

October 6, 2021

Chairman Ron Wyden  
Senate Committee on Finance  
219 Dirksen Senate Office Building  
United States Senate  
Washington, D.C. 20510-6200

Ranking Member Mike Crapo  
Senate Committee on Finance  
219 Dirksen Senate Office Building  
United States Senate  
Washington, D.C. 20510-6200

**RE: Patient Community Concerns with Drug Pricing Proposals**

Dear Chairman Wyden and Ranking Member Crapo:

We, the undersigned 46 organizations, on behalf of millions of American patients who live with complex, chronic health conditions such as HIV, autoimmune diseases, cancer, diabetes, lupus, multiple sclerosis, and hepatitis, are pleased that your committee and Congress are focused on advancing policies and measures that improve prescription drug affordability and access for the American people. We believe there are clear actions that Congress can take right now to help patients access, afford, and adhere to the medications they need to stay healthy. However, several proposals on the table would create great challenges for those we serve and have negative implications for vulnerable communities and future treatment innovations.

**As patient advocates, we greatly support policy solutions that would provide immediate relief to Americans to afford their medications that do not threaten prescription drug access and future drug development.**

This includes policies that have been proposed in current bills, along with others, that would help American seniors and other vulnerable patient communities better afford their prescription medications, including:

- **Cap annual out-of-pocket costs for Medicare Part D beneficiaries**, which would benefit millions of patients who rely on prescriptions to manage their health.
- **Create a “smoothing” mechanism in Medicare Part D** to ensure seniors with expensive annual drug costs can pay their out-of-pocket expenses throughout the calendar year rather than all at once.
- **Pass rebate savings on to patients** by basing cost-sharing on post-rebate drug prices rather than list prices.

- **Ensure insurance benefit design does not discriminate** against vulnerable beneficiaries that place undo cost-sharing on patients who rely on prescription drugs.
- **Ensure patient copay assistance counts** towards beneficiary deductible and out-of-pocket expenses.

**We continue to be concerned with some of the drug pricing proposals that give the government additional power to “negotiate” and set the price of prescription drugs.**

Several proposals before Congress include the use of “international reference pricing”—a policy that would threaten American patients’ ability to access new and innovative medicines for complex and hard-to-treat diseases. Today, the U.S. has [access to almost 90% of new drugs](#), while countries that have utilized price control mechanisms such as international reference pricing have access to just 47% of new medicines.

**Secondly, we are concerned that Congress is considering policies that would give an independent entity—such as the Institute for Clinical and Economic Review (ICER)—the authority to recommend drug prices for Medicare and private insurance.**

Evidence has demonstrated time and again that the methodology that ICER uses to determine drug value and make coverage recommendations for new drugs is flawed and discriminatory. Research has demonstrated that the quality-adjusted life years (QALY) methodology employed by ICER disadvantages [older Americans](#), those with [disabilities](#), and patients living with [rare conditions](#). The QALY measures the value of drugs based on the dollar value of one year of “perfect health,” a standard that many of the aforementioned patient populations may never meet. If Congress were to give price-setting authority to ICER or a similar entity, patients may never be able to access newer, more effective drugs for complex conditions that are deemed of low value by the QALY and ICER.

We appreciate your leadership and focus on patients as the Senate Finance Committee considers these proposals and more. We look forward to working with you to advance patient-centered policies that prove to help those we serve access their prescription drugs and experience better outcomes.

Should you have any questions or comments, please contact Carl Schmid, Executive Director of the HIV+Hepatitis Policy Institute, at [cschmid@hivhep.org](mailto:cschmid@hivhep.org).

Sincerely,

ACS CAN  
ADAP Advocacy Association  
Aimed Alliance  
Allergy & Asthma Network  
Alliance for Patient Access  
American Kidney Fund  
American Liver Foundation  
Autoimmune Association  
Autoimmune Encephalitis Alliance, Inc.

Beyond Type 1  
Bienestar Human Services  
California Health Collaborative  
CancerCare  
Caregiver Action Network  
Caring Ambassadors Program  
Chronic Care Policy Alliance  
Color of Crohn’s and Chronic Illness  
Community Access National Network (CANN)

Cystic Fibrosis Research Institute  
End Hep C SF  
Georgia AIDS Coalition  
Global Healthy Living Foundation  
Global Liver Institute  
Good Days  
HIV+Hepatitis Policy Institute  
ICAN, International Cancer Advocacy  
Network  
International Foundation for Autoimmune &  
Autoinflammatory Arthritis (AiArthritis)  
Lupus Foundation of America  
Mental Health America of Virginia  
METAvivor  
Multiple Sclerosis Association of America  
National Minority Quality Forum

National Pancreas Foundation  
Neuropathy Action Foundation  
No Patient Left Behind  
Oregon Rheumatology Alliance  
Partnership to Fight Chronic Disease  
Patients Rising Now  
PlusInc  
Project Sleep  
San Francisco Hepatitis C Task Force  
Sick Cells  
SISTERLOVE  
The Myositis Association  
Transplant Recipients International  
Organization (TRIO)  
US Hereditary Angioedema Association