
COALITION FOR ACCESSIBLE TREATMENTS

March 7, 2017

The Honorable Paul Ryan
Speaker
U.S. House of Representatives

The Honorable Mitch McConnell
Majority Leader
U.S. Senate

The Honorable Nancy Pelosi
Democratic Leader
U.S. House of Representatives

The Honorable Charles Schumer
Democratic Leader
U.S. Senate

Dear Speaker Ryan, Majority Leader McConnell, Democratic Leader Pelosi, and Democratic Leader Schumer:

On behalf of the millions of Americans living with chronic, disabling, and life-threatening medical conditions, the undersigned patient and provider organizations have joined together as the Coalition for Accessible Treatments (CAT) to advocate for policies addressing one of the greatest obstacles standing between patients and the treatments they need: high out-of-pocket costs. We write today to urge you to ensure healthcare legislation related to the Affordable Care Act (ACA) reduces out-of-pocket costs for patients and their families.

While advancements in science and medicine have yielded life-changing therapies for conditions like cancer, HIV, rheumatoid arthritis, multiple sclerosis, psoriasis, Crohn's disease, and other diseases, these treatments are increasingly out of reach for too many because of rising out-of-pocket costs. In addition to significant increases in premiums and deductibles over the past decade,ⁱ patients reliant on high-cost treatments have also seen their costs more than double as plans shift from a flat, reasonable copay to a coinsurance model that requires thousands of dollars in out-of-pocket spendingⁱⁱ. Research across disease states has demonstrated that the higher the out-of-pocket costs, the less likely patients are to fill prescriptions and refills and adhere to their treatments.^{iii,iv} Lack of adherence often results in patients with chronic illness becoming sicker and more costly to our overall healthcare system.

The ACA made significant progress in protecting our patients' access to such therapies. The law prohibited insurers from denying coverage or dropping coverage of anyone because of pre-existing conditions. It established an annual limit on the out-of-pocket costs that an insurance plan can require of a patient and a family and ended lifetime coverage caps. It also created a subsidy system to reduce cost-sharing for some low- and middle-income consumers purchasing coverage in state marketplaces and encouraged states to expand Medicaid to low-income Americans unable to afford coverage on the marketplace. It requires no-cost-sharing coverage of vital preventive services such as childhood vaccinations and disease screening. And it established a schedule for closing the Medicare Part D "donut hole" that led so many seniors to stop adhering to their treatments due to cost.

Even with these protections, there are still too many Americans who leave their prescriptions at the pharmacy counter due to cost—even in the face of disability or death. That’s why our coalition would like to work with you and your colleagues to help develop policies that continue to protect patients with chronic or life-threatening conditions attain access to the treatments they need.

While each of our individual organizations has additional perspectives on various aspects of the ACA, as the Coalition for Accessible Treatments, we are united in our support for innovative solutions that reduce barriers to necessary therapies. We are open to novel ideas and approaches but believe any legislation intended to address the ACA must achieve the following goals related to affordability:

- Reduce out-of-pocket costs by promoting lower deductibles, flat copays in place of coinsurance for essential therapies, access to necessary healthcare provider expertise, and no-cost-sharing preventive care;
- Prevent insurers from discriminating against patients with costly medical conditions through benefit packages designed to shift costs to the most vulnerable patients;
- Provide access to an insurance coverage option for low-income consumers that includes reduced cost-sharing so patients can afford to use their insurance when needed; and
- Provide premium and cost-sharing assistance to consumers purchasing coverage on the individual market.

On behalf of the millions of patients we represent, the Coalition for Accessible Treatments urges you to work with us and our colleagues in the patient and provider communities to ensure that no patient is left without the ability to get the treatment that can improve or save their lives.

Sincerely,

The AIDS Institute
Alliance for the Adoption of Innovations in Medicine
Alpha-1 Foundation
American Academy of Neurology
American Academy of Pediatrics
American Autoimmune Related Diseases Assn
American College of Rheumatology
American Society of Hematology
Arthritis Foundation
Crohn’s and Colitis Foundation
GBS-CIDP Foundation International
Hemophilia Federation of America
Hepatitis Foundation International

Immune Deficiency Foundation
Leukemia and Lymphoma Society
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America
National Hemophilia Foundation
National Organization for Rare Diseases
National Psoriasis Foundation
Patient Access Network Foundation
Pulmonary Hypertension Association
Scleroderma Foundation
Susan G. Komen
U.S. Hereditary Angioedema Association

List of organizations not in CAT's membership but supporting the request of this letter

American Liver Foundation
Digestive Disease National Coalition
Dystonia Medical Research Foundation
International Foundation for Functional Gastrointestinal Disorders
Interstitial Cystitis Association
Marfan Foundation
METAvivor
National Alopecia Areata Foundation
National Pancreas Foundation
NephCure Kidney International

ⁱ 2015 Employer Health Benefits Survey. The Kaiser Family Foundation website. Published September 22, 2015.

ⁱⁱ Peterson-Kaiser Health System Tracker. Kaiser Family Foundation analysis of Truven Health Analytics MarketScan Commercial Claims and Encounters Database, 2004-2014. Published April 12, 2016.

ⁱⁱⁱ Starner et al. "Specialty Drug Coupons Lower Out-Of-Pocket Costs and May Improve Adherence at the Risk of Increasing Premiums." *Health Affairs*. Oct 2014 33:10, pgs 1761-1769.

^{iv} Winn et al. "Factors Associated With Tyrosine Kinase Inhibitor Initiation and Adherence Among Beneficiaries With Chronic Myeloid Leukemia." *Journal of Clinical Oncology*. Dec 2016 34:36, pgs 4323-4328.