Prescription Drug Affordability Board threatens development of rare-disease drugs in Illinois

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By Laura Bonnell

Families grappling with the challenges of a loved one diagnosed with incurable diseases have more than enough to handle in their daily lives begging the question — why would Illinois lawmakers knowingly make their lives worse?

While it may sound appealing for lawmakers to promote bills that claim to reduce prescription drug costs and put money back in patients' pockets, the legislation to establish a Prescription Drug Affordability Board (PDAB) will likely do the opposite. Instead

of making medications more accessible, it risks undermining the research and development necessary for new treatments that patients rely on.

Proposals to implement Upper Payment Limits through the PDAB could have dire consequences. Recent findings from the Partnership to Fight Chronic Disease reveal that these measures may actually increase costs and restrict access to critical medicines.

77% of health plan payers believe UPLs would disrupt patient access to prescription drugs due to coverage changes and increased cost-sharing.

70% expect out-of-pocket costs for drugs to either rise or remain unchanged.

73% of respondents worry that UPLs could lead to shortages of essential medications.

Patients with chronic conditions, including those with rare diseases like cystic fibrosis, could find themselves facing higher costs and limited access to vital treatments. These are the challenges I face every day as the mother of two daughters, both diagnosed with cystic fibrosis as infants. Limits on medication coverage could deny them life-saving drugs now and in the future.

Poorly crafted policies at both the state and federal levels will disincentivize the investments necessary for research and development. This research is vital to the future of people like my daughters suffering from cystic fibrosis.

The U.S. has long been a leader in medication development, contributing more than half of all FDA-approved drugs between 2011 and 2020. However, government price-setting could threaten this legacy.

Bringing rare disease treatments to market is already an uphill battle, requiring years of research and billions of dollars in private sector investment. The Orphan Drug Act of 1983 has incentivized the development of orphan drugs — medications that treat only one specific condition — by protecting them from price controls. The Orphan Drug Act has been a game changer for people suffering from rare medical conditions.

Prescription Drug Affordability Boards are putting barriers in place to make it more difficult to access these orphan drugs and if enough states set up these boards — the incentives for drug manufacturers to continue to develop will all but disappear. There is no question that while well-intentioned, PDABs will make life harder for families like mine.

Lawmakers must take a thoughtful approach that does not jeopardize the future of innovative treatments and the hopes of countless patients. As we navigate these complex issues, it is crucial to consider the unintended consequences of policies like the PDAB and UPLs.

The health of countless individuals with chronic diseases depends on our ability to foster a healthcare environment that promotes innovation rather than stifles it. It's time for Illinois to prioritize the needs of patients over politics and ensure that access to essential medications remains a reality for families with real medical needs.

Laura Bonnell is a former radio news reporter in Detroit, now dedicated to raising awareness about cystic fibrosis through The Bonnell Foundation.