



June 5, 2019

The Honorable Lamar Alexander
Chairman
Senate Health, Education, Labor and Pensions Committee
US Senate
Washington, DC 20510

The Honorable Patty Murray
Ranking Member
Senate Health, Education, Labor and Pensions Committee
US Senate
Washington, DC 20510

Dear Chairman Alexander and Ranking Member Murray,

On behalf of more than 30,000 people with cystic fibrosis (CF) living in the United States, the Cystic Fibrosis Foundation is pleased to submit comments on your draft legislation, the "Lower Health Care Costs Act." We applaud your bipartisan effort to reduce health care costs, a critical issue for patients.

Cystic fibrosis is a life-threatening genetic disease that causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to serious infections. As a complex, multi-system condition, CF requires targeted, specialized treatment, and multiple medications. Health care costs are a real concern for families with CF. According to a 2018 study of the CF population, 45 percent of people with CF spend \$5,000 or more annually in out-of-pocket costs for copayments, coinsurance, and non-covered services.

We are pleased to offer the following comments on your draft legislation:

Title I: Ending Surprise Medical Bills

We support the goals of this section to make health care costs more transparent to patients and protect them from surprise medical bills. People with CF experience surprise medical bills just like other Americans, but as a population that already bears a significant out-of-pocket cost burden, these bills can be even more problematic. In the study mentioned above, researchers found that 58 percent of people with CF reported delaying or forgoing care due to cost. Adding an exorbitant, unexpected medical bill on top of other health care expenses can jeopardize access to critical, life-saving care for people with CF so we applaud the committee's efforts to address this important issue. Specifically, the requirements in the legislation to provide patients with advanced notice about any out-of-network care is an important protection for patients and would reduce the likelihood of unexpected out-of-network charges.

Title II: Reducing the Prices of Prescription Drugs

We commend the steps this legislation takes to address barriers to effective generic competition and promote biosimilars. We are particularly pleased at the inclusion of section 204

that seeks to improve competition and enhance access to insulin. Cystic fibrosis-related diabetes (CFRD) is a highly prevalent complication of CF, affecting more than 30 percent of people with CF over the age of 18. Individuals with CFRD often require insulin in addition to other medications to manage their underlying CF, so any efforts to improve competition and make insulin more affordable would have a substantial impact on the CF community.

Title III: Improving Transparency in Health Care

As patient advocates helping people with CF find adequate and affordable coverage that enables access to high-quality CF care, we appreciate consumer-centric efforts that improve some of the basic aspects of coverage and access. In particular, we see the benefit of sections 304 (protecting patients and improving accuracy of provider directory information) and 305 (timely bills for patients).

People with CF require access to highly specialized providers who often practice within CFF-accredited care centers. Accurate and timely information on whether CF clinicians and facilities are in-network is critical to successfully navigating a complex care regimen as well as choosing the right plan during open enrollment. Having access to descriptive and timely bills is also a step in the right direction for consumers, particularly people with CF who often incur costs on clinical care, ancillary services, and labs and other diagnostic services.

We believe that the non-governmental entity to improve the transparency of health care costs that is described in section 303 could be of great benefit to a variety of organizations and actors within government and the health care system. The advisory committee created in this section is an important addition because of the complex questions around operations and use of the data in the claims database. We recommend that the composition of committee members in section 303(a)(3)(B)(ii) be amended to include a patient representative on the committee. Given the serious questions the committee must advise on regarding privacy, security, and use of data, we believe that including a patient perspective is critical.

Title IV: Improving Public Health

We support efforts to address disparities in health care access and are pleased to see the inclusion of section 404 (expanding capacity for health outcomes). Leveraging technology, specifically telemedicine, is one way to potentially narrow gaps in access to specialty care. We believe the federal government has a role to accelerate and expand the use of telemedicine — paying additional attention to clinical and financing aspects to ensure stable and sustained delivery of care. We also urge policymakers to recognize that medically underserved populations reside in many different communities; it will be important to study how technology can help narrow gaps in access in urban, suburban, and rural areas.

Title IV: Improving the Exchange of Health Information

We support the goal of section 501 (requirement to provide health claims, network, and cost information) to make more information available to patients through application programming interfaces. With this information, patients will be better able to make informed decisions when choosing a plan and navigating care; for planning for out-of-pocket responsibilities; and for making treatment decisions with their doctors.

Thank you for the opportunity to comment on your draft legislation. It is an important first step in addressing the complex issues around affordability. It must be noted that this legislation does not address systematic issues facing our health care system related to drug affordability

and system sustainability. People with CF and other serious diseases are often exposed to significant cost sharing for necessary medical services, and this legislation will in most cases fail to address this harsh reality.

We look forward to continuing to work with you and the other committees in Congress as you further develop legislative proposals.

Sincerely,

Mary B. Dwight

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with the first name "Mary" being the most prominent.

Senior Vice President of Policy & Advocacy
Cystic Fibrosis Foundation