



# Chronic Care Policy Alliance

State Advocates  
Working Together  
to Bridge the Gaps  
in Chronic Care

July 18, 2025

Senate Committee on Health, Education, Labor, and Pensions  
428 Senate Dirksen Office Building  
Washington DC, 20510

Dear Chair, Ranking Member, and Members of the Senate HELP Committee:

On behalf of the [Chronic Care Policy Alliance \(CCPA\)](#), I write to recognize and commend Congress for the actions taken to improve healthcare access and affordability for Americans living with chronic conditions.

CCPA is a national network of state and regional advocacy organizations united by a shared mission to improve the lives of those living with chronic conditions. Through policy advancements, coalition building, and advocacy efforts, CCPA amplifies the voices of those managing complex healthcare needs and works to ensure consistent access to affordable treatments and high-quality care.

In the United States, chronic diseases are the leading causes of death and disability, [accounting for 90% of healthcare expenditures](#). Six in ten Americans [are managing at least one chronic condition](#), often [facing financial stress](#) that forces them to cut corners on essential health management. Congress can make a meaningful impact by prioritizing patient-centered policies that improve access to quality, affordable healthcare for individuals with chronic illnesses.

Midway through 2025, we are encouraged by early progress in key areas, including medication pricing transparency, affirming the policy of protecting patients with pre-existing conditions, FDA reforms to accelerate access to generics and biosimilars, and efforts to expose the harmful practices of Pharmacy Benefit Managers (PBMs).

We applaud Congress for elevating policy priorities that reflect our longstanding advocacy, including:

- **Ensuring all policies move patients toward better care.** Congress must pursue policies that directly reduce costs for patients, support the development of new and innovative treatments, and access to healthcare providers.

- **Including patient-focused policies in Medicare Part D** like the Inflation Reduction Act's (IRA) \$2,000 out-of-pocket cap, \$35 monthly cap on insulin, eliminating cost-sharing for vaccines, and ensuring co-pays are low and affordable for patients, demonstrate how policymakers can put patients first.
- **Addressing the IRA "Pill Penalty"** through support for the Ensuring Pathways to Innovative Cures (EPIC) Act (H.R.1492/S.832), which helps protect small-molecule drug innovation critical to cancer, rare disease, and mental health patients.
- **Improving PBM Transparency and Accountability**, with growing momentum to curb these opaque PBM practices and expand transparency to mitigate the harm they cause to both community pharmacies and patients.
- **Expanding Patient Access** through FDA modernization efforts that lower barriers to more affordable treatment options, including support for insulin affordability initiatives.
- **Addressing Obesity as a Chronic Disease** through support for the Treat and Reduce Obesity Act (TROA) which would expand Medicare coverage and allow for a multidisciplinary approach to treatment.
- **Protecting Innovation for Rare Diseases** by passing the Optimizing Research Progress Hope and New Cures (ORPHAN Cures) Act (H.R. 946.) as part of the recent reconciliation package, Congress has ensured that the IRA does not impede research or delay access to new treatments for individuals with rare and chronic conditions.

We urge continued action throughout the remainder of the year to advance additional reforms in the following areas:

### 1. Restore the 340B Program's Focus on Vulnerable Communities

The [340B Program](#), established more than 30 years ago, has been instrumental in enabling safety-net providers to deliver affordable medications and healthcare services to underserved populations. However, its rapid expansion and lack of transparency have undermined its original mission.

The existence of approximately [34,000 contract pharmacies](#) – [more than 70% of which are owned by large corporations](#) – has shifted focus away from its intended beneficiaries, leaving [patients to unfairly bear the brunt of the cost](#).

Congress can restore the integrity of the 340B program by:

- **Ensuring 340b Discounts Are Serving Vulnerable Patients:** Requiring hospitals and pharmacies to ensure patients see benefits from 340B funds.

- ***Prioritizing Safety Net Providers and Patient Access:*** Ensuring grantees can continue their valuable mission while incentivizing 340B entities to maintain facilities close to underserved patients.
- ***Improving Transparency And Accountability While Protecting the 340B Program from Abuse:*** Protecting the program from abuse by entities, like PBMs, who seem to have been [unfairly profiting from the program for years](#). New transparency measures should prevent misuse and ensure accountability for all covered entities and partners in the program.

## 2. Do More to Hold Pharmacy Benefit Managers (PBMs) Accountable

PBMs play a significant role in the healthcare system, but their predatory practices often increase costs and reduce access for patients. Despite [stalled progress in the 118th Congress](#), PBM reform remains critical to addressing systemic inequities in prescription drug pricing.

By driving up costs through rebate manipulation and restrictive formularies, PBMs create barriers to essential medications, disproportionately affecting patients with chronic illnesses.

Just last year, the [Federal Trade Commission \(FTC\) released a scathing review](#), highlighting how [PBMs inflate the costs of drugs](#), harming independent pharmacies and patients alike. Reforming PBM practices is essential to creating a healthcare system that prioritizes patients and ensures access to affordable, life-saving treatments.

Congress can cut waste in the healthcare industry by:

- ***Ensuring Transparency in Pricing and Rebates:*** Greater transparency and disclosures of rebates and pricing structures will allow for oversight and ensure patients directly benefit from negotiated discounts.
- ***Implementing Patient-Centered Practices:*** Reforms should ensure decisions prioritize clinical effectiveness and individual patient needs—not profit margins.
- ***Requiring Oversight and Accountability:*** Strong enforcement mechanisms are needed to prevent abusive practices and ensure PBMs act in the best interest of patients and health plans.

