



Tuesday, January 28, 2025
Oregon Senate Committee on Health Care
S.B. 718 – Establishes the Parkinson's Disease Registry (SUPPORT)

Good afternoon, Chair Patterson, Vice-Chair Hayden, and members of the committee. My name is Zach Hardy, and I am a State Government Relations Manager for The Michael J. Fox Foundation for Parkinson's Research (MJFF). Thank you for the opportunity to submit testimony in support of **S.B. 718**, which would establish a Parkinson's disease registry in Oregon.

MJFF was founded in 2000 and has been singularly dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today. To date, the MJFF has funded more than \$2 billion in research programs worldwide.

MJFF believes that establishing statewide registries for Parkinson's is a critical step in broadening our understanding of the disease. An Oregon Parkinson's disease registry will produce invaluable data for researchers while providing accurate statewide rates of incidence and prevalence.

A population-based registry is necessary to generate the data that will help researchers, treatment providers, and lawmakers determine the causes of the disease, evaluate the efficacy of treatment, uncover inequities in Parkinson's disease healthcare, and make decisions about the allocation of resources for prevention and treatment. This data will help identify high-risk groups, support patient contact studies, and serve as a valuable data resource to the research community.

By passing this legislation, Oregon would be joining California, Connecticut, Maryland, Massachusetts, Missouri, Nebraska, Nevada, New York, Ohio, South Carolina, Utah, Virginia, Washington, and West Virginia in collecting health information on Parkinson's disease.

According to the Centers for Disease Control and Prevention, Parkinson's disease is the second-most common and the fastest-growing neurological disease in the world. There are an estimated more than one million Americans currently living with Parkinson's disease, with about 90,000 more diagnosed each year.¹ The national cost associated with Parkinson's is approximately \$52 billion per year, with that cost projected to rise to nearly \$80 billion by 2037.²

The direct and indirect costs to care for the approximately 14,000 people, which we believe to be an undercount, living with Parkinson's in Oregon is estimated to be \$696 million per year. The discovery of

¹ "New Study Shows the Incidence of Parkinson's in the U.S. Is Nearly 50 Percent Higher than Previous Estimates." The Michael J. Fox Foundation for Parkinson's Research | Parkinson's Disease, 15 Dec. 2022, <https://www.michaeljfox.org/news/new-study-shows-incidence-parkinsons-us-nearly-50-percent-higher-previous-estimates>.

² "Study Finds Parkinson's \$52 Billion Economic Burden Double Previous Estimates." The Michael J. Fox Foundation for Parkinson's Research | Parkinson's Disease, 13 June 2019, <https://www.michaeljfox.org/news/study-finds-parkinsons-52-billion-economic-burden-double-previous-estimates>.

improved treatments and therapeutics, and ultimately a cure, for Parkinson's will not only change the lives of those living with Parkinson's and their families but would also be in the best economic interest of the state.

On behalf of The Michael J. Fox Foundation for Parkinson's Research and the community that we support, we urge this committee to support **S.B. 718**. Thank you for your consideration.

CONTACT:

Zach Hardy

State Government Relations Manager

The Michael J. Fox Foundation for Parkinson's Research

zhardy@michaeljfox.org — 202-638-4101, Ext. 225