Tardive Dyskinesia Awareness Week 2021

Toolkit/Resources
Foreword

As we approach Mental Health Month in May and recognize Tardive Dyskinesia (TD) Awareness Week during the first week (May 2-8), it is more important than ever to support people living with mental health conditions.

Recent research from the Kaiser Family Foundation Health Tracking Poll has shown that stress and worry related to the pandemic has had a negative impact on mental health, taking an emotional toll on 53% of adults in the U.S.¹ About one-third of people surveyed expressed that the stress from the pandemic has negatively impacted their sleep (36%) or appetite (32%).¹ For individuals with mental illness, whose conditions often tend to be isolating, the anxiety and increased isolation resulting from these serious times can intensify.²

Some people living with a mental health condition may experience TD, a condition of uncontrollable movements affecting the face, torso, and/or other body parts. TD may develop after a few months of taking certain medications to treat bipolar disorder, depression, or schizophrenia. TD affects approximately 600,000 people in the U.S.³⁻⁶

The uncontrollable movements of TD may be disruptive to people’s lives due to the symptoms themselves and the impact they can have on emotional and social well-being, causing some people to feel embarrassed or judged by others or withdraw from society.⁷ During this unique time, acknowledging and recognizing the symptoms of TD is imperative to get the necessary support available.

In honor of TD Awareness Week, Neurocrine Biosciences is proud to share these resources to help engage policymakers, advocates, and others supporting people living with TD. Thank you for your participation in efforts around raising awareness of Mental Health Month and TD Awareness Week. Enclosed please find template materials that can be adapted for communication on social media and organization websites around TD Awareness Week.

If you have any questions, please reach out to the Neurocrine Biosciences team Michele Rest, Corporate Communications, (215-910-2138; mrest@neurocrine.com), Todd Bledsoe, Executive Director of Patient Engagement and Advocacy, (202-236-8202; tbledsoe@neurocrine.com) and Chuck Harman, Director of Patient Engagement and Advocacy (858-245-5871; charman@neurocrine.com).
Tardive Dyskinesia Awareness Week
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State-Level Statistics on Adults Living With a Mental Illness

Over the past 3 years, 33 states and Washington, DC, have declared the first week of May as Tardive Dyskinesia Awareness Week.

Below please find statistics that can be used in materials to explain the prevalence of adults living with a mental illness in each respective state. Of note, up to 30% of people receiving prolonged treatment with antipsychotics, which are commonly prescribed to treat bipolar disorder, depression, and schizophrenia, may develop TD.3,5,8

The below statistics have been secured from the 2021 State of Mental Health in America report by Mental Health America (MHA) (see page 18 in the MHA report for adult prevalence of mental illness by state).9

Alabama
- It is estimated that 794,000 adults in Alabama, or 21.39% of adults in the state, are living with a mental illness

Alaska
- It is estimated that 108,000 adults in Alaska, or 20.50% of adults in the state, are living with a mental illness

Arizona
- It is estimated that more than 1 million (1,030,000) adults in Arizona, or 19.24% of adults in the state, are living with a mental illness

Arkansas
- It is estimated that 457,000 adults in Arkansas, or 20.27% of adults in the state, are living with a mental illness

California
- It is estimated that more than 5.5 million (5,566,000) adults in California, or 18.54% of adults in the state, are living with a mental illness

Colorado
- It is estimated that 924,000 adults in Colorado, or 21.50% of adults in the state, are living with a mental illness

Connecticut
- It is estimated that 531,000 adults in Connecticut, or 19.03% of adults in the state, are living with a mental illness

Delaware
- It is estimated that 149,000 adults in Delaware, or 20.03% of adults in the state, are living with a mental illness

District of Columbia
• It is estimated that 125,000 adults in the District of Colombia, or 22.21% of adults in the district, are living with a mental illness

Florida
• It is estimated that more than 2.8 million (2,889,000) adults in Florida, or 17.39% of adults in the state, are living with a mental illness

Georgia
• It is estimated that more than 1 million (1,405,000) adults in Georgia, or 18.09% of adults in the state, are living with a mental illness

