April 24, 2019

Dear Representative Kuster:

On behalf of more than 30,000 people with cystic fibrosis (CF), the Cystic Fibrosis Foundation applauds your effort to protect people with pre-existing conditions in the individual marketplace by introducing The Protecting Americans with Preexisting Conditions Act of 2019 halting the implementation of the Section 1332 State Relief and Empowerment Waiver (1332 guidance). We are deeply concerned about the impact of the new 1332 guidance on the stability of the individual marketplace in states that choose to pursue policies that undermine the marketplace.

As you know, the 1332 guidance substantially relaxes the guardrails of coverage that people with pre-existing conditions such as CF rely on in the individual marketplace. Of particular concern, the new guidance would allow states to let individuals use advanced premium tax credits to purchase non-compliant short-term, limited duration insurance plans—which could further draw younger, healthy people out of the marketplace and drive up premiums for those who need comprehensive coverage. Furthermore, the guidance eliminates protections for vulnerable populations such as individuals with low incomes and those with serious health issues, such as people with CF, by removing the requirement to safeguard those populations under any waiver. This is of grave concern to the Foundation as these changes fundamentally alter the nature of the Section 1332 waiver program and jeopardize adequate, affordable coverage for people with CF in the individual market. Halting the implementation of this guidance will protect people with CF from the repercussions of these market destabilizing actions.

People with cystic fibrosis (CF) require a complex and demanding care regimen and face a life-long challenge of obtaining access to high-quality, affordable health care. Unfortunately, the new 1332 guidance fails to adequately protect our community and nearly 2,000 cystic fibrosis advocates sent comments asking Secretary Azar to withdraw the guidance.

Again, thank you for your leadership on this critical issue for people with pre-existing conditions like CF and we support your efforts to halt the implementation of the 1332 guidance and promote stability the individual marketplace for people with CF.

Sincerely,

Mary B. Dwight
Senior VP of Policy & Advocacy
Cystic Fibrosis Foundation