



May 8, 2019

The Honorable Ann McLane Kuster
 United States House of Representatives
 320 Cannon House Office Building
 Washington, D.C. 20515

Re: Letter of Support from 23 Patient and Consumer Advocacy Organizations for H.R. 986

Dear Representative Kuster:

Our 24 organizations, representing the interests of the millions of patients and consumers who live with serious, acute, and chronic conditions, have worked together for many months to ensure that patient voices are reflected in the ongoing Congressional debate regarding the accessibility of health coverage for all Americans and families. Today, we write in strong support of your legislation to protect people with pre-existing conditions who receive coverage in the individual marketplace. *The Protecting Americans with Preexisting Conditions Act of 2019*, H.R. 986, would require the Administration to rescind its Section 1332 State Relief and Empowerment Waivers Guidance, released on October 22, 2018¹ (1332 guidance). We are concerned about the impact that this guidance could have on the people we represent and applaud your introduction of this bill.

In March 2017, we identified three overarching principles to guide and measure any work to further reform and improve the nation's health insurance system. Our core principles are that health insurance

¹ Accessed online at <https://s3.amazonaws.com/public-inspection.federalregister.gov/2018-23182.pdf>.

coverage must be adequate, affordable, and accessible.² Together, our organizations understand what individuals and families need to prevent disease, manage health, and cure illness. Our organizations are deeply concerned about how the new 1332 guidance will affect the individual marketplace's stability in states that choose to pursue some of the policies allowed under this guidance, including those that promote short term plans and other substandard coverage. We are pleased that this legislation represents a significant and meaningful step towards protecting all Americans from coverage that does not cover what they need to promote their health and well-being.

As you know, the 1332 guidance substantially erodes the guardrails governing coverage that people with pre-existing conditions such as cystic fibrosis, lung disease, cancer, cardiovascular disease, diabetes, rare disorders, pregnant women, and many others 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, healthier people out of the risk pool for comprehensive insurance and drive up premiums for those who need comprehensive coverage. The guidance also eliminates protections for vulnerable populations, such as individuals with low incomes and those with chronic and serious health issues, by removing the requirement to safeguard those populations under any waiver. We are deeply concerned by this as these changes fundamentally alter the nature of the Section 1332 waiver program and jeopardize adequate, affordable coverage for people with pre-existing conditions in the individual market. Halting the implementation of this guidance will protect people with pre-existing conditions from the repercussions of these market destabilizing actions.

H.R. 986 represents a significant step towards protecting patients and consumers. Yet, we also recognize that there is much more that needs to be done to improve upon our current system of care, including making coverage more accessible and affordable. Up until this year, health insurance enrollment has steadily increased, and, with it, the promise of a more diverse risk pool and greater protection for people with serious health care needs. However, the recent reinterpretation of the guidelines is jeopardizing enrollment. Shortened enrollment periods, fewer resources for outreach and education and less funding for consumer navigators not only creates confusion for consumers but directly impacts the number of individuals who enroll in Marketplace coverage. Without Congressional action, these trends will make it harder for many to access coverage and will further contribute to the destabilization of insurance markets and result in higher premiums for many enrollees.

Making high-quality coverage and care more affordable is also a high priority for the people that we represent. Passage of legislation that expands access to and the level of advance premium tax credits, fixes the family glitch, creates a nationwide reinsurance program, and reduces systemic health care costs could significantly ease the cost burden for people of all income levels who rely on the individual marketplace for coverage. We urge Congress to support legislation that maintains the quality of coverage while expanding access and affordability.

Again, thank you for your leadership on this critical issue for people with pre-existing conditions. We support your efforts to halt the implementation of the 2018 guidance, ensuring the guidance from 2015 remains intact and promoting stability in the individual marketplace. We urge members of Congress to vote for H.R. 986.

² Health care reform principles. American Heart Association website. http://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_495416.pdf.

Sincerely,

Hemophilia Federation of America
National Health Council
Cystic Fibrosis Foundation
Epilepsy Foundation
March of Dimes
National Coalition for Cancer Survivorship
American Heart Association
Alpha-1 Foundation
American Liver Foundation
Susan G. Komen
National Hemophilia Foundation
WomenHeart: The National Coalition for
Women with Heart Disease

National Multiple Sclerosis Society
Muscular Dystrophy Association
Lutheran Services in America
American Lung Association
National Alliance on Mental Illness
National Patient Advocate Foundation
Arthritis Foundation
Leukemia & Lymphoma Society
American Cancer Society Cancer Action
Network
National Organization for Rare Disorders
Pulmonary Hypertension Association
Cancer Support Community

Cc: United States House of Representatives