

# DBSA Survey Center

## Experiences with Tardive Dyskinesia

Summary Report: November 2017

### BACKGROUND

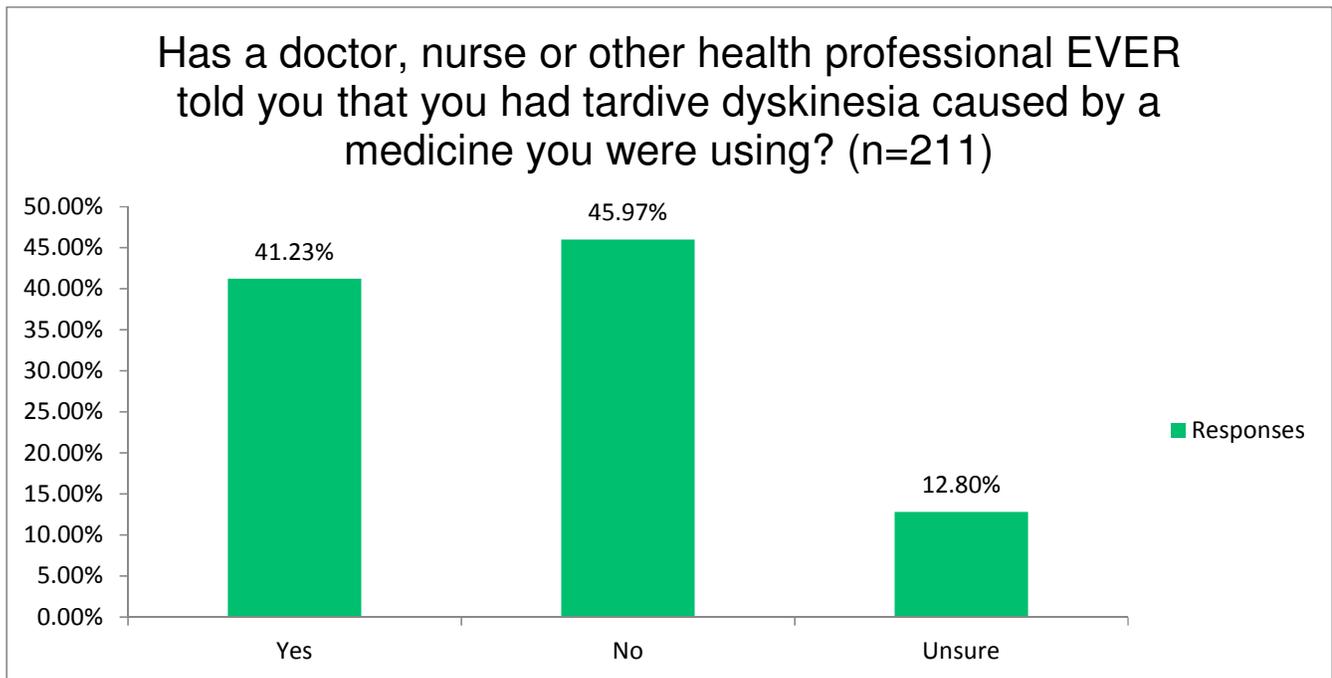
From 8/14/17- 9/4/17, DBSA administered a survey to gather information on people who have been diagnosed with tardive dyskinesia (TD). This condition affects the nervous system and is often caused by long-term use of antipsychotic medications, which are sometimes used to treat bipolar disorder and depression. Side effects usually involve repetitive, involuntary movements. While most side-effects will dissipate once medication is stopped, TD can last long after the medication has been discontinued and, in some cases, may even be permanent. This survey focused on the impact of the condition as well as whether any treatment has been successful.

Individuals were invited to complete the survey through DBSA's newsletters distributed to individual constituents and local chapters as well as through social media and Facebook Ads. DBSA also shared the survey with other organizations to promote within their networks. 211 individuals responded.

