

Dear Members of the 117th Congress,

As organizations advocating to ensure that millions of individuals have timely and affordable access to quality medical treatments, we are urging lawmakers to reconsider the drug pricing policies included in the most recent version of the Build Back Better Act. We appreciate the inclusion of a generous out of pocket cap on patient Part D spending as well as the options for patients to “smooth” or spread their cost-sharing over the year in the legislation. However, several provisions are of significant concern as they threaten to destroy the burgeoning pipeline for new drugs, biologics, and biosimilars.

Of particular concern, this proposed legislation would subject medicines to potential government price-setting well before their exclusivities expire. This is problematic for our communities because these exclusivity protections remain critical to incentivizing the research and development of medicines post-approval. In fact, they are so essential that Congress deliberated and enacted (on a bipartisan basis) these exclusivities to encourage pediatric, rare, and orphan disease research. This proposal undermines the very steps Congress has taken to promote this critical research. We understand that R&D into treatments for cancers and rare diseases is costly, lengthy, and risky. That is why our group and many others fought and advocated for these very incentives to be enacted into law. This proposal unwinds much of the progress that has been made in incentivizing the development of innovative medicines to treat cancer and rare disease.

Furthermore, because the legislation permits the government to begin setting the prices of some medicines just 9-13 years after approval, it creates a disincentive for generic and biosimilar medicines to be developed, which are projected to save patients, employers, and payors billions of dollars over the next decade. Many organizations have spent years educating patients in our communities about the role and value of biosimilars. Congress could quickly erode that work with these provisions that would likely deter biosimilar development.

Policies that allow the government to pick winners and losers are not patient-centered – in fact, they perpetuate existing problems within our healthcare system. Patients living with cancer or other serious medical diseases need drug pricing policies that encourage broad access to existing treatments and future development of new treatments, so we can help patients in our communities to get better.

Patients fighting serious illnesses need help – and the pricing provisions like an out-of-pocket cap and smoothing will certainly deliver that. At the same time, the price setting proposals will have an undoubted impact on research into rare, pediatric, and orphan disease – at the expense of patients who are waiting and hoping for the development of these medicines. We thank you for continuing to refine your proposals to deliver savings for patients of today and hope for patients in the future.

Sincerely,

Global Colon Cancer Association  
Action CF  
American Behcet's Disease Association (ABDA)  
Area Agency on Aging and Disabilities for SW Washington  
Autoimmune Association  
BioNJ  
Born a Hero, Research Foundation  
California Access Coalition  
Caregiver Action Network  
Chronic Care Policy Alliance  
HealthCare Institute of New Jersey (HINJ)  
Hereditary Neuropathy Foundation  
ICAN, International Cancer Advocacy Network  
The Latino Coalition Inc.  
Let's Kick ASS AIDS Survivor Syndrome  
Liver Coalition of San Diego  
Lupus and Allied Diseases Association, Inc.  
Mayors Committee on Life Sciences  
National Hispanic Council on Aging  
The National Puerto Rican Chamber of Commerce  
Neuropathy Action Foundation  
Nevada Chronic Care Collaborative  
Rare Access Action Project  
Regarding Cancer  
RetireSafe  
SLC6A1 CONNECT  
Small Business & Entrepreneurship Council  
Vets Place Northwest- Welcome Home