### **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.<sup>3-6</sup>

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.<sup>7</sup> 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; <a href="mailto:mrest@neurocrine.com">mrest@neurocrine.com</a>), Todd Bledsoe, Executive Director of Patient Engagement and Advocacy, (202-236-8202; <a href="mailto:tbledsoe@neurocrine.com">tbledsoe@neurocrine.com</a>) and Chuck Harman, Director of Patient Engagement and Advocacy (858-245-5871; <a href="mailto:charman@neurocrine.com">charman@neurocrine.com</a>).

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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.<sup>3,5,8</sup>

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

#### **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.<sup>1-4</sup> 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.<sup>5</sup>

**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.<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. Despite this, research shows a gap in awareness and need for further education. 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.

**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 <a href="https://www.ninds.nih.gov/Disorders/All-Disorders/Tardive-Dyskinesia-Information-Page">https://www.ninds.nih.gov/Disorders/All-Disorders/Tardive-Dyskinesia-Information-Page</a>

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

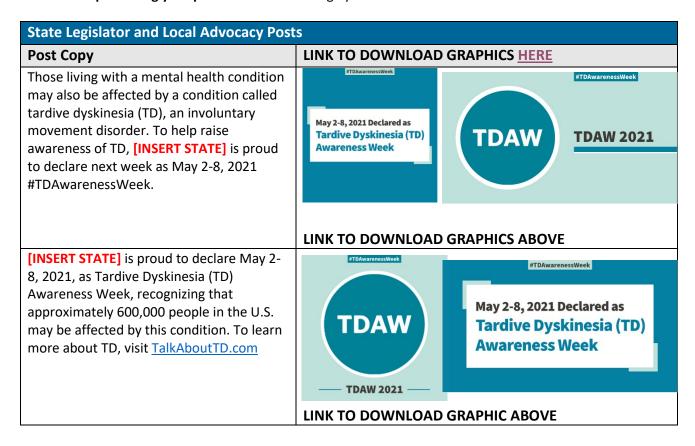
#### References

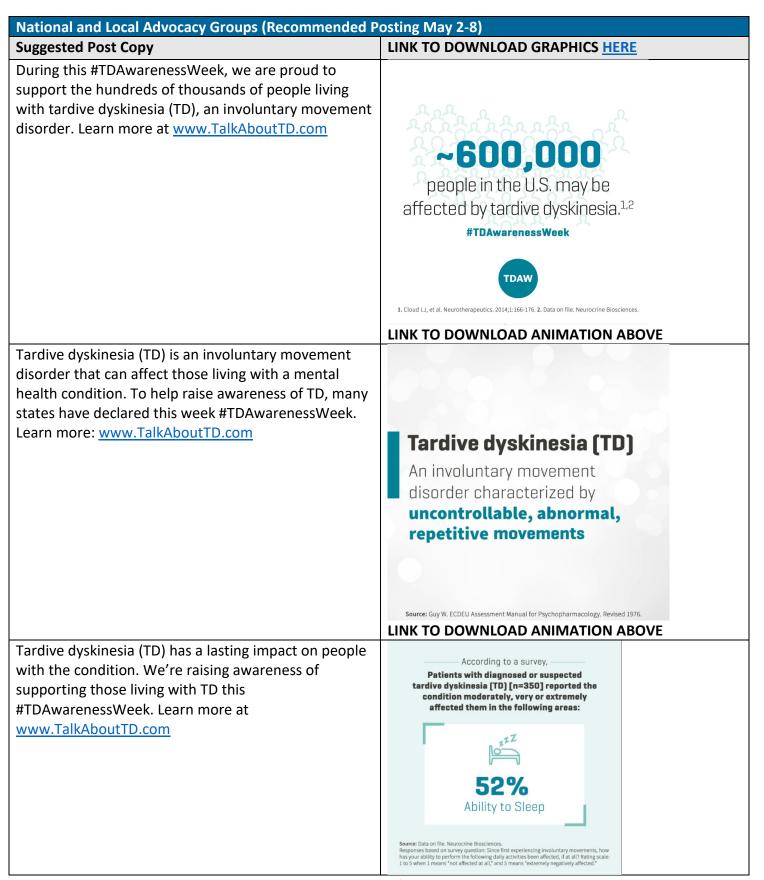
- 1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. American Psychiatric Association; 2013:712.
- 2. Kenney C, Hunter C, Davidson A. Metaclopramide, an increasingly recognized cause of tardive dyskinesia. *J Clin Pharmacol*. 2008;48(3):379-384.
- 3. Cloud LJ, Zutshi D, Factor SA. Tardive dyskinesia: therapeutic options for an increasingly common disorder. *Neurotherapeutics*. 2014;11(1):166-176.
- 4. Data on file. Neurocrine Biosciences.
- 5. NAMI. Mental health by the numbers. Accessed February 5, 2021. https://www.nami.org/learn-more/mental-health-by-the-numbers
- 6. Carbon M, Hsieh CH, Kane JM, Correll CU. Tardive dyskinesia prevalence in the period of second-generation antipsychotic use: a meta-analysis. *J Clin Psychiatry*. 2017;78(3):e264-e278.
