



I am essential

February 10, 2017

The Honorable Tom Price  
Secretary of Health and Human Services  
200 Independence Avenue SW  
Washington, D.C. 20201

Re: Maintaining and Enforcing Important Patient Protections & Access to Prescription Drugs

Dear Mr. Secretary:

**I Am Essential** is a broad coalition of patient and community organizations representing millions of patients and their families dedicated to the protection of quality, comprehensive, and affordable health care. We look forward to working with you and your Department on ensuring that *all* patients have affordable coverage and access to quality care and treatment. As representatives of patients, we, **the undersigned 200 organizations**, support your stated goals of accessibility, affordability, quality, responsiveness, choices and transparency, and innovative patient-centered care. **As you begin your tenure as Secretary of Health and Human Services and review the Patient Protection and Affordable Care Act (ACA) and consider potential revisions to it and its implementing regulations and guidance, we urge you to maintain the many important protections patients have gained that ensure they can access the care and treatment their providers prescribe.** We particularly urge you to continue enforcing and not repeal the patient protections outlined below as you implement the President's January 20<sup>th</sup> Executive Order, "Minimizing the Economic Burden of the Patient Protection and Affordable Care Act Pending Repeal."

While it is not a perfect law, the ACA has provided health coverage and improved access to care for tens of millions of Americans living with chronic and serious health conditions, many of whom were previously uninsured or underinsured. If they lose access and coverage for even one day, their health and well-being can be immediately jeopardized. Therefore, providing them with continuous coverage and consistent care and treatment must be your number one priority. Furthermore, we cannot afford to lose the numerous patient protections described below, which have improved access to quality health care for *all* beneficiaries, including those who already had health coverage.

### **Patient Protections in Current Law**

The existing law provides many important patient protections that are some of the most popular features of the ACA among beneficiaries and are the heart of *patient*-centered reform: no longer can individuals living with pre-existing conditions be denied coverage or charged higher premiums based on their health status, nor can plans discriminate against individuals in their marketing or after issuing them coverage; beneficiaries have the right to appeal adverse coverage decisions; lifetime coverage limits have been eliminated, annual out-of-pocket costs are capped, and most Marketplace enrollees can take advantage of financial assistance to make premiums and/or cost-sharing more affordable; and Qualified Health Plans must provide sufficient choice of providers and transparent, simplified information to help beneficiaries compare plans and understand their coverage.

The ACA helps guarantee all beneficiaries have access to a comprehensive set of health benefits and services by requiring every Qualified Health Plan offer ten categories of **Essential Health Benefits** that include services that meet a benchmark plan the state chooses. They include, among others, prescription drugs, ambulatory care, mental health and substance use disorder services, and preventive services. In the past, many health plans did not cover these services and treatments, so many patients could not find insurance coverage that met their needs and had to pay out-of-pocket or go without them. We cannot depend on insurance companies to automatically cover these services going forward. We strongly believe that any changes to our health coverage system must maintain this minimum set of benefits to ensure that beneficiaries, regardless of where they live or what health plan they choose, can receive the care and treatment they depend on or may need in the future.

Under **Section 1557** of the ACA, Americans are protected from discrimination on the basis of race, color, national origin, sex, disability and age by health programs and activities operated or funded by the U.S. Department of Health and Human Services, including Qualified Health Plans. These landmark protections are critical to fulfilling the requirement of preventing discrimination based on pre-existing health conditions and access to the healthcare that every American deserves.

### **Patient Protections in Regulations and Guidance**

While the law is the foundation for these protections, **I Am Essential** and others have been instrumental in ensuring that the implementing regulations and guidance meet beneficiaries' needs. These regulations have brought significant gains in access to adequate, affordable, and transparent health care, including prescription drug coverage and access, broad range of preventive services exempt from cost-sharing, standards for provider networks, plan selection tools and free in-person assistance, and prohibitions on discrimination by insurers.

