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

February 5, 2018

Re: Arizona Section 1115 Waiver Amendment Request: AHCCCS Works Waiver

Dear Secretary Azar:

Thank you for the opportunity to comment on Arizona’s 1115 Demonstration Waiver Amendment Request. While we recognize the need to put the state’s medical assistance program on a sustainable funding path, the Cystic Fibrosis Foundation recommends that the state pay special attention to the needs of individuals with rare genetic diseases who require multidisciplinary specialty care in any reform effort.

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 513 people in Arizona 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 is a crucial source of coverage for patients with serious and chronic health care needs, including 65 adults living with cystic fibrosis in Arizona. 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 the state to ensure the needs of CF patients are met as the state makes changes to the Arizona Health Care Cost Containment System (AHCCCS) Works program. Within the state’s 1115 Demonstration Waiver Amendment, we are concerned particularly with the following provisions:

**Work requirements**

On behalf of people with cystic fibrosis, we urge you to reject the state’s proposal to require work as a condition of Medicaid eligibility, especially for people with complex, lifelong conditions like cystic fibrosis. Community engagement and employment 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.

While we do not think work requirements are appropriate for the Medicaid population, we appreciate the state’s effort to exempt from work requirements those determined to be “medically frail,” which reflects the important reality that health status can significantly affect an individual’s ability to search for and sustain employment. While many people with CF work full or part-time, the 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, 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-consumming daily regimen.

As the state works to define these exemptions, we urge you to include cystic fibrosis as a defining condition for which an individual will be deemed medically frail. We urge the state to articulate a clear process for applying for an exemption based on “medically frail” conditions, as well as a timeline for determination. While applying for an exemption adds burden to patients, clear rules around the application process, eligibility requirements, and timeframe may lessen that burden and help ensure that eligible individuals are able to get an exemption.

**Lifetime coverage limit**

Given the administrative challenges that someone with CF could face in obtaining an exemption from a work requirement, we are particularly concerned with the state’s proposal to link work requirements to a five-year lifetime coverage limit. Implementing a five-year lifetime coverage limit for people with a life-threatening condition like CF because they were unable to satisfy work requirements or obtain an exemption is excessively punitive and prioritizes cutting state spending on Medicaid over patients’ access to care. For those with cystic fibrosis, 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.

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 Arizona 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 Feng, DrPH
Senior Director of Access Policy & Innovation
Cystic Fibrosis Foundation

Cori Daines, MD
Director, Pediatric Cystic Fibrosis Program
Tucson CF Center