

# Tardive Dyskinesia Awareness Week (TDAW) 2022

May 1-7, 2022

**Toolkit & Resources** 

**TDAW** 

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#### **About Tardive Dyskinesia Awareness Week**

As we approach Mental Health Awareness Month in May and recognize Tardive Dyskinesia [TD] Awareness Week during the first full week [May 1-7], it's critical that supporting people living with mental health conditions remains a focus. As 2022 marks the fifth year recognizing TD Awareness Week, we want to strengthen our efforts together as leading voices of support for the approximately 600,000 people in the U.S. affected by TD.<sup>1,2</sup>

Some people living with a mental health condition may also experience TD, a condition that includes uncontrollable movements affecting the face, torso, and/or other body parts. TD may develop after a few months of taking certain medications (antipsychotics) to treat bipolar disorder, depression, schizophrenia, or schizoaffective disorder.<sup>1,3,4</sup>

The uncontrollable movements of TD can have a negative impact on those living with the condition. TD movements can also impact daily tasks such as eating, sleeping, drinking, and even leaving the house.<sup>2,5</sup> Acknowledging and recognizing the symptoms of TD are important to get the necessary support and potential treatment.

#### How to Raise Awareness and Engage Online with TD Awareness Week

There are several ways to get the word out during this awareness week and to start the conversation around TD. For example, you can create a blog post from the template below, work with your local government to illuminate a building in TDAW blue, post on social media using the below graphics and so much more! We encourage you to use this guide and to reach out to us for support or suggestions on how to implement your own efforts in supporting TD Awareness Week.

Thank you for your participation in efforts to raise awareness of Mental Health Awareness Month and TD Awareness Week.

#### **Contact Information**

If you have any questions about the materials in this guide or how to use them, please reach out to the Neurocrine Biosciences team:

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#### **U.S. Adults Living with Mental Health Conditions and TD Statistics**

Below, please find fast facts around U.S. adults living with mental health conditions and those living with TD. We encourage you to use these facts in materials to support TD Awareness Week.

- 1 in 5 U.S. adults live with a mental illness<sup>6</sup>
- Research suggests the overall prevalence of TD following prolonged treatment with firstgeneration antipsychotics is up to 30%<sup>7</sup>
- Approximately 600,000 people in the U.S. may be affected by TD<sup>1,2</sup>

#### **U.S. Adults Prevalence of Any Mental Health Conditions**

Below, please find the prevalence of mental health conditions in each state. The percentage [%] refers to the percent of people in each state with mental health conditions and the number [#] indicates the number of people in each state with mental health conditions. For example, 21.29% or 794,000 people have a mental health condition in Alabama. The below statistics have been secured from the <a href="mailto:2022">2022</a> State of Mental Health in America report by Mental Health America [MHA] (see page 20 in the MHA report for adult prevalence of mental illness by state).8

States	%	#
Alabama	21.29	794,000
Alaska	21.47	113,000
Arizona	20.06	1,099,000
Arkansas	20.34	460,000
California	19.49	5,864,000
Colorado	23.20	1,014,000
Delaware	20.92	157,000
Florida	17.23	2,903,000
Georgia	17.88	1,406,000
Hawaii	17.45	185,000
Idaho	22.48	293,000
Illinois	19.18	1,858,000
Indiana	22.29	1,125,000
Iowa	18.50	441,000
Kansas	20.56	442,000
Kentucky	22.54	762,000

