



May 8, 2019

The Honorable Frank Pallone
 Charmian, House Energy & Commerce Committee
 2125 Rayburn House Office Building
 Washington, D.C. 20515

The Honorable Greg Walden
 Ranking Member, House Energy & Commerce Committee
 2322 Rayburn House Office Building
 Washington, D.C. 20515

Dear Chairman Pallone and Ranking Member Walden,

Our 35 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. 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 care must be **adequate, affordable, and accessible**.¹ Together, our organizations understand what individuals and families need to prevent disease, manage health, and cure illness. As the 116th Congress progresses, we welcome the opportunity to work with members on both sides of the aisle on solutions that will preserve coverage for individuals who are currently covered, extend coverage to those who remain uninsured, and lower costs and improve quality for all.

Prior to the Affordable Care Act (ACA), individuals who were in the most need of health insurance coverage – including older and sicker Americans and people living with pre-existing conditions – often found it difficult, if not impossible, to obtain health insurance that provided the coverage they needed. Many individuals were denied coverage due to their pre-existing conditions or were charged outrageous premiums and/or were left with inadequate benefit packages.

Without access to comprehensive health coverage they could afford, many patients with serious and chronic conditions were often forced to delay or forego necessary health care. Before the patient protections provided under the ACA, more than half of heart patients reported difficulty paying for their care and of those patients more than 40 percent said they had delayed care or had not filled prescriptions.² Uninsured patients with diabetes were six times as likely to forgo necessary medical care than those with coverage.³ Uninsured patients were less likely to be screened for cancer and more likely to be diagnosed with later stage disease which is harder to survive and more costly to treat.⁴

Individuals and families with pre-existing conditions rely on critical protections in current law to help them access comprehensive, affordable health coverage that meets their medical needs. Unfortunately, the arguments of the plaintiffs and the recent change of opinion by the Department of Justice in the *Texas v. U.S.* case⁵ continue to represent a serious threat to these protections. We are troubled by the argument made by the plaintiffs and DOJ that the court must invalidate the entire ACA due to Congress' repeal of the individual mandate, as many provisions of the ACA directly protect people with pre-existing conditions.

Our organizations appreciate that members of Congress share our concerns about the potential impact of *Texas v. U.S.* on people with pre-existing conditions. Several bills have been introduced in response to this case, from H.Res.14, which authorized the Speaker, on behalf of the House of Representatives, to intervene in the case of *Texas v. United States*, to S.1125, the Protect Act, and H.R.692, the Pre-existing Conditions Protection Act of 2019.

Some of these bills – including S. 1125 and H.R. 692 – attempt to provide protection to people with pre-existing conditions should the ACA be invalidated. We recognize and appreciate the sponsors' efforts, and know that in many cases, in response to stakeholder feedback, sponsors have revised previous drafts of these bills to offer additional protections for consumers, including those with pre-existing

¹ Health care reform principles. American Heart Association website. http://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_495416.pdf.

² *Affordable Access to Health Care: Top Priorities of Heart Disease and Stroke Patients: Results from an American Heart Association Patient Survey*, Am. Heart. Ass'n (2010). Available at https://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_432322.pdf.

³ J.B. Fox et al., *Vital Signs: Health Insurance Coverage and Health Care Utilization—United States, 2006-2009 and January-March 2010*, 59 *Morbidity & Mortality Wkly. Rep.* 1448, 1448 (2010).

⁴ E Ward et al., "Association of Insurance with Cancer Care Utilization and Outcomes, CA: A Cancer Journal for Clinicians 58:1 (Jan./Feb. 2008), <http://www.cancer.org/cancer/news/report-links-health-insurance-status-withcancer-care>.

⁵ *Texas v. United States*, No. 19-10011 (5th Cir.).

conditions. However, we remain concerned that the policies outlined in these bills fall far short of the comprehensive protections and coverage expansion included in current law.

As you are aware, current law requires issuers to comply with a set of provisions that work together to promote adequate, affordable, and accessible coverage for people with pre-existing conditions. A holistic approach that includes – but is not limited to - community rating, guaranteed issue, essential health benefits, cost-sharing limits, a prohibition of lifetime and annual limits, allowing young people to stay on their parents’ insurance to age 26, the ban on pre-existing condition exclusions, and other important provisions protect people with serious health care needs from discriminatory coverage practices and promote access to affordable coverage. Medicaid expansion also brought coverage to millions of Americans who were previously uninsured, many of whom went without vital care. These policies are inextricably linked and repealing any of them threatens access to critical care for people with life-threatening, disabling, chronic, or serious health care needs.

We hope that you will keep these critical patient protections and the interlocking functions of current law that safeguard coverage for consumers, patients, and individuals with pre-existing conditions at the front of your mind during the 116th Congress. We are grateful that Congress is committed to exploring both immediate and long-term approaches that can be taken to shore up and strengthen the individual insurance market and we remain ready and willing to work with Congress to achieve that goal and provide all Americans with the health care they need and deserve. If you have any questions about this letter, please contact Katie Berge, Federal Government Relations Manager for the American Heart Association at katie.berge@heart.org.

Sincerely,

United Way Worldwide
COPD Foundation
Hemophilia Federation of America
Susan G. Komen
Family Voices
American Heart Association
National Health Council
Epilepsy Foundation
March of Dimes
ALS Association
National Hemophilia Foundation
National Coalition for Cancer Survivorship
Alpha-1 Foundation
American Liver Foundation
National Multiple Sclerosis Society
WomenHeart: The National Coalition for Women with Heart Disease
American Cancer Society Cancer Action Network

Muscular Dystrophy Association
National Patient Advocate Foundation
Leukemia & Lymphoma Society
Lutheran Services in America
National Kidney Foundation
American Lung Association
Cystic Fibrosis Foundation
American Diabetes Association
National Psoriasis Foundation
National Alliance on Mental Illness
Adult Congenital Heart Association
Arthritis Foundation
Chronic Disease Coalition
Immune Deficiency Foundation
Cancer Support Community
National Organization for Rare Disorders
Pulmonary Hypertension Association
Juvenile Diabetes Research Foundation

Cc:

United States House of Representatives
United States Senate