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Comment on the draft guidance and recommendations put forth by the Connecticut Health Cost Commission (the Commission) on the topic of controlling prescription drug prices

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Public Citizen is a national, 501(c)3 nonprofit advocacy organization founded in 1971 to represent consumer interests in Congress, the executive branch, and the courts. We have more than 400,00 members and supporters, including nearly 20,000 in the state of Connecticut. Public Citizen's Access to Medicines Program works with partners worldwide to improve health outcomes by lowering the price of medicines through legal and legislative means.

The United States spends more on prescription drugs than any other country. In 2015 alone, the Department of Health and Human Services estimated that the U.S. spent $457 billion.[1] The federal government reserves only very limited powers to negotiate lower drug prices, despite the fact that Medicare Part D alone represents approximately 7% of total global prescription drug spending.[2]

Nearly one in five American adults aged 55 and older report skipping doses or not filling a prescription within the last 12 months.[3] This is unacceptable. Advance notice, public scrutiny, and review of the impact of high medicine prices are important first steps toward controlling drug prices.

The Connecticut Health Cost Commission's recommendations include many laudable provisions that go after high prescription drug prices. In particular, Public Citizen supports the first of the Commission's priority recommendations: to "Identify and investigate potential abuse in the pricing of both brand and generic drugs by creating a new Drug Review Board (DRB) and empowering it to investigate drug pricing decisions by manufacturers, both launch prices and price increases, with the purpose of determining if the prices are sufficiently unjustified in comparison to market norms and/or clinical value that it puts patient health at risk and therefore warrants referral to the Attorney General to pursue the manufacturer for a potential unfair trade practice violation."

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[1] U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. *Observations on Trends in Prescription Drug Spending.* March 2016: https://aspe.hhs.gov/pdf-report/observations-trends-prescription-drug-spending

[2] This ratio was calculated using IMS Health data for audited and unaudited markets: http://www.imshealth.com/deployedfiles/imshealth/Global/Content/Corporate/Press%20Room/Top_line_dat a/2014/World%20figures%202014.pdf

[3] Steven G Morgan and Lee, A. *Cost-related non-adherence to prescribed medicines among older adults: a cross-sectional analysis of a survey in 11 developed countries.* BMJ Open. 2017; 7(1): e014287. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5293866/

Public Citizen applauds the Commission's inclusion of both brand and generic drugs and investigations that look at high launch prices and price increases. As expressed in a report by Yale University, National Physician's Alliance, and Connecticut Universal Healthcare Foundation titled, "Curbing Unfair Drug Prices" and elsewhere,[4] targeting both generic and brand name prescription drug prices is necessary to capture information on all unjustified price increases. Maryland passed helpful legislation in 2017 to take action against generic pharmaceutical manufacturers for large price increases. The legislation was limited in scope by excluding brand-name pharmaceuticals. Connecticut's approach will target price increases regardless of the manufacturer, which is an improvement.

Taking on high launch prices is a key proposal for the Drug Review Board worth recognizing. Connecticut-based Alexion Pharmaceuticals launched its product, Soliris, in 2010 with a price tag of $409,000.[5] At the time, this was the highest priced medicine in the world. Over the last eight years the highest price has been pushed ever higher by therapies for rare disease. On January 4, 2018, the first viral gene therapy to receive FDA approval in the United States entered the market with a $850,000 price tag to treat a disorder which can result in blindness for patients.[6] The Commission's recommendation that launch prices be included in the DRB's scope of work is essential to curbing these abusive prices and slowing the growth of health care costs for the state.

Public Citizen also applauds the Commission's inclusion of consumer voices on the Drug Review Board. Consumer voices are pivotal for understanding the real-world consequences of high launch prices and annual price increases. In addition, Public Citizen encourages the inclusion of a conflict-of-interest policy for the DRB to ensure that the board remains free and independent of the massive influence of pharmaceutical industry trade groups and lobbyists who would seek to relax the rules over time. Those same trade organizations have spent millions in the last two years alone to defeat initiatives designed to put small limitations on drug prices in Ohio and California,[7] and are currently party to multiple lawsuits trying to overturn legislation.

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[4] Aaron Berman, Lee T., Pan, A., Rizvi, Z., and Thomas, A. *Curbing Unfair Drug Prices: A Primer for States.* Global Health Justice Partnership Policy Paper. August 2017. https://law.yale.edu/system/files/area/center/ghjp/documents/curbing_unfair_drug_prices-policy_paper-080717.pdf

[5] Ellie Dolgin. *World's most expensive drug receives second approval for deadly blood disease.* Nature Medicine. Sept 2011. http://blogs.nature.com/spoonful/2011/09/soliris.html

[6] Adam Feuerstein and Garde, D. *Spark prices its gene therapy as most expensive U.S. medicine — but with plans to ease cost concerns.* STAT Business. January 2018. https://www.statnews.com/2018/01/03/spark-gene-therapy-price/

[7] *See e.g.:* Rick Claypool. *Corporate Campaign War Chests Average 10-to-1 Advantage in State Ballot Race.* HuffPo. September 2016. https://www.huffingtonpost.com/rick-claypool/corporate-campaign-war-ch_b_12246506.html; Eric Sagonowsky. *'Dark money' and drugs: Ohio pricing activists cry foul over secret donors.* Fierce Pharma. August 2017. https://www.fiercepharma.com/pharma/ohio-drug-pricing-activists-file-complaint-over-dark-money-politics

Key to enforcing the findings of the DRB is the recommendation point (iii) from the draft guidance. The Commission lays out the need for legislation to give further authority to the Attorney General of Connecticut toward "pursu[ing] unfair trade practice or price gouging cases against pharmaceutical manufacturers" when the DRB finds them to have imposed unjustified increases or launch prices. Public Citizen encourages the Commission to work with consumer advocacy organizations in Connecticut as well as other key stakeholders to build out strong legislative authority and pass it promptly to ensure the DRB has the ability to enforce action.

Public Citizen also supports administrative recommendation (a), which would provide greater transparency of prescription drug prices in Connecticut. This recommendation requires more granular information be reported to the Connecticut Insurance Department (CID) and for the impact of price increases to be compiled into a public report.

Transparency measures such as the reports described in this recommendation and California's recently passed SB 17 are a good start to understanding and addressing the problems underlying high drug prices. Recent polls show that 86% Of Americans support transparency measures that require drug companies release information on how they set drug prices.[8]

Prescription drug prices are a leading driver of healthcare costs, yet the information on how these prices are set are close-held by corporations and rarely reported to the public. The requirements outlined in the draft guidance will provide greater transparency for prescription drug costs by requiring advance notice of price hikes to be reported to CID. The required reporting from insurers is also helpful in determining the larger impact on consumer's costs for premiums, co-payments, and co-insurance with high priced medicines.

Public Citizen applauds the detail sought by the recommendation, including the reporting of gross and net spending in order to reflect the impact of rebates on the system.

In all, the recommendations of the Commission are promising examples of innovative state-level policy to address high drug prices. While substantial reform is needed at the federal level to tackle the abuse of patents and other government-granted monopolies, the state of Connecticut is well poised to enact solutions that will increase the public's understanding of the impact of high drug prices. The recommendations are a promising step towards ensuring that drug corporations' unjust price increases and launch prices are put into check in the state of Connecticut.

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[8] *See:* Kaiser Health Poll Tracking, Key Findings September 2016: https://www.kff.org/health-reform/report/kaiser-health-tracking-poll-september-2016/