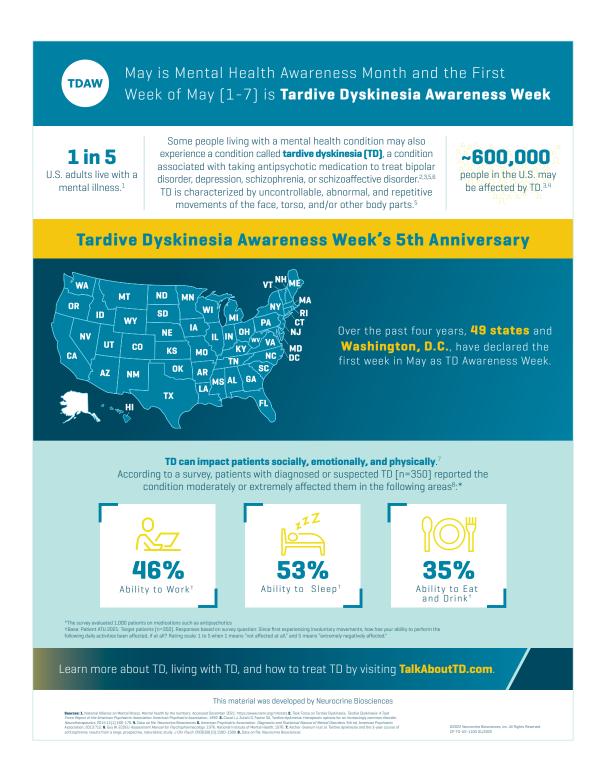
### U.S. Adults Living with Mental Illness and TD Statistics (continued)

States	%	#
Louisiana	21.21	734,000
Maine	22.10	238,000
Maryland	17.57	810,000
Massachusetts	21.15	1,157,000
Michigan	20.32	1,571,000
Minnesota	20.53	876,000
Mississippi	20.16	446,000
Missouri	22.71	1,056,000
Montana	20.81	171,000
Nebraska	20.30	290,000
Nevada	21.97	512,000
New Hampshire	22.37	243,000
New Jersey	16.37	1,122,000
New Mexico	21.39	338,000
New York	19.52	2,972,000
North Carolina	19.31	1,532,000
North Dakota	20.50	116,000
Ohio	23.64	2,112,000
Oklahoma	22.54	657,000
Oregon	23.75	783,000
Pennsylvania	19.70	1,963,000
Rhode Island	22.38	187,000
South Carolina	19.43	760,000
South Dakota	18.26	118,000
Tennessee	19.40	1,006,000
Texas	17.17	3,602,000
Utah	26.86	599,000
Vermont	22.25	112,000
Virginia	18.58	1,199,000
Washington	23.43	1,360,000
West Virginia	24.62	347,000
Wisconsin	20.19	904,000
Wyoming	22.56	98,000
National	19.86	49,564,000

<sup>\*</sup>According to SAMHSA, "Any Mental Illness [AMI] is defined as having a diagnosable mental, behavioral, or emotional disorder, other than a developmental or substance use disorder, assessed by the Mental Health Surveillance Study [MHSS] Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition—Research Version—Axis I Disorders [MHSS-SCID], which is based on the 4th edition of the *Diagnostic and Statistical Manual of Mental Disorders* [DSM-IV]."

### TD Infographic

**Download** the below infographic that provides an overview of TD and its impact on patients.



#### **Template Social Posts and Graphics**

We encourage you to use the hashtag **#TDAwarenessWeek** for all relevant content you post on social media. Throughout the week, we'll be publishing content on our **new** Neurocrine Twitter channel, **@Neurocrine** and will be interacting with content shared from this toolkit. Please tag us and **#TDAwarenessWeek** in your posts.

#### **Sample Posts**

Below are suggested template posts for your preferred social channel that can be tailored as appropriate. High resolution social graphics sized for Facebook, Twitter, Instagram, and LinkedIn can be found on **page 12.** The below social copy can be **downloaded here.** 

