



NATIONAL HEALTH COUNCIL

November 22, 2024

The Honorable Chuck Schumer
Majority Leader
United States Senate
322 Hart Senate Office Building
Washington, DC 20510

The Honorable Mike Johnson
Speaker
U.S House of Representatives
568 Cannon House Office Building
Washington, DC 20515

The Honorable Mitch McConnell
Minority Leader
United States Senate
317 Russell Senate Office Building
Washington, DC 20510

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
2433 Rayburn House Office Building
Washington, DC 20515

Dear Majority Leader Schumer, Speaker Johnson, Minority Leader McConnell, and Minority Leader Jeffries:

On behalf of the National Health Council (NHC), I am writing to ask that you include health care transparency and affordability provisions that are important to the patient community in any work that is completed in the current lame duck session. We recognize the factors affecting access and affordability are numerous and immense. We appreciate that progress was made throughout this Congress by both House and Senate committees on improvements to health care access, innovation, transparency and affordability. The NHC calls on Congress to act swiftly on the priorities below. Patients can't wait any longer for action. Adequate funding for federal health care programs is essential for the patient community, but we also need to advance policy that helps patients with the significant issues they are facing today.

Created by and for patient organizations more than 100 years ago, the NHC brings diverse organizations together to forge consensus and drive patient-centered health policy. We promote increased access to affordable, high-value, sustainable, equitable health care. Made up of more than 180 national health-related organizations and businesses, the NHC's core membership includes the nation's leading patient organizations. Other members include health-related associations and nonprofit organizations including the provider, research, and family caregiver communities; and businesses representing biopharmaceutical, device, diagnostic, generic drug, and payer organizations.

Some of the issues the NHC urges Congressional action on include telehealth extensions; the Safe Step Act; the rare pediatric disease PRV Program; transparency; and the patient share of drug cost savings. All these issues are bipartisan, have large swaths of support in Congress, have passed at least at the Committee level, and focus on legislation that is disease agnostic and affects all or large groups of patients.

Congress must further extend or make permanent telehealth flexibilities that expire at the end of the calendar year. Congress must act in the lame duck session to

further extend or make permanent telehealth flexibilities expiring at the end of the calendar year. The popularity of telehealth transcends party lines and offers essential support for patients with chronic conditions, disabilities, and those in rural areas, making it an indispensable element of modern health care.

The bipartisan Safe Step Act provides common-sense protection for patients and must be passed as part of the [Pharmacy Benefit Reform Act](#) end of year package.

The bipartisan Safe Step Act would ensure that employer health plans offer a fast and medically reasonable step therapy exceptions process. When medically inappropriate, step therapy can delay needed care for months and lead to negative health outcomes for patients.

Congress must pass the five-year reauthorization of the Rare Pediatric Disease Patient Voucher Program. Incentives that drive innovation into rare and understudied areas are critical, and for many years the pediatric rare disease voucher program has offered these incentives. This must continue.


The NHC asks Congress to examine transparency across the health care system and work with patients and advocates to approach legislative proposals to increase transparency holistically. The health care system is complex and opaque, which too often undermines informed patient decision-making and health. This includes hospitals, health care providers, insurers, pharmacy benefit managers (PBMs), and manufacturers. This lack of transparency can make it difficult for patients seeking appropriate and timely care. With better data on the incentives, disincentives, and decision-making in the health care system, patient organizations would be able to better analyze legislative and regulatory proposals and advocate for needed change. H.R.5378, the [Lower Costs, More Transparency Act](#) passed by the House, accomplishes several of these goals.

Congress should enact legislation that directly reduces out-of-pocket expenses by ensuring negotiated savings are shared with patients. The NHC supports the concept of patients sharing in the savings realized by rebates, whether it be through rebate passthrough or policies that tie cost sharing to negotiated rates. This includes, but is not limited to, Section 203 of the [Better Mental Health Care, Lower-Cost Drugs, And Extenders Act](#) passed by the Senate Finance Committee.

Conclusion

Please do not hesitate to contact Jennifer Dexter, Vice President of Policy, if you or your staff would like to discuss these issues in greater detail. She is reachable via e-mail at jdexter@nhcouncil.org.

Sincerely,



Randall L. Rutta
Chief Executive Officer