

Helping Patients Living with Tardive Dyskinesia (TD)



Tardive dyskinesia (TD) is a movement disorder marked by involuntary, abnormal, and repetitive movements of the face, torso, and other parts of the body. It is most often caused by the prolonged use of certain medications, particularly those prescribed to treat mental health conditions such as schizophrenia, bipolar disorder, and depression, as well as some anti-nausea medications.

The symptoms of TD can be persistent and, in many cases, profoundly disabling. It is estimated that at least 800,000 Americans may be living with this condition. For those affected, TD can significantly interfere with daily activities, disrupting essential functions like sleeping, eating, dressing, working, and socializing.



About the Center for Patient Advocacy Leaders

The Center for Patient Advocacy Leaders (CPALs) is an evolution of a program called PALS that was developed in 2002. PALS was created to bring together diverse patient advocacy leaders to improve their advocacy capacity and to identify ways to collaborate and unify the voices of many around common health policy issues. Since 2016 CPALs has been housed within The AIDS Institute. Work continues to be across disease states and populations, and driven by an advocate-centered model, we call *By Advocates, For Advocates*. The Center is better positioned to harness staff talents and more broadly utilize the resources, knowledge and the collective actions of health advocacy leaders and their grassroots constituents to further their health and healthcare priorities. CPALs has been committed to TD for several years through PALS United for Movement Disorders, an initiative that brings together health advocacy and policy leaders to coalesce around common goals to raise the profile of movement disorders, like TD, and advance patient-centered solutions.

About the Movement Disorders Policy Coalition

The Movement Disorders Policy Coalition (MDPC) is a non-profit advocacy coalition that brings together advocacy groups, health care providers, patients and other stakeholders to inform policy impacting patient-centered care for people living with movement disorders. MDPC advocates at the federal, state, and health plan levels for key health reforms that increase access and personalized care.

For additional information please contact:

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Tardive Dyskinesia Policy Priorities

Increase TD Education and Awareness

Educating the public and healthcare community about tardive dyskinesia (TD) is essential. Early recognition and diagnosis can help improve quality of life and increase a person's ability to participate in daily activities we take for granted, such as dressing, eating without choking, socializing, and working. Many people living with TD may not realize their symptoms are related to their medication, leading to delays in seeking help or receiving proper care.

Raising awareness also helps reduce stigma—TD can cause visible and often misunderstood physical movements that may lead to social isolation or discrimination.

Additionally, education empowers patients and caregivers to advocate for the development of safer treatment options and work collaboratively with healthcare providers to manage both mental health conditions and conditions associated with the use of mental health medications, such as TD. The American Psychiatric Association has recommended screening for at-risk patients every 6 months; it is important that health care providers understand and act upon this standard of care. Patients who take antipsychotic medications are at risk and deserve regular screening for the development of TD.

Ultimately, greater awareness leads to earlier intervention, improved outcomes, and a more compassionate, informed society.

TD Awareness Week

May 4-10, 2025

Tardive Dyskinesia Awareness Week is observed during the first full week of May, to coincide with the start of Mental Health Awareness Month. This year is the 8th anniversary of TD Awareness Week. All states and the District of Columbia have recognized TD Awareness Week, and resolutions to recognize this week have been introduced in both the US House and Senate.

To support TD Awareness Week, please post stats and infographics about TD on social media. Please use the hashtag **#TDawarenessweek** and **#Screen4TD**.

FY2026 Labor-HHS Subcommittee Appropriations Request

Certified Community Behavior Health Clinic (CCBHC) Technical Assistance Grant – CPALs and MDPC respectfully request that Congress provides \$500,000 to the Substance Abuse and Mental Health Services Administration (SAMHSA) to generate “technical assistance” related to routine screening, prevention, and early intervention for physical health conditions commonly associated with long-term use of antipsychotic medications, like tardive dyskinesia (TD).

The goal of this technical assistance is to promote screening and fill knowledge gaps within this setting of care.