### SURVEY RESULTS

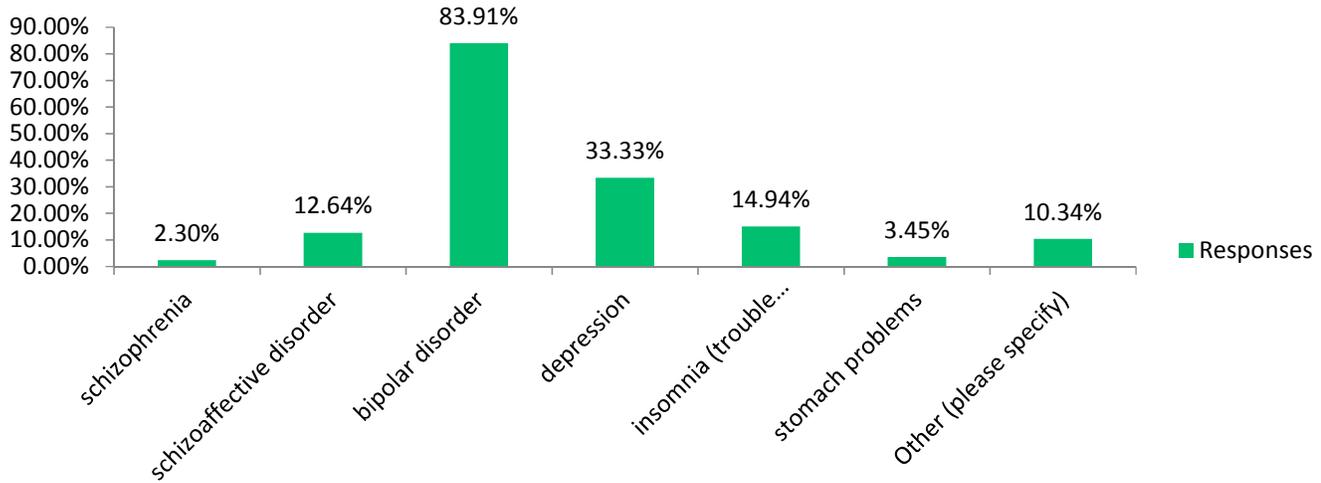
#### DIAGNOSIS

About 41% of the respondents reported having been diagnosed with tardive dyskinesia at any point in their life. Nearly 13% were unsure if they have ever been diagnosed. As the focus was on those with a diagnosis of tardive dyskinesia, only those who answered yes to this question moved on the next question.



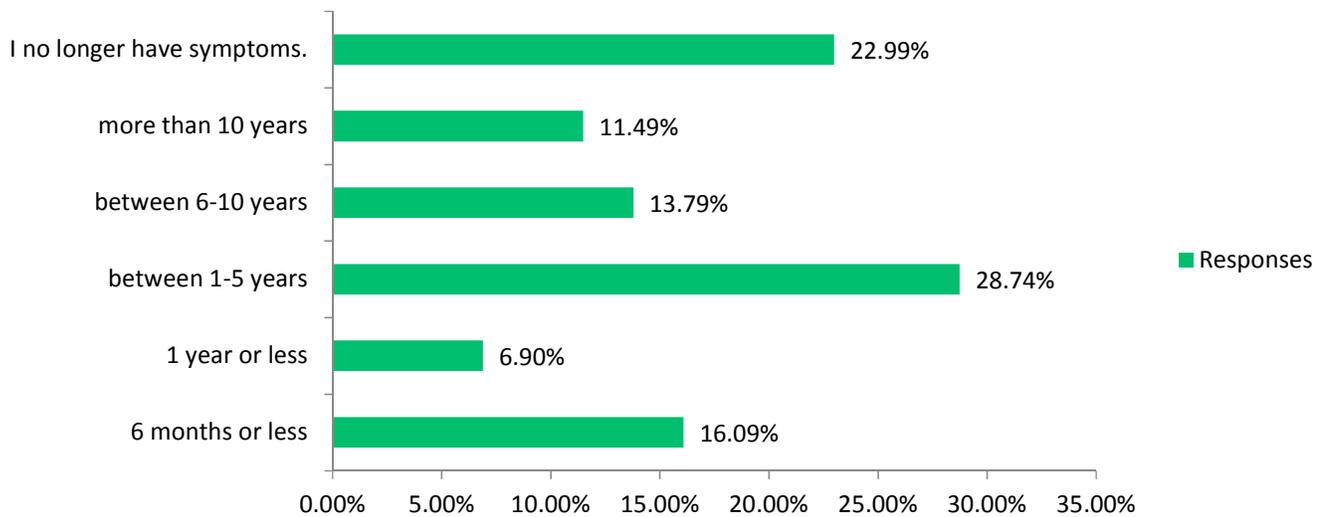
The vast majority (nearly 84%) of respondents had been diagnosed with bipolar disorder. A little more than 1/3 had been diagnosed with depression. Respondents were allowed to select more than one answer. Since DBSA focuses on depression and bipolar disorder, these percentages were not surprising.

