



September 19, 2018

The Honorable Thom Tillis  
 United States Senate  
 185 Dirksen Senate Office Building  
 Washington, DC 20510

Dear Senator Tillis:

Our 33 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**.<sup>1</sup> Together, our organizations understand what individuals and families need to prevent disease, manage health, and cure illness.

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

<sup>1</sup> Health care reform principles. American Heart Association website. [http://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm\\_495416.pdf](http://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_495416.pdf).

arguments of the plaintiffs in *Texas v. U.S.* – a lawsuit brought by 20 states and two individual plaintiffs – represent a serious threat to these protections. In this case, the plaintiffs argue that the court must invalidate the entire Affordable Care Act (ACA) due to Congress’ repeal of the individual mandate. We are further troubled that the Department of Justice has also declined to defend the constitutionality of many of the ACA provisions that directly protect people with pre-existing conditions.

While we are pleased to see that you share our concerns about the potential impact of *Texas v. U.S.* on people with pre-existing conditions, as evidenced by your recent introduction of the Ensuring Coverage for Patients with Pre-Existing Conditions Act (S.3388), the safeguards presented in this legislation fall far short of the patient protections encompassed in existing law. This bill as written is far from an adequate replacement for the protections for individuals with pre-existing conditions that are provided under current law.

Current law requires issuers to comply with a set of provisions which work together to promote adequate, affordable, and accessible coverage for people with pre-existing conditions. Specifically, community rating, guaranteed issue, essential health benefits, cost-sharing limits, and the ban on pre-existing condition exclusions protect people with serious health care needs from discriminatory coverage practices. These policies are inextricably linked and removing any of them threatens access to critical care for people with life-threatening, disabling, chronic, or serious health care needs.

### **Adequacy**

Health care must be *adequate*, covering the services and treatments patients need, including patients with unique and complex health care needs. It is paramount that protections including the Essential Health Benefit (EHB) requirement, the ban on annual and lifetime caps, caps on out-of-pocket costs, and restrictions on premium rating be preserved in all health care plans to which they currently apply.

We were particularly disappointed that S. 3388 fails to include an outright ban on pre-existing condition exclusions. While a consumer with pre-existing conditions can gain coverage, the bill would allow issuers to underwrite plans to exclude any type of care based on medical history or health status. For example, under S. 3388 a patient with a history of cancer may be able to gain coverage, but an issuer would still be allowed to exclude coverage for screenings or treatment for a reoccurrence. Continuing to allow issuers to sell plans that undermine access to comprehensive coverage directly contradicts the presumed intent of this legislation, puts consumers at risk for catastrophic healthcare costs or being forced to delay care, and creates additional confusion for consumers and patients.

### **Affordability**

Our second principle recognizes that illness and disease impacts individuals across the economic spectrum. We believe that everyone – regardless of their economic situation – should be able to obtain the treatment they need to manage, maintain, or improve their health. This means that coverage should be *affordable*, including reasonable premiums and cost-sharing, and that individuals with pre-existing conditions should be protected from being charged more for their coverage.

Although this legislation protects against higher rates based on health status, we remain concerned that it leaves patients and consumers exposed to higher premiums based on other factors that can be used as proxies for health status, such as age, gender, or occupation. For instance, there is no limit on how much more insurers in the individual market could charge a 50-year-old with heart disease because of his age. Insurers could also charge higher rates to a woman of childbearing age because of her gender. This legislation would exacerbate the affordability challenges facing many Americans today by neglecting to maintain current protections and subjecting patients to even higher premiums should the ACA be completely invalidated.

## **Accessibility**

Lastly, health care coverage must be *accessible*. All people, regardless of employment, health status or geographic location, should be able to gain coverage without waiting periods or undue barriers to coverage. While we appreciate that the legislation would continue to prohibit insurers from denying coverage to individuals with pre-existing conditions, we are deeply troubled that, absent other quality and financial protection standards, this provision would offer only minimal assurance to consumers.

## **Conclusion**

While we do not yet know the outcome or scope of the ruling in the *Texas v U.S.* case, failure to preserve key ACA provisions could have catastrophic implications for both the insurance markets and the millions of patients who rely on them. Partially restoring only two (guaranteed issue and some rating protections) of the multiple provisions that currently protect patients is inadequate and would leave many people without the level of coverage they need and deserve. Should the ACA be struck down and this legislation implemented as a replacement, consumers with pre-existing conditions would face significant financial and coverage barriers. In short, for people with pre-existing conditions, the bill would provide access to coverage in name only.

We share your interest in continuing to make health insurance accessible to Americans with pre-existing conditions and appreciate your efforts to preserve certain protections in law, regardless of the outcome of *Texas vs. US*. However, the “Ensuring Coverage for Patients with Pre-Existing Conditions Act” as currently drafted, falls far short of providing coverage and security to your constituents, including those who are or will face significant health care needs. We urge you and your Senate colleagues to reconsider your approach to S. 3388 and ensure that any future legislation provides protections for people with pre-existing conditions that are the same or better than those included in current law.

Our organizations stand ready to work with you on solutions that serve the patients we represent and would be pleased to meet with you about how this legislation can be improved to meet the needs of people with pre-existing conditions.

Sincerely,

Adult Congenital Heart Association  
Alpha-1 Foundation  
ALS Association  
American Cancer Society Cancer Action Network  
American Diabetes Association  
American Heart Association  
American Liver Foundation  
American Lung Association  
Arthritis Foundation  
Chronic Disease Coalition  
COPD Foundation  
Crohn’s & Colitis Foundation  
Cystic Fibrosis Foundation  
Epilepsy Foundation  
Family Voices  
Global Healthy Living Foundation  
Hemophilia Federation of America

Leukemia & Lymphoma Foundation  
Lutheran Services in America  
March of Dimes  
Mended Little Hearts  
Muscular Dystrophy Association  
National Alliance on Mental Illness  
National Coalition for Cancer Survivorship  
National Health Council  
National Hemophilia Foundation  
National Kidney Foundation  
National Multiple Sclerosis Society  
National Organization for Rare Disorders  
National Patient Advocate Foundation  
Susan G. Komen  
United Way Worldwide  
WomenHeart: The National Coalition for Women with Heart Disease

Cc:

Leader Mitch McConnell  
Minority Leader Charles Schumer  
Senator Lamar Alexander  
Senator Patty Murray

Senator Chuck Grassley  
Senator Joni Ernst  
Senator Lisa Murkowski  
Senator Bill Cassidy

Senator Roger Wicker  
Senator Lindsey Graham  
Senator Dean Heller  
Senator John Barrasso  
Senator Shelley Moore Capito  
Senator Johnny Isakson  
Senator Dan Sullivan  
Senator John Hoeven