With respect to prescription drugs, **I Am Essential** supported common sense Essential Health Benefits regulations and guidance that help patients access the medications prescribed by their providers. Plans are required, among other things, to:

- design and implement their benefits, including formularies, in a way that does not discriminate based on individual's health condition, age, or disability;

- make their formularies and cost-sharing information accessible to both enrollees and potential enrollees, including tiering and utilization management information;
- cover a minimum number of drugs in each U.S. Pharmacopeial Convention therapeutic class that is based on a benchmark that each state selects;
- use pharmacy and therapeutics (P&T) committees to develop and regularly update their formularies with newly approved drugs and according to treatment guidelines;
- have an exceptions and appeals process to access medications not on a plan's formulary with an emergency fill requirement;
- allow certain third-party entities to contribute to premiums and patient cost-sharing;
- provide certain preventive medications and vaccines at zero cost-sharing; and
- allow beneficiaries to access drug benefits at retail pharmacies.

In addition, through the annual Notice of Benefit and Payment Parameters process, we have been able to improve upon these protections each year through provisions such as the standardized benefit plans that bring more transparency and impose some cost-sharing limits on prescription drugs and, in some instances, exclude drugs from a plan's deductible. In an effort to improve the Marketplaces for insurers and thereby improve beneficiaries' coverage options, we support including prescription drug usage for certain health conditions in the Risk Adjustment program, which is set to begin in the 2018 benefit year.

Individual states have also implemented their own patient protections, including requiring standardized plan options, which have cost-sharing limits and exclude prescription drugs from the deductible, while others prohibit high coinsurance and mid-year formulary changes. These protections have improved both the patient experience and the Marketplace, and must be maintained and can be used as a model for the federal government and other states.

**Section 1557** nondiscrimination regulations also protect people living with chronic and serious conditions by making it illegal for health plans to implement benefit designs or marketing practices that are discriminatory. Unfortunately, we have observed that some insurance plans limit beneficiary access to critical medications in ways that we believe are discriminatory. For example, some plans place all or almost all medications to treat certain conditions on the highest cost tier or do not cover all the necessary or treatment guideline recommended medications providers prescribe for patients. Some insurers design their plans with other barriers such as high beneficiary cost-sharing for brand and "specialty" medications, including extremely high coinsurance and deductibles. Some use excessive utilization management techniques, such as step therapy requirements, targeting treatments for specific diseases. While others remove medications from their formularies mid-year, a practice that is particularly harmful to patients on established regimens or whose condition requires a particular treatment.

Such practices, often targeted at specific chronic and serious conditions, not only make it difficult to access necessary medications but also discourage people living with those conditions

from enrolling in these plans. To stop plans from engaging in these practices and ensure beneficiaries have a choice of plans through which they can access the care and treatment they need, Section 1557 and its implementing regulations must be maintained and properly enforced.

We look forward to working with you and your Department as you review the current law and suggest potential changes to the ACA and its implementing regulations and guidance. As you do, we remind you of the importance of maintaining health care for those who already have coverage and the critical patient protections that are already in place. As you make any changes, we urge you not to go back on the promise of affordable and quality care and treatment for everyone, especially those living with chronic and serious health conditions.

Should you have any questions or comments, please contact: Carl Schmid, Deputy Executive Director, The AIDS Institute, [cschmid@theaidsinstitute.org](mailto:cschmid@theaidsinstitute.org); Beatriz Duque Long, Senior Director, Government Relations, Epilepsy Foundation, [bduquelong@efa.org](mailto:bduquelong@efa.org); or Andrew Sperling, Director of Federal Legislative Advocacy, National Alliance on Mental Illness, [asperling@nami.org](mailto:asperling@nami.org). Thank you very much.

