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.

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
Cancer*Care*
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