulmonary exacerbations, infections, and other events are common and can take someone out of the workforce temporarily or for long periods of time. Furthermore, many patients bear a significant treatment burden, amounting to hours of chest physiotherapy, delivery of nebulized treatments, administration of intravenous antibiotics, and/or other activities required to maintain or improve their health, which can interfere with their ability to work. For these reasons, many people with CF experience periods when they are unable to work or attend school, despite being ineligible for disability benefits.

Kentucky’s own estimates show that implementing this waiver would result in loss of coverage for 95,000 individuals over the five-year demonstration period.1 While we appreciate the state’s decision to exempt from

employment and community engagement requirements those who are deemed “medically frail,” we are deeply concerned that some individuals with CF will either not understand the exemption process or not qualify for an exemption—and will therefore be among the people losing coverage. All Kentuckians with CF, regardless of employment or disability status, should have equal access to vital health care coverage.

**Coverage lock-outs for failure to comply with redetermination and reporting requirements**

We understand the state’s aim to align Kentucky HEALTH program features with those of the commercial market. However, we have serious concerns about the provisions that establish lock out periods. Disenrolling individuals and locking them out of coverage for up to six months because they were unable to satisfy premium, community engagement, or redetermination requirements could jeopardize the health of people with a life-threatening condition like cystic fibrosis. For people with CF, continuous health care coverage is a necessity and interruptions in coverage can lead to lapses in care, irreversible lung damage, and costly hospitalizations—compromising the health and well-being of those with the disease. As we have seen in preliminary reports from the Arkansas Works program, more than 70 percent of those required to report community engagement hours or apply for an exemption are now at risk for disenrollment because of their failure or inability to submit a report. This underscores the concern that many people may have trouble complying with new eligibility requirements and, in the case of Kentucky, could result in a dangerous lapse in coverage for someone with CF.

Furthermore, the classification of failure to report changes in circumstance within ten days as “fraudulent activity” is a mischaracterization, as there may be people who are unable to comply or fail to understand the process for completing redetermination paperwork or reporting changes that may impact eligibility. For instance, more than a third of people with CF experience at least one hospitalization per year. Since hospitalizations associated with CF last 22 days on average, many people living with this disease would be unable to report a change in circumstance within the proposed ten-day reporting period or complete redetermination paperwork on time. Using such terminology may discourage participation in the program by those fearful of inadvertently committing “fraud” because they are unable to report changes within the ten days, putting even more people at risk of being uninsured.

Given the above information, we urge you to reconsider your approval of Kentucky’s 1115 waiver and proposal to implement work requirements. The proposed policy would likely result in loss of health coverage for thousands of Kentuckians and does not align with Medicaid’s core program objective of furnishing coverage.

The Cystic Fibrosis Foundation appreciates the opportunity to provide input on these important policy changes. As the health care landscape continues to evolve, we look forward to working with the state of Kentucky to ensure access to high-quality, specialized CF care and improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward.

Sincerely,

**Mary B. Dwight**  
Senior VP of Policy & Patient Assistance Programs  
Cystic Fibrosis Foundation

**Lisa B. Feng, DrPH**  
Senior Director of Access Policy & Innovation  
Cystic Fibrosis Foundation

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3 CF Patient Registry, 2015