### What health conditions do you/did you have that required you to take a medicine that caused tardive dyskinesia? Please check all that apply. (n=87)



When asked how long they had experienced tardive dyskinesia symptoms, nearly 23% reported 1 year or less; about 29% reported between 1-5 years; 25% reported more than 6 years and 23% reported no longer having symptoms.

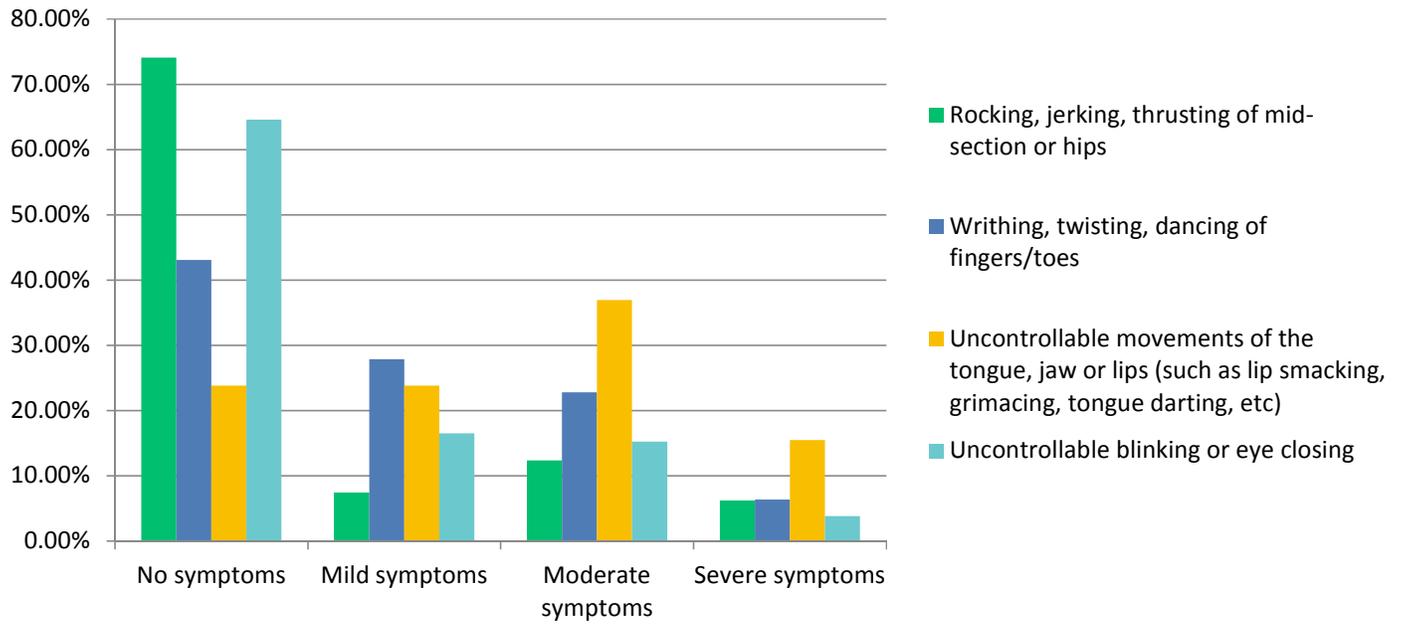
### How long have you had symptoms of tardive dyskinesia? (n=87)