#### **Government, Advocacy and Professional Organization Use:**

- [Group Name] is proud to support the 5th Annual #TDAwarenessWeek. Tardive dyskinesia is a condition of uncontrollable movements, which may develop from taking certain mental health medications. Learn more at TalkAboutTD.com
- Today the [Building] in [City] is being lighted with blue to commemorate #TDAwarenessWeek. Tardive dyskinesia (TD) is a condition of uncontrollable movements affecting ~600k people in the U.S. Learn more: TalkAboutTD.com
- May 1st marks the beginning of the 5th Annual #TDAwarenessWeek. We're proud to support the ~600,000 people in the U.S. affected by TD. Learn more about this condition at TalkAhoutTD.com
- The first full week of May is officially recognized as #TDAwarenessWeek. The week, occurring during #MentalHealthAwarenessMonth, serves to educate the community on tardive dyskinesia (TD), a condition of uncontrolled movements. Learn more at: TalkAhoutTD.com
- #DYK: Uncontrollable movements caused by tardive dyskinesia (TD) can look or feel different from person to person, and manifest differently from day to day. This #TDAwarenessWeek, commit to learning more at TalkAboutTD.com
- Tardive dyskinesia (TD) is a condition of uncontrollable movements, which may develop from taking certain important mental health medications. To help raise awareness, many states across the country have recognized this week #TDAwarenessWeek. Learn more at TalkAboutTD.com
- This #TDAwarenessWeek, we are helping bring awareness of tardive dyskinesia (TD). Explore first-hand stories from individuals living with the condition at TalkAboutTD.com

- Tardive dyskinesia (TD) presents itself uniquely in everyone who develops it. This #TDAwarenessWeek, learn how you can identify TD signs, symptoms and potential treatment options at TalkAboutTD.com
- What do you know about tardive dyskinesia (TD)? This week is the 5th Annual #TDAwarenessWeek, and we are proud to help spread the word about this condition. To learn more, visit TalkAboutTD.com
- As of this year, all 50 states and D.C. have recognized the first week of May to be #TDAwarenessWeek, shining a light on tardive dyskinesia (TD), a condition that causes uncontrollable movements. Learn more about TD at TalkAboutTD.com
- Tardive dyskinesia (TD) can have a big impact on individuals' lives in fact, those with diagnosed or suspected TD reported it can affect everyday activities, including their ability to work, eat, and sleep. Learn more: TalkAboutTD.com #TDAwarenessWeek
- This #TDAwarenessWeek, we're spreading the word about tardive dyskinesia, a condition of uncontrollable movements. Learn more at TalkAboutTD.com

#### **Specific For Government Use:**

#### **Government - State Advocacy:**

- Tardive dyskinesia (TD) is a condition of uncontrollable movements and affects
   ~600k people in the U.S. alone. [State] is proud to recognize the first full week of May
   as #TDAwarenessWeek. To learn more, visit TalkAboutTD.com
- #DYK: The first full week of May is officially recognized by [State] as
   #TDAwarenessWeek. The week, occurring during #MentalHealthAwarenessMonth,
   serves to educate the community on tardive dyskinesia (TD), a condition of uncontrolled movements. Learn More: TalkAboutTD.com
- [State] is proud to recognize this week as #TDAwarenessWeek. Tardive dyskinesia (TD) affects ~600k people in the U.S. and is a condition of uncontrollable movements, which may develop after taking certain important mental health medications. Learn more: TalkAboutTD.com
- The [Gov/Legislative Body] has declared May 1-7 #TDAwarenessWeek. For the fifth year, this week recognizes the emotional and physical impact that movement disorders like tardive dyskinesia (TD) can have on people and their families. Learn more about TD at TalkAboutTD.com

- [State] recognizes the first full week of May as #TDAwarenessWeek. This year is the 5th year dedicated to raising awareness of tardive dyskinesia, an involuntary movement disorder that affects ~600,000 people in the U.S. Learn more at TalkAboutTD.com
- We and [Tag Governor handle] recognize the first full week of May as #TDAwarenessWeek. We are committed to raising awareness of mental health conditions and related movement disorders, like tardive dyskinesia (TD).
- Thank you [Gov/Legislative Body or Tag Governor handle] for your continued support in recognizing #TDAwarenessWeek and support of individuals who have been diagnosed with tardive dyskinesia, a movement disorder.