## 3. Ensure the IRA Protects Innovation and Lowers Costs

The implementation of the Medicare Drug Price Negotiation Program (MDPNP) has only loosely included patient input and fails to address the glaring, unintended consequences. CCPA encourages Congress to take a collaborative, patient-first approach and focus on reforms that will more directly benefit patients.

Additionally, the IRA's so-called "pill penalty" presents a significant threat to innovation, particularly in oncology and rare disease research and development. This provision disincentivizes investment in single-source drug innovations – often the backbone of groundbreaking treatments for complex and life-threatening diseases.

The United States stands as [a global leader in biotechnology](#) and remains at the forefront of drug innovation. The ability to fund life-saving treatments is essential for maintaining this position of leadership. Without reform, the "pill penalty" risks stalling progress in medical research and limiting future treatment options for patients with chronic and rare conditions.

Congress can improve the negotiation program and ensure it benefits patients by:

- ***Ensuring A Level Playing Field for the Innovation of Medications:*** Passing the Ensuring Pathways to Innovative Cures (EPIC) Act (H.R.1492/S.832) to equalize eligibility timelines, resolve the "pill penalty," and foster innovation for patients.
- ***Implementing Oversight Requirements and Patient Protections:*** Protecting patient access by ensuring negotiation does not delay access to therapies, particularly those for rare and chronic conditions.

#### **4. Improve Early Cancer Detection and Care for Chronic Conditions**

Early screening and consistent access to regular care are critical to preventing and managing chronic diseases, which account for [90% of the \\$4.1 trillion in annual U.S. healthcare costs](#). Conditions like heart disease, diabetes, and cancer are far more treatable, and even preventable, when detected early.

Many Americans live in healthcare deserts, areas with limited or no access to essential healthcare services. Expanding access to early screening and preventive care is one of the most effective ways to improve health outcomes and reduce disparities.

Congress can improve access to care by:

- ***Accelerating Early Screenings for Cancer:*** Diagnosing cancer early saves lives. The Medicare Multi-Cancer Early Detection Screening Coverage Act (H.R.842/S.339) would provide patients in Medicare access to FDA-approved multi-cancer early detection screening tests.
- ***Broaden Access Care through Pharmacies:*** Pharmacists are the most accessible health providers for many Americans. [Nine in 10 Americans](#) live within five miles of a pharmacy, and patients visit their community pharmacist approximately [twice as frequently](#) as they visit primary care physicians. The Ensuring Community Access to pharmacist Services Act

(ECAPS) (H.R.3164) would allow for Medicare coverage of pharmacist-administered tests and treatments for common respiratory illnesses.

- **Ensuring Access to Preventative Care, Including Vaccines:** Identifying health risks early and protecting against serious infectious diseases, reduce hospitalizations, lower healthcare costs, and save lives.
- **Make Permanent Telehealth Flexibilities:** Telehealth flexibilities, initially implemented during the COVID-19 pandemic, have shown significant benefits in expanding access to care, especially for rural and underserved populations. These flexibilities have also improved efficiency and reduced costs for both patients and providers. Telehealth flexibilities must be made permanent.

At the same time, we urge Congress to avoid policy directions that could undermine access, innovation, or patient safety. In particular:

- **Reconsider Actions That Would Reduce Coverage or Access to Vaccinations.** Vaccines have played an instrumental role in transforming life, public health, and shaping history. To say their impact has been profound is an understatement. Through disease prevention and national well-being, vaccines have changed lives and changed the world for the better. Communication mishandling during the pandemic and continued confusion of the positive impact of vaccines has undermined their confidence and use. This is already leading to a resurgence in diseases we once thought eradicated in the U.S. While you continue to reexamine various vaccination protocols, we encourage the use of vaccine and the support of those making the vaccines to maintain the health and protect the people from transmissible diseases which have no cure.
- **Oppose Foreign Reference Pricing and “Most Favored Nation” (MFN) Models** in Medicaid or Medicare. These frameworks, modeled after international systems, may lower government spending, but they do so at the expense of timely access to innovative therapies. Such policies threaten critical health programs, outsource U.S. health decisions to foreign countries, and rely on discriminatory value frameworks such as Quality-Adjusted Life Years (QALYs). Avoid Broad-Based Price Setting Mechanisms that disconnect payment from clinical value and patient outcomes.

Price caps and centralized government price-setting, especially when based on foreign models, which have been shown to result in reduced access to breakthrough therapies and stifled investment in innovation.

- **Reject Drug Importation Proposals That Sidestep FDA Safety Protocols.** While well-intentioned, importation policies create significant risks of counterfeit or substandard medications and may jeopardize supply chains in both the U.S. and abroad.
- **Avoid Policies That Risk Coverage Loss.** We are concerned that misguided policies could unintentionally limit access to critical health coverage, particularly for individuals who rely on safety-net programs. Proposals that reduce funding for Medicaid or Medicare, shorten enrollment periods, or introduce complex eligibility requirements may create barriers to care and increase the risk of coverage loss. We encourage policymakers to carefully consider the impact of such measures and prioritize policies that support stable, continuous access to coverage.

We remain committed to working alongside Congress to build a more equitable, transparent, and patient-centered healthcare system. CCPA offers its partnership to help craft and implement reforms that reduce costs without compromising care, access, safety, or innovation.

Thank you for your leadership and ongoing commitment to the health and well-being of Americans with chronic conditions. We look forward to continuing collaboration throughout the year.

Sincerely,



**Elizabeth Helms**

Founder & Director

Chronic Care Policy Alliance