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

June 14, 2018  

Re: Ohio’s Group VIII Work Requirements and Community Engagement 1115 Waiver  

Dear Secretary Azar,  

Thank you for the opportunity to comment on Ohio’s Group VIII Work Requirements and Community Engagement 1115 waiver. On behalf of people with cystic fibrosis (CF), we write to express our concern that work and community engagement requirements create an additional barrier to accessing the high-quality care that people with chronic conditions like CF need. We are reassured by the state’s response to stakeholder comments, in which the state committed to implementing the waiver in a way that is least burdensome for beneficiaries and preserving access to Medicaid for those who qualify. However, we remain concerned that people with CF are at risk of losing coverage and seek further clarification in the definition of those who are exempt because they are “physically or mentally unfit to work.” As such, we ask you to direct the state to specifically and automatically exempt people with cystic fibrosis.  

Cystic fibrosis is a life-threatening genetic disease that affects 1,534 people in Ohio 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. Medicaid plays an important role in helping this patient population access the high-quality care and treatment necessary to maintain or improve health. Work and community engagement requirements introduce additional barriers to access, which may cause interruptions and delays in treatment and care. Continuous access to high-quality, specialized CF care is essential to the health and well-being of people with cystic fibrosis.  

Making work a condition of Medicaid eligibility could threaten access to care for people with CF, as their ability to work can vary 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. Maintaining sustained employment may not be possible due to the time required to undergo necessary treatment, which includes an intense and time-consuming daily regimen.  

We were pleased to see the state intends to further define exemptions by including “physically or mentally unfit to work” in state regulations; however, we ask you to direct the state to specify a lifetime exemption for people with CF. We recommend the state use its own data to identify people with CF for exemption in order to minimize the risk of inappropriate disenrollment and administrative burden on
recipients. The state’s efforts to clarify who will be eligible for an exemption reflects the important reality that health status can significantly affect an individual’s ability to search for and sustain employment, and we ask you to ensure that people with CF are included in this exemption.

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 Ohio 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,

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