- 7. Mental Health America. 2021 State of Mental Health in America. Accessed February 5, 2021. https://www.mhanational.org/research-reports/2021-state-mental-health-america
- 8. Ascher-Svanum H, Zhu B, Faries D, Peng X, Kinon BJ, Tohen M. Tardive dyskinesia and the 3-year course of schizophrenia: results from a large, prospective, naturalistic study. *J Clin Psych*. 2008;69(10):1580-1588.
- 9. Data on file. Neurocrine Biosciences.
- 10. Caroff S, Yeomans K, Lenderking W, et al. RE-KINECT: a prospective study of the presence and healthcare burden of tardive dyskinesia in clinical practice settings. *J Clin Psychopharmacol*. 2020;40(3):259-268.

#### **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 <u>@TalkAboutTD Twitter</u> and the <u>Talk About TD Facebook</u> 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 <u>Facebook page</u> or <u>@TalkAboutTD</u> Twitter handle when publishing your post. We also encourage you to use #TDAwarenessWeek in all relevant content.





# 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 www.TalkAboutTD.com

# 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 ANIMATION ABOVE

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

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="https://www.TalkAboutTD.com">www.TalkAboutTD.com</a>



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



Over the past three years, 33 states and Washington, D.C., have declared the first

#### TD is an involuntary movement disorder

that may develop after a few months TD is characterized by uncontrollable, abnormal and repetitive movements of



**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\*\*







- † Base: Poders ATU 2020. Target patients (diagnosed TD or suspected 100 in –350 that were "moderately, very or continuity attacked" in these areas by their involuntary movements. The survey evaluated 1,000 patients on medications such as antisportation.

  Responses based on survey questers. To what extent is the physical impact or your institutionary movements insurating? Rading scale: 1 to 5 where 1 means "not as all insurating" and 5 means "contented yinserating".

  Responses based on survey questers. These does experiencing involuntary movements, how has your ability to periorm the reliability daily activities been arrespond to a large Rading scale: 1 to 5 when 1 means "not arrespond a varieties of a sit of an 5 means respond to 5 means are produced and the survey questers."