#### **Government - Elected Officials:**

- [This year, Last year, or in 20XX], I signed the #TDAwarenessWeek proclamation encouraging [State] citizens to learn more about tardive dyskinesia (TD), a real condition of involuntary movements that affects ~600k people in the U.S. Learn more about TD at TalkAboutTD.com
- [State] is proud to recognize this week as #TDAwarenessWeek. Tardive dyskinesia (TD) affects ~600k people in the U.S. and is a condition of uncontrollable movements, which may develop after taking certain important mental health medications. Learn more: TalkAboutTD.com
- The [Gov/Legislative Body] has declared May 1-7 #TDAwarenessWeek. For the fifth year, this week recognizes the emotional and physical impact that movement disorders like tardive dyskinesia (TD) can have on individuals and their families. Learn more: TalkAboutTD.com
- Today I join [Tag Governor handle] in recognizing the first full week of May as #TDAwarenessWeek for people who have been diagnosed with tardive dyskinesia (TD), an involuntary movement disorder, in [State]. Visit TalkAboutTD.com for more.
- Thank you [Gov/Legislative Body or Tag Governor handle] for your leadership in recognizing #TDAwarenessWeek and support of people who have been diagnosed with the involuntary movement disorder, tardive dyskinesia.

#### **Government - First Spouses:**

- [State] recognizes the first full week of May as #TDAwarenessWeek to raise awareness about tardive dyskinesia (TD), an involuntary movement disorder that can affect people living with mental health conditions. Learn more at TalkAboutTD.com
- Today I'm joining [Tag Spouse Handle] to bring awareness to tardive dyskinesia, a real, lasting condition of involuntary movements which affects ~600,000 people in the U.S. Learn more about the 5th anniversary of #TDAwarenessWeek at TalkAboutTD.com

#### For Biotech Association Use:

- Six years ago, there were no FDA approved treatments for tardive dyskinesia (TD).
   Today, there are two approved treatments available for individuals. This week, we recognize #TDAwarenessWeek and the work that has been done to support those living with TD.
- Without innovation there may never have been treatments for tardive dyskinesia (TD). This week as we support #TDAwarenessWeek, we recognize the biopharmaceutical industry and its investment in creating medicines to treat unmet medical needs.
- [Group Name] is proud to support the 5th Annual #TDAwarenessWeek. Tardive dyskinesia (TD) is a condition of uncontrollable movements, which may develop from taking certain mental health medications. Learn more at TalkAboutTD.com
- [Group Name] officially recognizes the first full week of May as #TDAwarenessWeek. The week, occurring during #MentalHealthAwarenessMonth, serves to educate the community on tardive dyskinesia (TD), a condition of uncontrolled movements. Learn More: TalkAboutTD.com

#### **Suggested Graphics**

We encourage you to **download these graphics** to incorporate into your social media posts, cover images, or existing messaging to help spread awareness during TD Awareness Week.



#### **Test Your Knowledge Fact Sheet**

Bust common myths about TD by **downloading** the Test Your TD Knowledge fact sheet.

#### Test Your Tardive Dyskinesia (TD) Knowledge

Myth: TD movements only occur in the face and are always rapid and jerky in appearance.

Fact: Specific TD movements may include the following and could affect the face, torso, and/or other body parts.<sup>1,2</sup> Movements may appear rapid and jerky and/or slow and writhing.<sup>1,2</sup>



Lip smacking, puckering, or pursing



Tongue darting or protrusion



**Excessive** blinking



Jaw chewing, clenching, or side-to-side movements



Twisting or dancing fingers and toes

#### Myth: There are no known specific risk factors for why people develop TD.

Fact: TD symptoms can start after taking antipsychotics for a few months.3.4 In addition to taking mental health medicine, the following factors may also play a role in your risk for TD:

- Having a mood disorder, such as depression or bipolar disorder<sup>5</sup>
- Older age (55+)6

Myth: It takes a couple of years, at least, for TD to develop.