#### IMPACT

Uncontrollable movements of the tongue, jaw or lips was the most often experienced symptom (76%) our respondents reported. About 15% marked this symptom as severe, 37% as moderate and 24% as mild. Writhing, twisting, and dancing of fingers/toes was more likely to be listed as moderate (23%) or mild (28%). Uncontrollable blinking or eye closing was seen as severe only 4% of the time, moderate 15% of the time, and mild about 16% of the time. Only 25% of respondents reported having this symptom. Similarly only 26% of respondents reported experiencing rocking, jerking, thrusting of the mid-section or hips. When present, this symptom was reported as severe roughly 6% of the time, moderate about 12% of the time and mild only 7% of the time.

For each of the following tardive dyskinesia symptoms, select the option that best fits your experience (n=86)



On a scale of 1-5 (1 being no interference and 5 being severe interference) participants felt that TD's impact on their social life and leisure activities was 3.82 showing a significant interference.

Using the same scale, participants said that TD's impact on their family life and home responsibilities was slightly lower at 3.20.

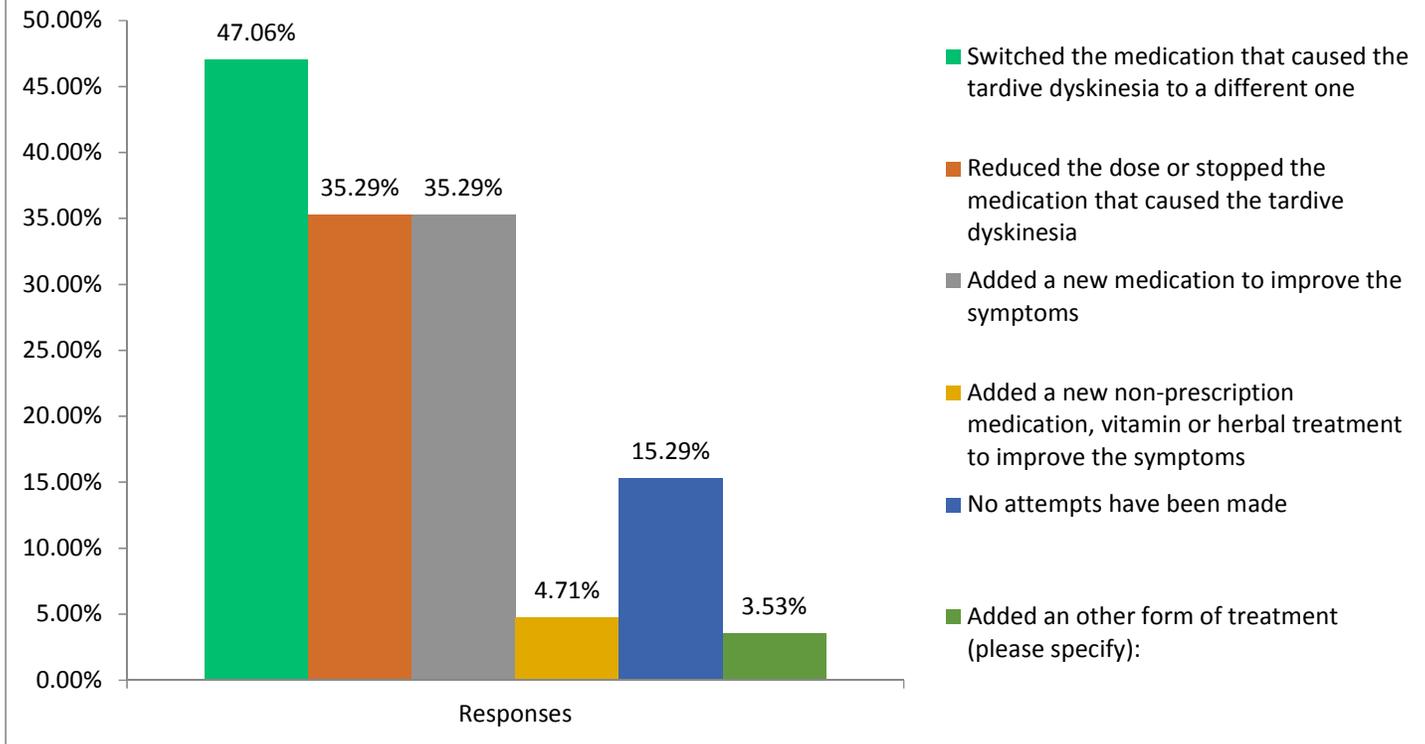
Of those who were employed (45% of respondents), TD's impact on participants' work fell in the middle at 3.42 on the 1-5 scale.

