



NATIONAL HEALTH COUNCIL

January 9, 2025

The Honorable John Thune
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 Chuck Schumer
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 Thune, Speaker Johnson, Minority Leader Schumer, and Minority Leader Jeffries:

On behalf of the National Health Council (NHC), I am writing to share the priorities of the patient community as you begin the 119th Congress. Patients have the greatest stake in the decisions you will be making affecting health care access, affordability, and innovation. We encourage you to collaborate with the NHC and our members as key partners in shaping patient-centered health care policies that meet the needs of all people with chronic diseases and disabilities.

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.

The patient community welcomes the chance to work together to advance several important priorities:

Continue serving the nearly 80 million Americans in all 50 states receiving Medicaid.

Medicaid is a critical lifeline for patients and provides insurance for nearly 80 million people across every state in the country. It ensures people with disabilities can access critical home and community-based services and secure meaningful job opportunities. And it helps working people stay healthy. Any changes to the fundamental structure of Medicaid that would harm people with chronic diseases and disabilities must be opposed.

Prevent health insurance premium increases. To ensure consumers could afford their coverage, Congress established advance tax credits in the Affordable Care Act to help lower the cost of health insurance purchased in the Marketplaces. In 2021, Congress made two temporary but critically important changes to the tax credits: it increased the amount of the tax credits and capped premium costs at 8.5% of annual income for individuals and families earning more than 400% FPL. In response to their success, Congress extended these enhanced tax

credits in 2022 through the end of 2025. Since the enhanced APTCs were first enacted in 2021, they have helped 9.4 million Americans gain access to high-quality and affordable health coverage. Congress should work to prevent premium increases, which may force patients and consumers to forgo essential, high-quality coverage upon which they have come to rely.

Swiftly extend or permanently authorize telehealth flexibilities expiring in March.

Congress must act to further extend or make permanent the telehealth flexibilities expiring in March. The usefulness 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.

Pass the bipartisan Safe Step Act. The bipartisan Safe Step Act would ensure that employer health plans offer a fast and medically reasonable step therapy exceptions process. Medically inappropriate step therapy can delay needed care for months, resulting in adverse health outcomes for patients.

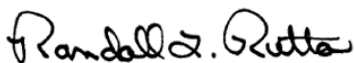
Reauthorize the Rare Pediatric Disease Priority Review Voucher Program. Incentives that drive innovation into rare and understudied areas are critical, and for many years the pediatric rare disease voucher program has offered these incentives. This must continue by approving the program's five-year reauthorization.

Work with patients and advocates across the health care system 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 encompasses hospitals, 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.

Enact legislation that directly reduces out-of-pocket expenses by ensuring negotiated savings are shared with patients. The NHC supports policies that enable patients to directly share in savings from rebates, such as rebate passthroughs or cost sharing tied to negotiated rates.

As Congress begins the 119th Congress, we look forward to working together to advance patient-centered health policy issues. Please do not hesitate to contact me or have your staff contact Jennifer Dexter, Vice President of Policy, to discuss these issues in greater detail. She is reachable via e-mail at jdexter@nhcouncil.org.

Sincerely,



Randall L. Rutta
Chief Executive Officer