Fact: TD may develop after a few months of taking certain types of mental health medicine (antipsychotics) to treat bipolar disorder, depression, schizoaffective disorder, or schizophrenia.3,5,9

Myth: Once you stop taking your mental health medicines your TD symptoms will stop. Fact: TD is a chronic condition that is often persistent and generally does not go away without treatment.5,10

Myth: There are no FDA-approved treatment options for adults who live with TD.

Fact: There are FDA-approved treatments for TD. If you or someone you know is experiencing symptoms, it's important to talk to a healthcare professional about potential treatment options.

Learn more about TD, living with TD, and how to treat TD by visiting TalkAboutTD.com

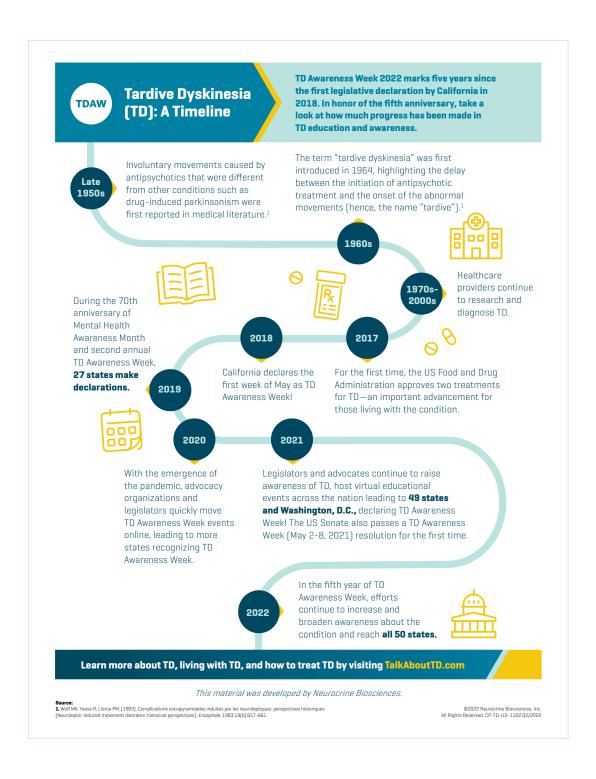
This material was developed by Neurocrine Biosciences.

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#### Tardive Dyskinesia and TD Awareness Week Through the Years Timeline

Learn about when TD was first recognized and when treatments became available for the condition by **downloading** this fact sheet.



#### **National and State-Level Backgrounders**

These backgrounders are intended to be for a print and/or digital capacity and provide an overview of TD prevalence rates and symptoms associated with the condition.

#### **Download the National Backgrounder**

Available in two versions, black and white and color, this backgrounder is intended to be used at a national level to show broad, overarching mental health statistics in the U.S.

#### **Tardive Dyskinesia Awareness Week** Raise awareness for tardive dyskinesia (TD) during TD Awareness Week's 5th anniversary Tardive dyskinesia is an involuntary movement disorder that is TD is estimated to affect associated with taking certain medications (antipsychotics) to treat bipolar disorder, depression, schizophrenia, or schizoaffective disorder. <sup>13</sup> I is characterized by uncontrollable, abnormal, and repetitive movements of the face, torso, and/or other body parts.<sup>8</sup> ~600,000 people in the United States<sup>2,5</sup> Even though TD can look or feel different from day to day, TD is a real, chronic condition and symptoms may be persistent.<sup>3</sup> Imagine a patient who is struggling to control their mental health and then is faced with uncontrollable movements, including.<sup>3,4</sup> Lip puckering or smacking Tongue darting, sticking out, or pushing inside of cheek Excessive blinking or squinting again and again Excessive blinking or squinting again and again These involuntary movements associated with TD can impact patients socially, physically, and emotionally, and making them feel embarrassed or judged by others and, in some cases, lead them to withdraw from society and isolate themselves from the outside world.<sup>18-8</sup> Despite the number of people impacted by the condition, many people are still unfamiliar with TD. 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 of TD, states are being asked to declare Tardive Dyskinesia Awareness Week during the first full week of May 1-7, 2022. may is also mental inearth revalences within, and as we with on inclease awareness and support for those impacted by mental health conditions, it is important to remember that those living with a mental illness and taking antipsychotics for a prolonged time may develop or already have TD. 1 in 5 Over the past 4 years, and entering the 5th anniversary, 49 states, Washington, DC, and a broad coalition of mental health advocacy organizations recognized the first week of May as Tardive Dyskines Awareness Week. mental illness.9 Learn more about TD, living with TD, and how to treat TD by visiting TalkAboutTD.com. This material was devaloped by Neurocrine Ringriences