## TREATMENT

The most common treatment tried to reduce or eliminate symptoms of TD was switching medications (47%).

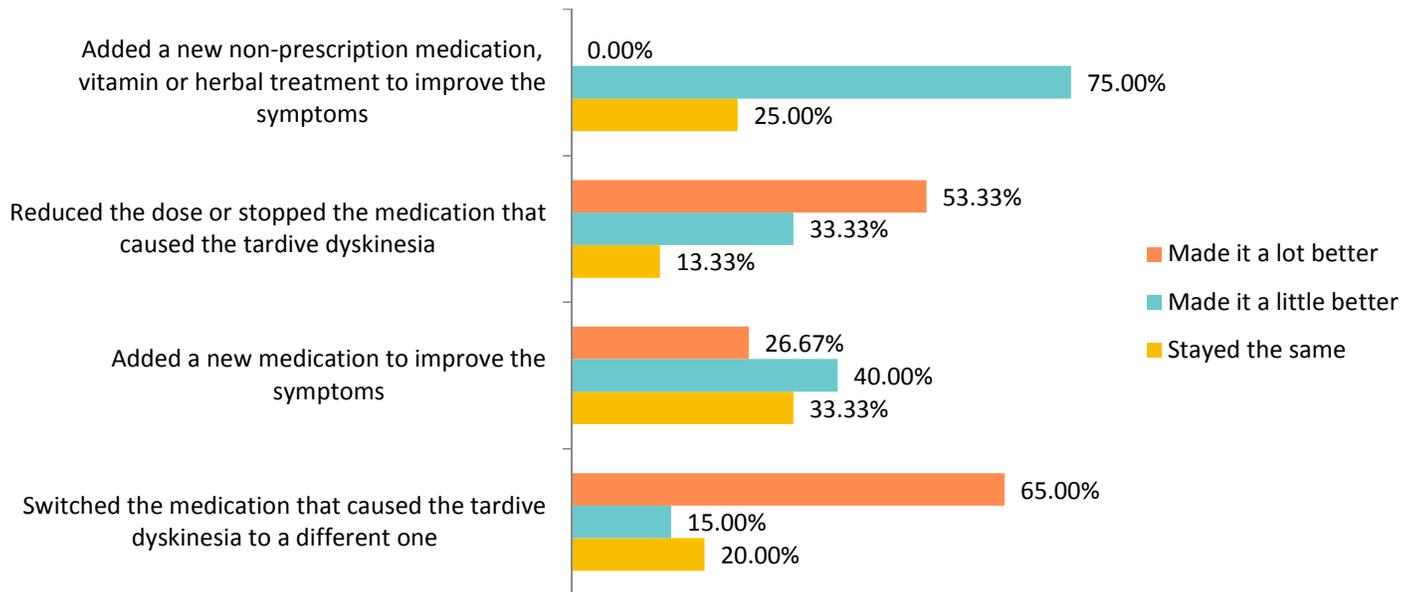
Participants report that 35% of doctors tried reducing or stopping the medication that caused the TD. 35% also report that their doctor tried adding a new medication to improve the symptoms of TD. Over 15% say that their doctor has not tried any treatment. The least common treatments tried were adding a non-prescription medication, vitamin or herbal supplement (4.7%) and adding another form of treatment (3.5%)

