# SB 718 STAFF MEASURE SUMMARY

## Senate Committee On Health Care

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| **Prepared By:** | Daniel Dietz, LPRO Analyst |
| **Sub-Referral To:** | Joint Committee On Ways and Means |
| **Meeting Dates:** | 1/28 |

### WHAT THE MEASURE DOES:

The measure creates a registry system to collect data on Parkinson’s disease in Oregon.

DETAILED SUMMARY:

- Defines Parkinson’s disease and Parkinsonisms, which includes related conditions that cause a combination of the movement abnormalities seen in Parkinson’s disease.
- Directs the Oregon Health Authority (OHA) to create a registry system for the collection and dissemination of information on the incidence and prevalence of Parkinson’s disease, to begin operating before July 1,2026.
- Allows OHA to contract with a third party to administer the registry.
- Requires health care facilities, licensed health care practitioners, and clinical laboratories that diagnose or treat Parkinson’s to report to the registry. Prohibits disciplinary action or damages against providers who disclose protected data when acting in good faith.
- Allows patients to opt out of data collection.
- Creates a Parkinson’s Disease Registry Advisory Committee to advise the OHA on implementation and operation of the registry, including data collection.
- Directs the Advisory Committee to submit a report on findings and recommended legislation to interim committees of the Legislative Assembly no later than December 1 of each year.
- Takes effect on the 91st day following adjournment sine die.

Fiscal impact: Not yet issued
Revenue impact: Not yet issued

### ISSUES DISCUSSED:

### EFFECT OF AMENDMENT:

No amendment.

### BACKGROUND:

Parkinson’s disease is a disorder of the central nervous system (the brain and spinal cord) that affects movement ( link to “Understanding Parkinson’s Disease,” Oregon Health & Sciences University). Parkinson’s disease causes motor (movement) symptoms, such as hand tremor, and non-motor symptoms, including low blood pressure. Researchers estimate that Parkinson’s disease occurs in Oregon at a rate of 1151.28 per hundred thousand Oregonians (link to NPJ Parkinsons Dis. (2019), using Medicare data to estimate statewide prevalence).

Fourteen states have Parkinson’s disease registries, according to the Michael J Fox Foundation for Disease Research. While the registries vary in structure and administration, most serve to collect data on incidence of disease and evaluate access to diagnosis and treatment. The Washington State Parkinson Disease Registry, for example, is administered by the University of Washington and allows patients to opt into studies performed by university researchers.