Sincerely,

Academy of Nutrition and Dietetics  
ADAP Advocacy Association (aaa+)  
Adult Congenital Heart Association  
Advocates for Responsible Care (ARxC)  
AIDS Action Baltimore  
AIDS Foundation of Chicago  
The AIDS Institute  
AIDS United  
Alliance for Aging Research  
Alpha-1 Foundation  
American Academy of HIV Medicine  
American Association on Health and Disability  
American Behcet's Disease Association  
American Lung Association  
American Sexual Health Association  
American Society for Metabolic and Bariatric Surgery  
Amida Care  
APLA Health  
Arthritis Foundation  
Asian & Pacific Islander American Health Forum  
Asian Health Coalition

Association for Behavioral Healthcare - Massachusetts  
Association of Asian Pacific Community Health Organizations (AAPCHO)  
Association of Nurses in AIDS Care  
Asthma and Allergy Foundation of America  
Blue Faery: The Adrienne Wilson Liver Cancer Association  
BOLT  
Bronx Lebanon Hospital Family Medicine  
Broward Health  
California Chronic Care Coalition  
California Hepatitis C Task Force  
Cascade AIDS Project  
Center for Independence of the Disabled, NY  
Charleston (WV) Parkinson's Support Group  
CHOW Project  
Chronic Disease Coalition  
Coalition on Positive Health Empowerment  
Colorado Federation of Families  
Community Access National Network (CANN)  
Cutaneous Lymphoma Foundation  
Dysautonomia International

Easter Seals Massachusetts  
Epilepsy California  
Epilepsy Foundation  
Epilepsy Foundation Central & South Texas  
Epilepsy Foundation Eastern PA  
Epilepsy Foundation Heart of Wisconsin  
Epilepsy Foundation Houston/Dallas-Fort Worth/West Texas  
Epilepsy Foundation Louisiana  
Epilepsy Foundation Middle & West Tennessee  
Epilepsy Foundation New England  
Epilepsy Foundation Northwest  
Epilepsy Foundation of Alabama  
Epilepsy Foundation of Arizona  
Epilepsy Foundation of Colorado  
Epilepsy Foundation of Connecticut  
Epilepsy Foundation of Delaware  
Epilepsy Foundation of East Tennessee  
Epilepsy Foundation of Florida  
Epilepsy Foundation of Georgia  
Epilepsy Foundation of Greater Chicago  
Epilepsy Foundation of Greater Cincinnati and Columbus  
Epilepsy Foundation of Greater Southern Illinois  
Epilepsy Foundation of Hawaii  
Epilepsy Foundation of Indiana  
Epilepsy Foundation of Kentuckiana  
Epilepsy Foundation of Long Island  
Epilepsy Foundation of Metropolitan New York  
Epilepsy Foundation of Michigan  
Epilepsy Foundation of Minnesota  
Epilepsy Foundation of Mississippi  
Epilepsy Foundation of Missouri & Kansas  
Epilepsy Foundation of Nevada  
Epilepsy Foundation of New Jersey  
Epilepsy Foundation of North Carolina  
Epilepsy Foundation of North Central Illinois, Iowa, Nebraska  
Epilepsy Foundation of Northeastern New York  
Epilepsy Foundation of Oklahoma

Epilepsy Foundation of Southeast Tennessee  
Epilepsy Foundation of the Chesapeake Region  
Epilepsy Foundation of Utah  
Epilepsy Foundation of Vermont  
Epilepsy Foundation of Virginia  
Epilepsy Foundation of Western Wisconsin  
Epilepsy Foundation Southeast Wisconsin  
Epilepsy Foundation Western Ohio  
Epilepsy Foundation Western/Central PA  
Epilepsy\_Pralid, Inc.  
Fabry Support & Information Group  
Fight Colorectal Cancer  
Genetic Alliance  
Georgia Equality  
Georgia Rural Urban Summit  
GLMA: Health Professionals Advancing LGBT Equality  
Global Colon Cancer Association  
The Global Healthy Living Foundation  
Global Justice Institute, Metropolitan Community Churches  
HCV Advocate  
The Health Initiative  
HealthyWomen  
Hemophilia Association of the Capital Area  
Hemophilia Council of California  
Hep B United  
Hep Free Hawaii  
Hepatitis B Foundation  
Hepatitis C Allies of Philadelphia  
Hepatitis Foundation International  
Hermansky-Pudlak Syndrome Network  
Hispanic Health Network  
HIV Medicine Association  
HIV/AIDS Alliance of Michigan  
IFAA  
International Pain Foundation  
International Pemphigus & Pemphigoid Foundation  
Kubatana Support Group  
Lakeshore Foundation  
Latino Commission on AIDS  
Legal Action Center