## How has your doctor attempted to address your tardive dyskinesia? Please check all that apply. (n=85)



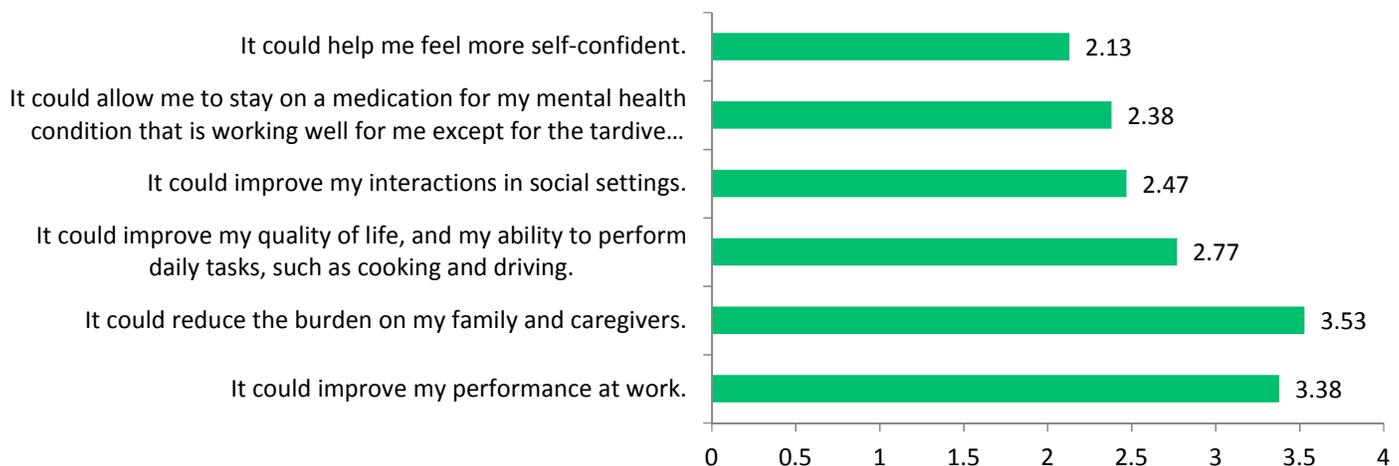
When asked how the treatments tried impacted TD symptoms, it is important to note that none made symptoms worse. Switching the medication that caused the TD (65%) and reducing the dose or stopping the medication that caused the TD (53%) resulted in the greatest improvement in symptoms. While adding a non-prescription medication, vitamin or herbal treatment did not make symptoms a lot better, 75% of respondents did say that it made symptoms a little better. A significant percentage in each treatment group shared that their symptoms remained the same regardless of the treatment tried.

## How has your doctor's treatment of your tardive dyskinesia impacted your symptoms? (n=72)



Participants were also asked to rate several potential reasons that they may wish to treat their TD. On a 5 point scale (1 being most important and 5 being least important), respondents rated an increase in self-confidence (2.13/5), staying on their medication (2.38/5) and improving their interactions in social settings (2.47) as the most important. Burden on family and friends came in as the least important at 3.53 on a 5 point scale.

## Please rate from most important (1) to least important (5) the following reasons for treating your tardive dyskinesia? (n=80)



### SUMMARY AND DISCUSSION

The results of this survey indicate that the impact of tardive dyskinesia on social and leisure time, family time and work is significant. It was also telling to see that over 15% of people had not yet tried anything to improve their TD symptoms. It is unclear from this survey whether this is due to participant refusal or lack of options provided by clinicians, or both.

Fortunately, this survey also shows that for many, treatments that have been tried have been successful in improving the symptoms a little and in some cases, a lot.

DBSA hopes to utilize the information gained through this survey to increase awareness of TD symptoms and show the negative impact this condition can have on individuals living with TD.