Hawaii
• It is estimated that 187,000 adults in Hawaii, or 17.58% of adults in the state, are living with a mental illness

Idaho
• It is estimated that 311,000 adults in Idaho, or 24.46% of adults in the state, are living with a mental illness

Illinois
• It is estimated that more than 1.7 million (1,754,000) adults in Illinois, or 18.06% of adults in the state, are living with a mental illness

Indiana
• It is estimated that more than 1 million (1,129,000) adults in Indiana, or 22.51% of adults in the state, are living with a mental illness

Iowa
• It is estimated that 473,000 adults in Iowa, or 19.89% of adults in the state, are living with a mental illness

Kansas
• It is estimated that 420,000 adults in Kansas, or 19.59% of adults in the state, are living with a mental illness

Kentucky
• It is estimated that 746,000 adults in Kentucky, or 22.14% of adults in the state, are living with a mental illness

Louisiana
• It is estimated that 715,000 adults in Louisiana, or 20.63% of adults in the state, are living with a mental illness
Maine
- It is estimated that 223,000 adults in Maine, or 20.82% of adults in the state, are living with a mental illness

Maryland
- It is estimated that 781,000 adults in Maryland, or 16.96% of adults in the state, are living with a mental illness

Massachusetts
- It is estimated that more than 1.1 million (1,155,000) adults in Massachusetts, or 21.22% of adults in the state, are living with a mental illness

Michigan
- It is estimated that more than 1.4 million (1,469,000) adults in Michigan, or 19.07% of adults in the state, are living with a mental illness

Minnesota
- It is estimated that 819,000 adults in Minnesota, or 19.32% of adults in the state, are living with a mental illness

Mississippi
- It is estimated that 431,000 adults in Mississippi, or 19.49% of adults in the state, are living with a mental illness

Missouri
- It is estimated that 993,000 adults in Missouri, or 21.44% of adults in the state, are living with a mental illness

Montana
- It is estimated that 163,000 adults in Montana, or 20.00% of adults in the state, are living with a mental illness

Nebraska
- It is estimated that 257,000 adults in Nebraska, or 18.08% of adults in the state, are living with a mental illness

New Hampshire
- It is estimated that 221,000 adults in New Hampshire, or 20.56% of adults in the state, are living with a mental illness

New Jersey
- It is estimated that more than 1.1 million (1,112,000) adults in New Jersey, or 16.14% of adults in the state, are living with a mental illness
New Mexico
• It is estimated that 300,000 adults in New Mexico, or 19.10% of adults in the state, are living with a mental illness

Nevada
• It is estimated that 474,000 adults in Nevada, or 20.67% of adults in the state, are living with a mental illness

New York
• It is estimated that more than 2.8 million (2,802,000) adults in New York, or 18.25% of adults in the state, are living with a mental illness

North Carolina
• It is estimated that more than 1.4 million (1,469,000) adults in North Carolina, or 18.77% of adults in the state, are living with a mental illness

North Dakota
• It is estimated that 108,000 adults in North Dakota, or 19.13% of adults in the state, are living with a mental illness

Ohio
• It is estimated that more than 1.9 million (1,906,000) adults in Ohio, or 21.40% of adults in the state, are living with a mental illness

Oklahoma
• It is estimated that 592,000 adults in Oklahoma, or 20.43% of adults in the state, are living with a mental illness

Oregon
• It is estimated that 731,000 adults in Oregon, or 22.45% of adults in the state, are living with a mental illness

Pennsylvania
• It is estimated that more than 1.8 million (1,814,000) adults in Pennsylvania, or 18.23% of adults in the state, are living with a mental illness

Rhode Island
• It is estimated that 178,000 adults in Rhode Island, or 21.32% of adults in the state, are living with a mental illness

South Carolina
• It is estimated that 706,000 adults in South Carolina, or 18.31% of adults in the state, are living with a mental illness
South Dakota
- It is estimated that 112,000 adults in South Dakota, or 17.49% of adults in the state, are living with a mental illness

Tennessee
- It is estimated that 937,000 adults in Tennessee, or 18.26% of adults in the state, are living with a mental illness