Let's Talk About Change  
Liver Health Connection  
The Lupus Alliance of Long Island/Queens  
Lupus Alliance of Upstate New York  
Lupus and Allied Diseases Association, Inc.  
Lupus Foundation of America  
Lupus Foundation of Florida  
Lupus Foundation of Northern California  
Lupus Foundation of Pennsylvania  
Lupus Foundation of Southern California  
Lupus LA  
Malecare Cancer Support  
MANA, A National Latina Organization  
MANNA (Metropolitan Area Neighborhood  
Nutrition Alliance)  
Men's Health Network  
Mental Health America  
Mental Health Colorado  
The Michael J. Fox Foundation  
Midwest Asian Health Association  
MLD Foundation  
NAACP  
NAMI Mass - National Alliance on Mental  
Illness of Massachusetts  
NAMI North Carolina  
Nashville CARES  
NASTAD (National Alliance of State &  
Territorial AIDS Directors)  
National Alliance on Mental Illness (NAMI)  
National Association of Hepatitis Task Forces  
National Association of Nutrition and Aging  
Services Programs (NANASP)  
National Black Nurses Association  
National Consumers League  
National Council for Behavioral Health  
National Council of Asian Pacific Islander  
Physicians  
National Eczema Association  
National Gay & Lesbian Chamber of  
Commerce  
National Hemophilia Foundation  
National Hispanic Council on Aging  
National Hispanic Medical Association  
National LGBTQ Task Force

National Minority Quality Forum  
The National Multiple Sclerosis Society  
National Patient Advocate Foundation  
National Psoriasis Foundation  
National Stroke Association  
National Viral Hepatitis Roundtable  
Neuropathy Action Foundation  
New Jersey Association of Mental Health and  
Addiction Agencies, Inc.  
New Yorkers for Accessible Health Coverage  
Noahs Hope  
North East Medical Services  
Obesity Action Coalition  
Obesity Medicine Association  
The Obesity Society  
PCA Blue Inc.  
Pharmaceutical Access for Community-based  
Service Providers (PACSP)  
Planned Parenthood Federation of America  
Platelet Disorder Support Association  
Positive Health Solutions  
Positive IMPACT Health Centers  
Positive Women's Network - USA  
Prevent Blindness  
Project Inform  
PXE International  
Rush to Live  
Saint Joseph's Mercy Care Services, Inc.  
Scleroderma Foundation  
Sjogren's Syndrome Foundation  
Southern AIDS Coalition  
Southern HIV/AIDS Strategy Initiative (SASI)  
Susan G. Komen  
The Swan Project  
Thomas Judd Care Center @ Munson Medical  
Center  
Treatment Action Group  
Triangle Pastoral Counseling  
U.S. Pain Foundation  
Unity Wellness Center  
University of Mississippi Medical Center  
Usher 1F Collaborative, Inc.  
The Veterans Health Council  
Vietnam Veterans of America

Virginia Hemophilia Foundation  
Wellness and Education Community Action  
Health Network (WECAHN)

Western Pennsylvania Chapter of the  
National Hemophilia Foundation

cc: Ms. Seema Verma  
Mr. Andrew Bremberg  
Ms. Katy Talento