



Statement in Opposition to State Prescription Drug Affordability Board (PDAB) Legislation 2024

The Michael J. Fox Foundation for Parkinson's Research (MJFF) respectfully opposes legislation to establish or expand prescription drug affordability boards being considered by state legislatures. MJFF strongly supports access to affordable medications, but the long term and shortsighted consequences of this legislation will have harmful effects on the pipeline for new and innovated medications and life-saving therapies.

As the world's largest nonprofit funder of Parkinson's research, MJFF is dedicated to accelerating research and clinical breakthroughs that will improve therapeutics and treatments for the more than one million Americans living with PD. The Foundation pursues its goals through an aggressively funded, highly targeted research program coupled with active global engagement of scientists, Parkinson's patients, business leaders, clinical trial participants, donors, and volunteers. Since its inception in 2000, the Foundation has funded \$1.7 billion in research to date.¹

There are estimated to be more than 1 million Americans currently living with Parkinson's disease, with about 90,000 more diagnosed each year.² According to the Centers for Disease Control and Prevention, Parkinson's disease is the second most common and the fastest-growing neurological disorder in the world. Per year, the cost of PD nationally is at least \$58 billion and the direct and indirect costs to care for the approximately 1 million living with Parkinson's in the US and will rise to nearly \$80 billion by 2037.³

Regulating drug prices through an in-state government-appointed Board will upend a global system of research and development, manufacturing, and delivery that could lead to medication shortages and inappropriate use of utilization management (UM) such as step therapy and prior authorization. This can lead to delays in care with severe medical consequences when a person living with Parkinson's disease is unable to properly take their daily medications to ease symptoms. Patients living with Parkinson's are particularly susceptible to these kinds of insurance practices which do not align with clinical guidelines for what the provider deems is in the patient's best interest and can lead to disease worsening and put their health at unnecessary risk.⁴

Parkinson's patients already experience lengthy time in seeking and receiving their diagnosis, diminished ability to work and lost wages due to early retirement or career impact, and anxiety over costs to find proper treatment, especially in rural areas lacking neurological specialists.

This legislation does not address the adverse variables in state issued insurance benefit design nor seeks to reform predatory practices for other stakeholders in the determination of medication costs such as Pharmacy Benefit Managers (PBMs) and payers who dictate the terms of coverage and availability of access to medications.

For the reasons stated above and behalf of the thousands of researchers and millions of patients in the Parkinson's community, we urge you to reject this legislation.

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The Michael J. Fox Foundation for Parkinson's Research

¹ Michael J. Fox Foundation Announces Significant Breakthrough in Search for Parkinson's Biomarker, PR Newswire, April 2023, <https://www.prnewswire.com/news-releases/michael-j-fox-foundation-announces-significant-breakthrough-in-search-for-parkinsons-biomarker-301796029.html>.

² Destro, Christina, "New Study Shows the Incidence of Parkinson's in the U.S. is Nearly 50 Percent Higher than Previous Estimates." Dec. 2022, <https://www.michaeljfox.org/news/new-study-shows-incidence-parkinsons-us-nearly-50-percent-higher-previous-estimates>.

³ "The Economic Burden of Parkinson's Disease," Lewin Group, July 2019, <https://www.lewin.com/resources/publications/economic-burden-parkinsons.html>.

⁴ Nature Portfolio Journal: Care Access and Utilization Among Medicare Beneficiaries Living with Parkinson's Disease, 2023, <https://www.nature.com/articles/s41531-023-00523-y>.