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

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#### **Backgrounder on TD Awareness Week**

Audience	Download Backgrounders
For national advocacy groups:	Download Backgrounders Here
For state officials/local advocacy chapters:	Download Individual State Backgrounders Here
Includes backgrounders for individual state use that	
include state-by-state mental health statistics	

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

Tardive dyskinesia (TD) is a condition of uncontrollable movements affecting the face, torso, and/or other body parts. <sup>12</sup> TD may develop after a few months of taking certain medications to treat bipolar disorder, depression, or schizophrenia. <sup>1,2,5</sup>

TD is estimated to affect ~600,000 people in the United States<sup>3,4</sup>

Even though TD can look or feel different from day to day, the symptoms may be persistent and often are irreversible. I Imagine a patient who is struggling to control their mental health and then is faced with uncontrollable movements, including 2.6:

- · Lip puckering, pouting, or smacking
- Tongue darting, sticking out, or pushing inside of cheek
- Excessive blinking or squinting again and again
- Jaw biting, clenching, or side-to-side movements
   Twisting hands or dancing fingers
- Rocking, leaning back, or torso and hip shifting
- Gripping feet or stretched toes

These involuntary movements associated with TD can impact patients socially, physically, and emotionally, <sup>7</sup> 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.<sup>27-9</sup>

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 2-8 2021.

[In [state],[number] people, or [XX%] of adults in the state, live with a mental illness.]  $^{10}$  OR [1 in 5 US adults live with a mental illness.]  $^{11}$ 

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, 33 states, Washington, DC, and a broad coalition of mental health advocacy organizations 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 and following @TalkAboutTD on Twitter and Facebook



#### References:

Reference:
A contract Psychiatric Association (Deyroetic and State Intel Menual of Menual District And State Only American District Association (2012). 2. Each Force on Builded Districts in English Districts Association (2012). 2. Each Force on Builded Districts in English Districts Association (2012). 2. Each Force on Builded Districts in English Districts Association Association Association (2012). 2. Each Force on Builded Districts in English Districts Association Association (2012). 2. Each Force Only Association (2

#### References

- Hamel L, Kearney A, Kirzinger A, Lopes L, Munana C, Brodie M. KFF Health Tracking Poll July 2020. Kaiser Family Foundation. July 27, 2020. Accessed on February 18, 2021. https://www.kff.org/coronavirus-covid-19/report/kff-health-tracking-poll-july-2020
- Centers for Disease Control and Prevention. Coronavirus disease 2019 (COVID-19): coping with stress. Accessed September 21, 2020. https://www.cdc.gov/coronavirus/2019-ncov/daily-lifecoping/managing-stress-anxiety.html
- 3. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. American Psychiatric Association; 2013:712.
- 4. Kenney C, Hunter C, Davidson A. Metaclopramide, an increasingly recognized cause of tardive dyskinesia. *J Clin Pharmacol*. 2008;48(3):379-384.
- 5. Cloud LJ, Zutshi D, Factor SA. Tardive dyskinesia: therapeutic options for an increasingly common disorder. *Neurotherapeutics*. 2014;11(1):166-176.
- 6. Data on file. Neurocrine Biosciences.
- 7. Ascher-Svanum H, Zhu B, Faries D, Peng X, Kinon BJ, Tohen M. Tardive dyskinesia and the 3-year course of schizophrenia: results from a large, prospective, naturalistic study. *J Clin Psych*. 2008;69(10):1580-1588.
- 8. Carbon M, Hsieh CH, Kane JM, Correll CU. Tardive dyskinesia prevalence in the period of second-generation antipsychotic use: a meta-analysis. *J Clin Psychiatry*. 2017;78(3):e264-e278.
- 9. Mental Health America. *2021 State of Mental Health in America*. Accessed February 5, 2021. https://www.mhanational.org/research-reports/2021-state-mental-health-america
- 10. NAMI. Mental health by the numbers. Accessed February 5, 2021. <a href="https://www.nami.org/learn-more/mental-health-by-the-numbers">https://www.nami.org/learn-more/mental-health-by-the-numbers</a>
- 11. Data on file. Neurocrine Biosciences.
- 12. Caroff S, Yeomans K, Lenderking W, et al. RE-KINECT: a prospective study of the presence and healthcare burden of tardive dyskinesia in clinical practice settings. *J Clin Psychopharmacol*. 2020;40(3):259-268.