#### **Download the State-Level Backgrounder**

Available in color-only versions, this local version has been developed for all 50 states and Washington D.C. These are intended to be used at a state level, as each backgrounder has mental health statistics that are specific to each state.



#### **Template Post / Email**

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

[IF SENDING AS AN EMAIL, INSERT: Dear Constituents/All,]

**FOR STATES:** [INSERT OFFICE OF STATE OFFICIAL] is proud to sponsor the resolution declaring the first full week of May (1-7), 2022, as Tardive Dyskinesia (TD) Awareness Week in the state of [INSERT STATE].

**FOR LOCAL ADVOCACY CHAPTERS:** We are pleased to recognize the first full week of May [1-7], 2022, as Tardive Dyskinesia (TD) Awareness Week in the state of [INSERT STATE].

**FOR NATIONAL ADVOCACY GROUPS:** This Mental Health Awareness Month, we are proud to recognize the first full week of May (1-7), 2022, 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, schizophrenia, or schizoaffective disorder. TD affects approximately 600,000 people in the U.S.<sup>1-4</sup> By declaring the first week of May as TD Awareness Week, **(FOR STATE OFFICIALS/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 Awareness Month, an important time to acknowledge the 1 in 5 US adults living with a mental illness.<sup>5</sup>

## FOR STATE OFFICIALS/LOCAL ADVOCACY CHAPTERS - PULL FROM ABOVE STATE STATS ON PAGES 5 & 6:

Specifically, approximately [XXX,XXX] adults in [INSERT STATE] are living with a mental illness, and many people with a mental illness may also have TD.<sup>6,7</sup>

**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.<sup>8</sup> Despite this, research shows a gap in awareness and need for further education.<sup>9</sup> 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 could negatively impact 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.<sup>10</sup>

**FOR STATES:** Thank you for your commitment to raising awareness of tardive dyskinesia and supporting the mental health community. **[**OFFICE OF STATE OFFICIAL**]** encourages everyone across **[**INSERT STATE**]** to acknowledge the first full week of May as TD Awareness Week. To learn more about mental illness and TD, visit TalkAboutTD.com.

**FOR LOCAL ADVOCACY CHAPTERS:** Thank you for your commitment to raising awareness of tardive dyskinesia and supporting the mental health community. We encourage everyone across [INSERT STATE] to acknowledge the first full 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 <a href="mailto:ninds.nih.gov/Disorders/All-Disorders/">ninds.nih.gov/Disorders/All-Disorders/</a> Tardive-Dyskinesia-Information-Page

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

#### Reference Block for Template Post / Email

- 1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. American Psychiatric Association; 2013:712.
- 2. Kenney C, Hunter C, Davidson A. Metaclopramide, an increasingly recognized cause of tardive dyskinesia. *J Clin Pharmacol.* 2008;48(3):379–384.
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#### References [outside of pages 16-17 references]

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- 2. Data on File. Neurocrine Biosciences.
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# Tardive Dyskinesia Awareness Week (TDAW) 2022

May 1-7, 2022

# **Toolkit & Resources**

