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

August 29, 2018  

Re: Granite Advantage Health Care Section 1115(a) Demonstration Waiver  

Dear Secretary Azar,  

On behalf of people with cystic fibrosis (CF), we write to express our serious concern with the state’s proposals to add work and community engagement requirements as a condition of Medicaid eligibility and eliminate retroactive coverage. Work and community engagement requirements are barriers to accessing the high-quality care that people with CF, and other chronic diseases, need. Furthermore, retroactive coverage in Medicaid helps ensure continuous access to care, which is critical for people with CF to maintain their health. Given these concerns, we strongly urge CMS to reject these provisions of the state’s waiver proposal.  

CF is a life-threatening genetic disease that affects 209 people in New Hampshire and 35,000 people 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. Medicaid is a crucial source of coverage for patients with serious and chronic health care needs—including one-third of adults with CF—and the program plays an important role in helping this patient population access the high-quality care and treatment necessary to maintain or improve health.  

Within the state’s 1115(a) Demonstration Waiver Amendment, we are concerned with the following provisions:  

Work and Community Engagement Requirements  
The Cystic Fibrosis Foundation has serious concerns regarding the impact of proposed community engagement requirements on coverage for people living with cystic fibrosis. Making work a condition of Medicaid eligibility threatens access to care for people with CF, as their ability to work can vary greatly over time with changes in health status. Declines in health status due to pulmonary exacerbations, infections, and other events are common and can take someone out of the workforce for significant periods of time. Patients bear a significant treatment burden as well, 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.
Even for those who can work or participate in community engagement activities, the burden of reporting requirements could also put coverage at risk. 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 for someone with CF, this could result in a life-threatening gap in coverage.

We urge you to reject this policy.

However, if you approve this waiver, we ask you to direct the state to use its own data to identify people with CF for an automatic lifetime exemption. This would minimize the risk of inappropriate disenrollment and the administrative burden on recipients.

**Waiving Retroactive Coverage Requirement**

We also oppose the state’s proposal to waive retroactive coverage. Retroactive coverage allows individuals with chronic conditions, like cystic fibrosis, to receive care and treatment immediately and avoid incurring medical debt, rather than waiting for their official Medicaid eligibility determination. A medical complication could be serious enough to make someone with CF eligible for Medicaid by health status or preclude them from working, jeopardizing their employer-sponsored insurance coverage. We ask CMS to reject this proposal and require the state to continue to provide three months of retroactive coverage for individuals, especially those with serious medical conditions like cystic fibrosis.

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 New Hampshire to ensure access to high-quality, specialized CF care and improve the lives of all people with cystic fibrosis.

Sincerely,

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