



January 23, 2023

Senator Deb Patterson, Chair
Health Care Committee
Oregon State Senate
State of Oregon
900 Court Street NE, S-215
Salem, OR 97301

Submitted Electronically

RE: SUPPORT for SB 401 – Study for TD and Movement Disorders

Dear Senator Patterson:

On behalf of the Movement Disorders Policy Coalition (MDPC), I am writing in support of SB 401, a bill requiring the Oregon Health Authority to study movement disorders, such as tardive dyskinesia (TD), and report its findings to public health and health care related committees of the Legislative Assembly by September 15, 2024.

MDPC respectfully urges the Senate Health Care Committee to issue a favorable report and pass this bill out of committee. By doing so, and with ultimate passage by both chambers of the Legislative Assembly, the State of Oregon will help support TD patients, caregivers and providers through:

- Outlining existing resources related to movement disorders including TD;
- Identifying opportunities to expand these resources; and
- Presenting a strategy for ensuring equitable treatment for minority populations.

The Movement Disorders Policy Coalition (MDPC) serves as a platform from which stakeholders, including health care providers and patients, can provide input on policy decisions impacting patient-centered care for those living with movement disorders. As a coalition of stakeholders across the movement disorders space, MDPC advocates at the federal, state, and health plan levels for key health reforms that increase access to personalized care for patients with movement disorders such as tardive dyskinesia, Parkinson's disease, essential tremor, Tourette Syndrome and Huntington's disease.

Movement disorders – such as Parkinson's Disease, Huntington's Disease, Tourette Syndrome, or TD – are potentially disabling, and often irreversible, neurological conditions which present challenges to millions of people in the United States. These challenges include physical symptoms such as tremor, impaired speech, rigidity, and involuntary twitching as well as psychiatric symptoms stemming from the disorder itself or a reaction to symptoms. These symptoms lead to disruptions to everyday life which complicate the simple, day-to-day tasks those without movement disorders take for granted, like feeding or dressing oneself, and present a burden to caregivers who must balance the needs of loved ones with their own.

TD, for example, is an involuntary, sometimes irreversible movement disorder that can occur due to use of antipsychotics, commonly prescribed to treat bipolar disorder, schizophrenia, and depression, or other medications. Those with TD experience involuntary, repetitive movements of their face, limbs or torso – movements that can be uncomfortable or painful. According to a survey of people diagnosed with TD, the condition affects their ability to do everyday activities; more than half (61 percent) reported a negative

impact to their ability to sleep, with almost as many people (47 percent) noting a negative impact on their ability to work.¹

Additionally, people living with movement disorders, like TD or Tourette Syndrome, often face stigma, which can worsen mental health symptoms and cause embarrassment or withdrawal from society.² However, despite the fact that more than 500,000 people in the United States are affected by TD, the condition is still widely unknown or misunderstood due to a lack of public awareness and too few resources available to patients, providers and caregivers.

Now, Oregon has the opportunity to positively impact awareness and access to resources for this disease community across the state and beyond. We urge the Committee to issue a favorable report on SB 401 and urge swift passage by the Legislative Assembly. By demonstrating interest in this matter, the Committee will help support patients, providers and caregivers and improve care.

On behalf of the Movement Disorders Policy Coalition and our membership, thank you for your leadership on this important issue. If we can provide further details or answer any questions, please reach out to Josie Cooper at jcooper@allianceforpatientaccess.org.

Sincerely,



Josie Cooper Executive Director
Movement Disorders Policy Coalition

¹ Ascher-Svanum, H. et al. Tardive dyskinesia and the 3-year course of schizophrenia: results from a large, prospective, naturalistic study. *J Clin Psych.* 2008;69(10):1580-1588.

² Cloud LJ, Zutshi D, Factor SA. Tardive dyskinesia: therapeutic options for an increasingly common disorder. *Neurotherapeutics.* 2014;11(1):166-176.