

November 4, 2025

Reject Price Setting Policies that Compromise Patient Access to Medications

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

On behalf of the **Ensuring Access through Collaborative Health (EACH) and Patient Inclusion Council (PIC)**, we write to urge Congress to reject government drug price-setting proposals that risk limiting access to essential therapies while failing to address the real causes of patient unaffordability. Our coalition supports reforms that reduce what patients actually pay for prescription medications, without discouraging medical innovation or narrowing treatment choices.

The Risks of Government Price-Setting

Proposals that impose government-set price ceilings or benchmark U.S. prices to foreign markets threaten to undermine patient access and the long-term development of new treatments. Centralized price controls may appear to lower costs on paper but often lead to **restricted formularies, longer approval timelines, and fewer new therapies reaching patients.**

Policies that target price tags rather than these structural barriers risk worsening the problem they aim to solve. This approach severs drug payment from clinical outcomes and patient value and risks discouraging investment in next-generation therapies. Arbitrary price caps or centralized rate-setting mechanisms are blunt tools that ignore disease complexity and patient diversity.

Healthcare reforms must enhance, not hinder, the ability of physicians and patients to select treatments based on medical need.

Ensure the Medicare Negotiation Program Does Not Harm Patients

The Medicare Negotiation Program authorized by the Inflation Reduction Act remains to be an untested and unknown mechanism. As we approach the implementation of the first round of Maximum Fair Prices (MFPs), we urge Congress to implement patient safeguards and reforms that will ensure that patient access to existing and future cures is not compromised:

- Implement clear patient-access safeguards to prevent payers from implementing new and potentially harmful utilization management measures for any drugs in classes subject to MFP.
- Advance the Ensuring Pathways to Innovative Cures (EPIC) Act (H.R.1492/S.832), which would equalize eligibility timelines for all drugs, eliminate the “pill penalty,” and sustain investment in small-molecule treatments.

- Support the Protecting Patient Access to Cancer and Complex Therapies Act (H.R.4299), ensuring rebate obligations within the Medicare negotiation process are implemented in ways that safeguard coverage for complex conditions.
- Reject expansion of the negotiation program before the program's real-world impact is understood.

Reject “Most Favored Nation” and Foreign Reference Pricing Models

Congress should firmly oppose efforts to import foreign reference pricing into the American drug market. These policies could compromise both patient access and ongoing medical innovation by importing foreign systems that do not reflect the same standards of care or innovation ecosystem:

- Oppose proposals to tether U.S. prices to those in foreign countries, including the Fair Prescription Drug Prices for Americans Act (S.1587/H.R.3375) and the Global Fairness in Drug Pricing Act (H.R.3493). These and similar bills would set artificial ceilings based on international markets where patients routinely face restricted formularies, slower access to new therapies, and reduced treatment choice.
- Urge against executive actions or regulations that implement “Most Favored Nation” models or foreign reference pricing. Such unilateral efforts would bypass the legislative process and risk destabilizing patient access nationwide.

Enact Reforms that Address Patient-Identified Obstacles

Our [Patient Experience Survey](#) shows that affordability challenges rarely stem from list prices alone:

- 20% of patients paying only \$0–\$10 monthly still found their medicines unaffordable due to insurance restrictions, cumulative costs, or accumulators.
- 100% of patients who discontinued a treatment for “affordability reasons” did so because of insurance or coverage barriers, not drug price.
- 71% of specialty-drug patients with copay assistance said their treatment was affordable, compared to only 38% without such assistance.

To meaningfully reduce what patients pay, we encourage Congress to prioritize reforms rooted in patient experience:

- **Hold Pharmacy Benefit Managers Accountable**
 - Prohibit spread pricing and require full disclosure of reimbursement and rebates.
 - Replace percentage-based PBM compensation with flat-fee service models.
 - Ensure negotiated discounts and rebates are passed to patients.
 - Require full transparency of PBM contracts, rebate flows, and formulary design.
- **Cap and Smooth Patient Out-of-Pocket Costs**
 - Implement annual limits on patient prescription spending.

- o Adopt payment-smoothing mechanisms to distribute costs evenly over the year.
- **Expand and Protect Assistance Programs**
 - o Preserve manufacturer copay assistance.
 - o Ban accumulator and maximizer programs that nullify patient aid.
 - o Strengthen federal assistance for low-income or under-insured patients.
 - o Create a centralized clearinghouse to help patients obtain financial support.

Conclusion

We urge Congress to reject unproven or imported price-control schemes and focus instead on **patient-centered affordability reforms** that address real-world barriers to care. Policies grounded in patient experience, not government price ceilings, will deliver lasting relief and preserve access to innovation for future generations.

We thank you for your commitment to drug affordability and stand ready to work with you to design reforms that prioritize patient access and real affordability solutions.

Sincerely,
National Scleroderma Foundation