Texas
- It is estimated that more than 3.3 million (3,347,000) adults in Texas, or 16.21% of adults in the state, are living with a mental illness

Utah
- It is estimated that 550,000 adults in Utah, or 25.25% of adults in the state, are living with a mental illness

Vermont
- It is estimated that 104,000 adults in Vermont, or 20.65% of adults in the state, are living with a mental illness

Virginia
- It is estimated that more than 1.1 million (1,115,000) adults in Virginia, or 17.38% of adults in the state, are living with a mental illness

Washington
- It is estimated that more than 1.2 million (1,269,000) adults in Washington, or 22.23% of adults in the state, are living with a mental illness

West Virginia
- It is estimated that 337,000 adults in West Virginia, or 23.80% of adults in the state, are living with a mental illness

Wisconsin
- It is estimated that 859,000 adults in Wisconsin, or 19.26% of adults in the state, are living with a mental illness

Wyoming
- It is estimated that 88,000 adults in Wyoming, or 20.34% of adults in the state, are living with a mental illness
Template Website Post or Email Brief

Enclosed is a templated website post or email brief, which each local state official or advocacy organization can tailor to (1) share as an email to internal and external distribution lists and (2) post on respective websites. Placeholders are included throughout to tailor content accordingly. We recommend sharing this content on Monday, May 3, in the morning to kick off the week.

[IF SENDING AS AN EMAIL, INSERT:

Dear Constituents/All,]

FOR LOCAL ADVOCACY CHAPTERS: We are pleased to recognize the first full week of May (2-8), 2021, as Tardive Dyskinesia (TD) Awareness Week in the state of [INSERT STATE].

FOR NATIONAL ADVOCACY GROUPS: This Mental Health Month, we are proud to recognize the first full week of May (2-8), 2021, as Tardive Dyskinesia (TD) Awareness Week to help increase awareness and support people living with this burdensome condition.

Tardive dyskinesia, or TD, is a condition of uncontrollable movements affecting the face, torso, and/or other body parts. TD may develop after a few months of taking certain medications to treat bipolar disorder, depression, or schizophrenia. TD affects approximately 600,000 people in the U.S.1-4 By declaring the first week of May as TD Awareness Week, [LOCAL ADVOCACY CHAPTERS: [INSERT STATE is]; FOR NATIONAL ADVOCACY GROUPS: [states around the country are]] helping to raise awareness around:

- The impact TD can have on a person’s physical, emotional, and social well-being
- The signs and symptoms associated with TD
- The importance of working with one’s doctor to manage the condition, including talking about available treatment options

May is also Mental Health Month, an important time to acknowledge the 1 in 5 US adults living with a mental illness.5

LOCAL ADVOCACY CHAPTERS - PULL FROM ABOVE STATE STATS ON PAGE 4: Specifically, approximately [XXX,XXX] adults in [INSERT STATE] are living with a mental illness, and many people with a mental illness may also suffer from TD.6,7

FOR ALL: The uncontrollable movements of TD may be disruptive to people’s lives due to the symptoms themselves and the impact they can have on emotional and social well-being.8 Despite this, research shows a gap in awareness and need for further education.9 Data from the RE-KINECT study, the largest ever real-world screening study of patients with clinician-confirmed possible TD, demonstrated that the involuntary movements associated with TD had a negative impact on a patient's health-related quality of life. The study found that 75% of people in this group (n=204) affirmed feeling self-conscious or embarrassed about involuntary movements.10

FOR LOCAL ADVOCACY CHAPTERS: Thank you for your commitment to raising awareness of tardive dyskinesia and in supporting the mental health community. We encourage everyone across [INSERT STATE] to acknowledge the first week of May as TD Awareness Week. To learn more about mental illness and TD, visit [INSERT ADVOCACY GROUP WEBSITE].
FOR NATIONAL ADVOCACY GROUPS: [INSERT ADVOCACY GROUP] commends the declaration of TD Awareness Week by states across the country and applauds their efforts to bring broader awareness to a condition that can have an impact on a person’s life. To learn more about TD, visit https://www.ninds.nih.gov/Disorders/All-Disorders/Tardive-Dyskinesia-Information-Page

[IF SENDING AS AN EMAIL, INSERT SIGNATURE:
Sincerely,
NAME
TITLE]

References

Template Social Media Posts

Below are suggested template posts for your preferred social channel that can be tailored as appropriate. Neurocrine Biosciences will also be posting from the @TalkAboutTD Twitter and the Talk About TD Facebook page, which we welcome you to follow and engage with during TD Awareness Week. Please note all high-resolution graphics are sized for Facebook, Twitter, Instagram, and LinkedIn and can be found in the below links.

