

1/22/2023

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

RE: SUPPORT for SB 401 – OHA Tardive Dyskinesia Study

Dear Senator Patterson:

We applaud your efforts to recognize, raise awareness, and highlight the needs of those with tardive dyskinesia (TD), a debilitating medication-induced movement disorder estimated to affect 600,000 people in the United States.

Individuals most often develop TD by following their doctor's recommendations to treat their underlying mental health conditions using antipsychotics. TD can also be caused by medications indicated for nausea and gastroparesis by drugs which also block dopamine receptors in the brain.

TD is an often-permanent movement disorder that most often causes abnormal, involuntary facial movements such as grimacing, protrusion of the tongue, rapid eye blinking and other symptoms that can be embarrassing and socially stigmatizing. TD can also affect movement of the limbs, trunk, fingers/toes, and even respiratory and digestive systems. Those with TD report that this disorder "moderately or extremely affects" their quality of life in the following areas: ability to work (46%), ability to sleep (53%), and ability to eat and drink (35%).

TD can also influence an employer's decision on whether they hire an applicant. This then affects the ability to obtain housing and pay for other essentials. This disorder is most prevalent in women over 55 taking these drugs; those at highest risk are of African-American descent. According to experts, about 70% of those with the condition haven't been formally diagnosed.

By raising awareness of the risks of TD and helping to encourage screening and analyzing the resources available for this patient population, Oregon is in step with many other states across the country. In fact, just last year, all 50 states and the District of Columbia for the first-time recognized TD Awareness Week, which occurs annually during the first full week of May.

The National Organization for Tardive Dyskinesia (NOTD) is the only 501(c)(3) non-profit organization solely dedicated to advocating for those with TD. We provide services such as online support groups, education for patients and practitioners, and we have developed tools such as a smartphone app to accurately monitor patient movements and help assess the effectiveness of treatments.



We stand ready to support the Oregon Health Authority with access to the latest knowledge regarding TD and assistance in potentially revising your treatment algorithm to align with organizations including the American Academy of Neurology.

Thank you for raising awareness to this often-overlooked disorder. On behalf of the legions of patients who deal with this often-permanent disorder, we appreciate all your efforts.

Warmest regards,

A handwritten signature in blue ink that reads "Kathleen A. Shea". The signature is written in a cursive, flowing style.

Kathleen A. Shea, M.A., M.P.H.

Founder and President

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