Q&A - Illinois Prescription Drug Affordability Board

1. **What is a Prescription Drug Affordability Board (PDAB)?**
    - The PDAB is an independent body that reviews affordability challenges for Illinois consumers and has the ability to set upper payment limits on prescriptions. The board holds the pharmaceutical industry accountable for the prices it sets so Illinois residents can afford their life-saving medications.
    - It would be made up of nonpartisan leaders in healthcare economics, health policy, and clinical medicine with no personal or financial stake in the pharmaceutical industry.
    - A broad-based nonpartisan coalition of nurses, doctors, public health advocates and more are urging lawmakers to create a PDAB to lower the cost of prescription drugs and be a voice for consumers.

2. **Who would be on the Prescription Drug Affordability Board?**
    - The PDAB would be made up of nonpartisan leaders in healthcare economics, health policy, and clinical medicine with no personal or financial stake in the pharmaceutical industry appointed by the governor.
    - Their sole purpose is to check the pharmaceutical industry's power by making prescription drugs more affordable and will use a data-based approach to set limits on the most expensive drugs.

3. **Does the pharmaceutical industry support this type of board?**
    - The pharmaceutical industry opposes any regulation that could affect their profits – and patients pay the price. That's why small business owners, faith leaders, healthcare professionals, public health advocates, and patients demanding accountability are urging lawmakers to do more to rein in the high cost of prescription drugs in Illinois.

4. **What states have enacted PDABs?**
    - Colorado, Maine, Maryland, Minnesota, New Hampshire, Washington, Oregon
    - Michigan, New Jersey, New Mexico, Virginia, and Pennsylvania are working to create similar boards as well.

5. **Would these bills stifle innovation in the pharmaceutical industry or do we run the risk of manufacturers pulling out of Illinois if these bills pass?**
    - That's a scare tactic by Big Pharma.
    - Innovation for new treatments will continue because it is supported by taxpayers through federal grants and because it opens new markets that benefit the pharmaceutical companies themselves.
    - Illinois lawmakers should vote to create a PDAB because it will use established strategies that are based on rate-setting throughout the healthcare industry that are already underway in other states.
    - A PDAB will help lower the cost of prescription drugs for Illinois residents and bring much-needed accountability, oversight, and transparency to balance out the enormous power of big pharmaceutical companies, so they are more responsive to consumers.

6. **Isn't there already enough regulation to help with the high cost of prescription drugs?**
    - Too many people can't afford their prescriptions or must choose between buying groceries and paying utility bills so they can get insulin and other life-saving medications they need.
    - Altarum Healthcare Value Hub found that 54% of Illinois residents surveyed said they are "worried" or "very worried" about affording the cost of prescription drugs.
    - The same survey found that 28% of Illinois adults reported that they cut pills in half or skipped doses of medicine due to concerns about cost. 86% of Illinoisans endorsed "creating a Prescription Drug Affordability Board to examine the evidence and establish acceptable costs for drugs"
    - Pharmaceutical companies have more than 1,800 lobbyists and is one of the most powerful special interests making campaign contributions and wielding influence to protect its golden goose and avoid oversight.
    - Nearly three in 10 Americans have skipped prescribed medicine because of the cost while the biggest pharmaceutical company more than tripled its profits over the last two years.
    - People of color are more likely to be uninsured and are therefore disproportionately hit hardest by ongoing rises in the list prices for prescription drugs. Without insurance they are more likely to pay the full price of prescription drugs as the majority of prescription drug assistance programs support those who have insurance. Even when Black and Hispanic Americans do have health insurance, they are more likely to ration their medications because of the cost and if they have an illness are more likely to use fewer medications because of their cost than white Americans with the same illness. Communities of color generally experience higher rates of illnesses like diabetes, asthma and more, having greater need for prescription medication. What we are doing right no is not working to support all Illinoisans and Americans.

7. **What types of drugs will the PDAB establish upper payment limits for?**
    - That would be up to the independent board to decide using a data-based approach to set limits on the most expensive drugs for Illinois consumers.
    - The types of drugs that will likely be considered might include drugs for cancer, autoimmune diseases, and diabetes.

8. **Aren't middlemen like pharmacy benefit managers (PBMs) to blame for high prices?**
    - Upper Payment Limits would affect every entity in the supply chain – including PBMs.
    - PBM's can also play a role in the high cost of prescription drugs, but this particular fix will target the control that the pharmaceutical industry has over market prices.

9. **Won't this kill research jobs and innovation — and possibly make some drugs unavailable in Illinois?**
    - In fact, the profit margins of the big drug companies are almost three times the average profit margin of the other industries in the United States.
    - There are many studies of the amount of money it costs to bring a drug to market and studies that show that those costs are consistently less than the revenue a company will

receive from the product, even with a UPL. These studies have been conducted by the World Health Organization, Congress, and Harvard.

- Taxpayers also support research and development with millions of dollars at the federal level every year.
- So, for pharmaceutical companies to say it will stifle research and innovation, or that they will have to scale back jobs or stop selling certain drugs is simply a scare tactic.
- An upper payment limit is intended to *increase* sales by removing cost barriers for patients. This also means a UPL increases access to the market for the product -- a goal of every drug company. There is no reason to boycott Illinois other than that a UPL violates a company's sense of entitlement.
- All US companies operate in Europe, Canada, and Japan where every country directly manages the price of drugs -- either launch price, reimbursement, prices increases or all three. No drug company boycotts these countries, no drug company has gone bankrupt in these countries. In fact, US companies increasingly set up R&D and manufacturing facilities in all these countries to appease governments and create drug distribution efficiencies.
- According to Small Business for America's Future, 75% of small business owners providing health coverage to employees say their healthcare costs have increased over the last four years and 48% have seen significant increases of 7% or more
- Nearly one in three small business owners providing health coverage to employees have considered dropping it—the vast majority (78%) because costs are high
- More than a third of small businesses providing healthcare coverage to employees have held off on hiring a new employee as a result of their rising healthcare costs. A PDAB would support small businesses.