Please consider tagging Neurocrine Biosciences’ Talk About TD Facebook page or @TalkAboutTD Twitter handle when publishing your post. We also encourage you to use #TDAwarenessWeek in all relevant content.

<table>
<thead>
<tr>
<th>State Legislator and Local Advocacy Posts</th>
<th>LINK TO DOWNLOAD GRAPHICS HERE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Post Copy</strong></td>
<td></td>
</tr>
<tr>
<td>Those living with a mental health condition may also be affected by a condition called tardive dyskinesia (TD), an involuntary movement disorder. To help raise awareness of TD, [INSERT STATE] is proud to declare next week as May 2-8, 2021 #TDAwarenessWeek.</td>
<td><img src="https://example.com/tardive-dyskinesia-graphic.png" alt="Image" /></td>
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</tbody>
</table>

[INSERT STATE] is proud to declare May 2-8, 2021, as Tardive Dyskinesia (TD) Awareness Week, recognizing that approximately 600,000 people in the U.S. may be affected by this condition. To learn more about TD, visit TalkAboutTD.com

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<thead>
<tr>
<th>LINK TO DOWNLOAD GRAPHICS ABOVE</th>
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<tbody>
<tr>
<td><img src="https://example.com/tardive-dyskinesia-graphic.png" alt="Image" /></td>
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</table>
During this #TDAwarenessWeek, we are proud to support the hundreds of thousands of people living with tardive dyskinesia (TD), an involuntary movement disorder. Learn more at www.TalkAboutTD.com

Tardive dyskinesia (TD) is an involuntary movement disorder that can affect those living with a mental health condition. To help raise awareness of TD, many states have declared this week #TDAwarenessWeek. Learn more: www.TalkAboutTD.com

Tardive dyskinesia (TD) has a lasting impact on people with the condition. We’re raising awareness of supporting those living with TD this #TDAwarenessWeek. Learn more at www.TalkAboutTD.com
<table>
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<tr>
<th>No 2 people living with tardive dyskinesia (TD) have the same story—so this #TDAwarenessWeek, we’re honoring all of them. Learn more about the involuntary movement disorder at <a href="http://www.TalkAboutTD.com">www.TalkAboutTD.com</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>Terrylin is just one of the many people living with tardive dyskinesia (TD). To help raise awareness of TD, states across the country have declared this week #TDAwarenessWeek. Learn more about TD at <a href="http://www.TalkAboutTD.com">www.TalkAboutTD.com</a></td>
</tr>
</tbody>
</table>

**LINK TO DOWNLOAD ANIMATION ABOVE**

> I wish for those who live with TD to come out and explain their condition to others, as you may often be met with kindness and inclusion. 🙏 - Shelly, Living with tardive dyskinesia

**LINK TO DOWNLOAD GRAPHIC ABOVE (also available in 1:1/square ratio for use on Facebook, Instagram, LinkedIn)**

> Each year, TD Awareness Week provides much needed support to people who struggle with this condition. 🙏 - Terrylin, Living with tardive dyskinesia

**LINK TO DOWNLOAD GRAPHIC ABOVE (also available in 1:1/square ratio for use on Facebook, Instagram, LinkedIn)**
Infographic

Download here: Download the Infographics Here

May is Mental Health Month and the First Week of May [2–8] is Tardive Dyskinesia Awareness Week

1 in 5 U.S. adults live with a mental illness.¹

Some patients affected by mental illness may also be impacted by a condition called tardive dyskinesia (TD).²

~600,000 people in the U.S. may be affected by TD.³,⁴

TD is an involuntary movement disorder that may develop after a few months of taking medication to treat bipolar disorder, depression or schizophrenia.³,⁵,⁶ TD is characterized by uncontrollable, abnormal and repetitive movements of the face, torso, and/or other body parts.⁶

Over the past three years, 33 states and Washington, D.C., have declared the first week in May as TD Awareness Week.

