MDHHS
Medical Services Administration
Bureau of Medicaid Policy and Health System Innovation
Attention: Medicaid Policy
P.O. Box 30479
Lansing, Michigan 48909-7979

August 10, 2018

Re: Healthy Michigan Plan Section 1115 Demonstration Waiver Extension Request Amendment

To whom it may concern:

Thank you for the opportunity to comment on Michigan’s Section 1115 Demonstration Waiver Extension Request Amendment. On behalf of people with cystic fibrosis (CF), we write to express our concern that work and community engagement requirements, lockout periods, and increased premiums are barriers to accessing the high-quality care that people with CF need. As such, we ask the state to specifically and automatically exempt people with cystic fibrosis from these requirements.

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 1,111 people in Michigan 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.

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 threatens access to care for people with CF, as their ability to work can vary with changes in health status. Implementing lock-out periods for those who failed to meet reporting requirements further penalizes those who need care the most. Declines in health status due to pulmonary exacerbations, infections, and other events can arise quickly 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.

Furthermore, we are concerned with the proposal to require individuals between 100%-133% of the federal poverty level to pay premiums of 5% of an individual’s income. While we understand that the state currently has a cost sharing component for these individuals, more than doubling premiums costs may impose unmanageable health care costs on financially vulnerable and medically complex adults. Our research shows that while 99% of people with CF have insurance, one-quarter of people delay or
skip care due to cost concerns. Therefore, increasing premiums for this population could jeopardize their ability to maintain coverage and access care.

We appreciate the state’s decision to exempt a person who is “medically frail” or has a medical condition that results in a work limitation from these requirements — which reflects the important reality that health status can significantly affect an individual’s ability to search for and sustain employment. We strongly urge the state to include cystic fibrosis in list of conditions that will be automatically exempt from work requirements, lock-out periods and premiums.

As experts in cystic fibrosis care and research, please consider us a resource during the rulemaking and implementation process to minimize unintended errors and ensure our population is exempt. In particular, should the state decide to exempt people with cystic fibrosis, we can provide clinical expertise on service utilization, co-morbidities, and other factors that may help the state ensure people with CF are accurately captured by the state’s algorithm.

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

Sincerely,

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