



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 20th 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; Beatriz Duque Long, Senior Director, Government Relations, Epilepsy Foundation, bduquelong@efa.org; or Andrew Sperling, Director of Federal Legislative Advocacy, National Alliance on Mental Illness, 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