

PATIENTS FOR AFFORDABLE DRUGS NOW™

March 5, 2018

Members of the Connecticut House of Representatives Insurance and Real Estate Committee,

Thank you for your work to lower drug prices. We are pleased to offer comments and support for HB 5384.

Patients For Affordable Drugs NOW is a bipartisan group focused exclusively on policies to lower prescription drug prices. To maintain our independence, we do not accept funding from any organizations that profit from the development or distribution of prescription drugs. We are about patients first, last, and always.

We have heard from over 350 Connecticut patients struggling under high drug prices. Greta Stifel from Berlin suffers from a rare cancer called neuroendocrine tumor carcinoid cancer. She told us, “my monthly tab for my drugs for my cancer treatment is \$25,000. I take hours out of my day fighting with the drug companies and my insurance plan to cover these exorbitant costs to keep me alive. I am so sick and tired of this; something must be done.” On the behalf of Greta and the other patients in Connecticut, we are pleased that the legislature has made addressing high drug prices a priority.

House Bill 5384 is a clear step in the right direction, however, we believe it could do more to help people.

First, we agree taxpayers deserve more transparency from pharmacy benefits managers (PBMs). Such provisions are helpful in understanding the impact of PBMs and how their rebates and discounts do and do not benefit patients.

But the drug pricing issue cannot be solved if high list prices set by the pharmaceutical manufacturers are not addressed. We encourage members to strengthen House Bill 5384 with the following changes:

1. Manufacturers should be required to report when the wholesale acquisition cost (WAC) increases by more than double the rate of inflation in the state.
2. Tying reporting to increases in premiums does not account for increases that are absorbed in higher copays/coinsurances and other out of pocket costs. Patients are affected by the high costs in many ways, not just premiums.
3. All prescription drugs, not just the 10 most expensive ones, that hit the double rate of inflation should be required to report information.
4. The content of the reporting should be comprehensive and include:
 - a. Research and development for the drug

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- b. Manufacturing costs for the drug
- c. Distribution costs for the drug
- d. Marketing and advertising costs for the drug
- e. Length of time the drug has been on the market
- f. US pricing history of the last 5 years
- g. Price of the drug in 5 other OECD countries

This bill lacks a form of accountability for the drug manufacturers. At a minimum, we recommend that the bill call for a penalty on pharmaceutical companies that unjustifiably increase prices by more than double inflation. Ultimately, we think it is vital that the state set up a system for ensuring price gouging cannot occur. Maryland, for example, is considering legislation giving authority to the Attorney General to hold companies accountable for large price increases.

Patients in Connecticut are suffering under drug prices. They are making impossible decisions about cutting doses in half and skipping meals due to high drug prices. Patients For Affordable Drugs NOW urges you to address prescription drug pricing along the entire pipeline. Connecticut patients are counting on you.

Sincerely,

David Mitchell
Founder
Patients For Affordable Drugs NOW