10. What happens if a drug manufacturer decides to boycott IL because of an upper payment limit?

- Drug manufacturers have continued sales when they face federally required discounts. For example, pharma sells to the Veteran's Administration at prices below the discounts that are federally mandated because each company wants the sales and wants a good position on the VA formulary. And the company does not want to cede market share to a competitor.
- This is simply a scare tactic, but there are a lot of reasons why that wouldn't happen. Drugs are sold through many wholesalers who do business across the country so it would be logistically difficult to discontinue distribution to one particular state.
- Pharmaceutical manufacturers already sell the same drug to different purchasers around the country at many different discounts, rebates and rates with the goal of remaining competitive and expanding their market share.
- Boycotting an entire state would not only wipe out a large part of their market share and open the door to their competition, it would be a major blow to their reputation.
- The purpose of the UPL is to improve affordability, which will potentially expand their sales and market share.
- Drug manufacturers participate in all non-US markets where rates are set on drugs in some way – at a profit

- IL has a consumer protection law that requires any product marketed in the state to be sold

11. Can this really work? Isn't it unconstitutional?

- Seven states have already established a PDAB to set upper payment price limits on the most expensive prescription drugs and other states are in the process of creating their own independent boards.
- The Supreme Court has ruled in favor of rate setting in healthcare

12. Won't this interfere with the doctor/patient relationship?

- That's completely false.
- In no way does a patient paying less for their prescription drugs affect their relationship with their doctor.
- That's why nurses, doctors, public health advocates and patients demanding accountability are urging lawmakers to do more to rein in the high cost of prescription drugs in Illinois.
- The high cost of drugs today stands between patients and doctors because patients can't get the treatments that their doctors prescribe.

13. Should specialty drugs be exempted from PDAB purview?

- No. A specialty drug is simply a drug that costs a lot of money -- literally.
- In Medicare, it is a drug that costs more than about $900/month -- a cost that is not unusual in today's market.
- The affordability of specialty drugs is a problem because patients often have very high cost sharing for these drugs.
- Medicare allows Part D patient cost share to be 25-30% of the cost of a specialty drug. Medicare rules are a benchmark for pharmacy benefits in the US more generally.

14. Should orphan drugs be exempted from PDAB purview?

- No. The new industry business model brings products to market with orphan drug status (treats a disease affecting less than 200000 people) and then builds the market from there.
- Orphan drug status can confer expedited FDA review, provide funding for clinical trials, eliminate FDA licensing fees, exempt a drug from the 340B deep discount sales program, prohibit another company from developing a drug to treat the disease (stronger protection than a patent) and more.
- With all these benefits and the potential for global sales worth billions of dollars, orphan drugs are potentially less financially risky than non-orphan drugs.

15. Why does Illinois need a PDAB if we have Medicare negotiation? Will UPLs be set at the Medicare rate?

- Our legislation would leverage federal drug price negotiations by automatically adopting any Maximum Fair Prices (MFPs) negotiated by Medicare as upper payment limits. This would expand the benefits of negotiated drug prices for those on Medicare to the other

62% of Illinoisans not on Medicare. Benefits will also expand as Medicare negotiates more drug prices in future years.

- The Medicare negotiation program is limited to drugs that have been on the market a long time and have no generic or biosimilar competition. A PDAB does not have that limitation.

16. **In other states, they have a list of triggers and criteria when you should start investigating a drug, what are the triggers for this legislation?**
    - PDAB works because it is expert driven and data driven.
    - The legislation directs the expert board to select the drugs to review with input from the stakeholder council based on any of the listed criteria, which include wholesale acquisition costs above certain threshold amounts, wholesale acquisition costs that increased faster than certain thresholds, and other affordability challenges for patients and health care systems brought to the board's attention.

17. **When is the earliest Illinoisans can expect relief for costs on medications?**
    - For the benefit of our constituents, we are committed to a successful and transparent process that considers all the important information about prescription drug costs here in Illinois.
    - Once the legislation is signed and members appointed, it could take several months to do their initial work.
    - That is why it's so important that we move this legislation without any unnecessary delays. And once it is started, the work of the board will continue and grow, with the benefits multiplying.

18. **What is the enforcement power of the PDAB? Do they hold any punitive powers?**
    - Once an upper payment limit is in effect, it is virtually self-enforcing because health insurers and employer plans will limit pharmacy reimbursements to no more than the upper payment limit so there is no incentive for pharmacies to buy a product costing more than the payment limit.
    - In addition, the legislation gives the attorney general authority to commence civil actions against anyone who violates the upper payment limit provision.

19. **Will patients see savings, or will health insurance companies continue to mark up the drugs?**
    - Uninsured patients and insured patients who have coinsurance or are within their deductible period will see reduced out-of-pocket costs for drugs that have a UPL immediately.
    - Patients who have set copays and have prescription expenses above their deductible will not see reduced out-of-pocket costs immediately, but the lower drug costs with a UPL will help health plans constrain growth in premiums over time.
    - Depending on the drug, a plan may move a drug to a lower copay tier. This could also result from consumer pressure, employer plan decisions and market competition among commercial health plans.

- All health plans, including ERISA plans, must comply with Medical Loss Ratio Federal rules. The law limits the amount of profit a plan can make relative to spending on medical care and quality improvement. The requirement came from the Affordable Care Act. It is enforced by state insurance regulators, the federal Department of Labor (for ERISA plans), and federal HHS (for Medicare and Medicaid plans and Exchange Market plans).