67% of those diagnosed with TD or suspected TD (n=350) reported that they were frustrated by their involuntary movements.⁷

TD can impact patients socially, emotionally and physically.⁸ According to a survey, patients with diagnosed or suspected TD (n=350) reported the condition moderately, very or extremely affected them in the following areas:⁷,⁹

52% Ability to Sleep¹

31% Ability to Work¹

29% Ability to Eat and Drink¹

Learn more by visiting www.TalkAboutTD.com and following @TalkAboutTD on Twitter.

¹ Based on survey conducted in 2016; patients diagnosed with TD or suspected TD (n=350) were asked “How much of the time are you frustrated by your involuntary movements?” The survey evaluated patients on medications such as antipsychotics.

² Responses based on survey question, “How does your condition impact your daily activities?”

³ Responses based on survey question, “How does your condition impact your daily activities?”

⁴ Responses based on survey question, “How does your condition impact your daily activities?”

⁵ Responses based on survey question, “How does your condition impact your daily activities?”

⁶ Responses based on survey question, “How does your condition impact your daily activities?”

⁷ Responses based on survey question, “How does your condition impact your daily activities?”

⁸ Responses based on survey question, “How does your condition impact your daily activities?”

⁹ Responses based on survey question, “How does your condition impact your daily activities?”

# Backgrounder on TD Awareness Week

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<thead>
<tr>
<th>Audience</th>
<th>Download Backgrounders</th>
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<tbody>
<tr>
<td>For national advocacy groups:</td>
<td>Download Backgrounders Here</td>
</tr>
<tr>
<td>For state officials/local advocacy chapters: <em>Includes backgrounders for individual state use that include state-by-state mental health statistics</em></td>
<td>Download Individual State Backgrounders Here</td>
</tr>
</tbody>
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## Tardive Dyskinesia Awareness Week

**Tardive dyskinesia (TD)** is a condition of uncontrollable movements affecting the face, tongue, and/or other body parts.** TD may develop after a few months of taking certain medications to treat bipolar disorder, depression, or schizophrenia.**

- Lid puffing, puffing, or smacking
- Tongue thrusting, sticking out, or pushing inside of cheek
- Excessive blinking or squinting again and again
- Jaw clenching, twitching, or side-to-side movements
- Twisting hands or shaking fingers
- Rocking, leaning back, or torso and hip shifting
- Dropping feet or stretched toes

These involuntary movements associated with TD can impact patients socially, physically, and emotionally, making them feel embarrassed or judged by others and, in some cases, may lead them to withdraw from society and isolate themselves from the outside world.**

Despite the number of people impacted by the condition, TD remains largely unknown. However, for patients living with TD, their families, and their caregivers, it is important to know that they are not alone.

In an effort to raise awareness about TD, many states are being asked to declare **Tardive Dyskinesia Awareness Week** during the first full week of May 8–14, 2021.

(\[state\] people, of adults in the state, live with a mental illness)** or **(1 in 5 US adults live with a mental illness)**

May is also Mental Health Month, and as we work to increase awareness and support for those impacted by mental health conditions, it is important to remember that those living with a mental illness may also have TD.

Over the past 3 years, 39 states, Washington, DC, and a broad coalition of mental health advocacy groups recognized the first week of May as **Tardive Dyskinesia Awareness Week.**

In 2021, states are continuing to declare Tardive Dyskinesia Awareness Week to recognize those living with this involuntary movement disorder.

It is critical that we recognize patients suffering from TD and the impact on their mental well-being.

Learn more by visiting [www.TalkAboutTD.com](http://www.TalkAboutTD.com) and following @TalkAboutTD on Twitter and Facebook.

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*References:*


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References


