



Jazz Pharmaceuticals Survey Highlights Prevalence of Misinformation and Misperception About Narcolepsy Among Americans

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Jazz Pharmaceuticals announces findings from a consumer survey underscoring a need for better understanding of sleep disorders

Among survey respondents who reported being familiar with symptoms of narcolepsy there were misperceptions about primary symptoms of the condition

DUBLIN, Sept. 30, 2019 /PRNewswire/ -- Jazz Pharmaceuticals plc (Nasdaq: JAZZ) today announced the results of a consumer survey of more than 1,000 Americans measuring public perception and knowledge of sleep disorders like narcolepsy. Narcolepsy is a serious condition that is often overlooked and misunderstood, and people with narcolepsy can live with symptoms for years before receiving a proper diagnosis.¹ It is estimated that half of people living with narcolepsy may not know they have the chronic neurological condition.²

The online survey, conducted by Toluna Analytics and sponsored by Jazz Pharmaceuticals, suggests that while most respondents claim to be familiar with narcolepsy, their information may be factually inaccurate and may be influenced by the entertainment industry.³ According to the survey results, most respondents (83%) reported they are aware of narcolepsy in that they have heard of the condition or are familiar with its symptoms (51% and 32%, respectively) and some respondents (17%) reported they've never heard of narcolepsy.³

Some of the respondents who reported they have heard of narcolepsy or are familiar with its symptoms said they heard about the condition from movies (24%) or television shows (35%).³ Additionally, 43% of survey respondents who are aware of narcolepsy believe people with narcolepsy fall down often because they lose consciousness while walking or standing.³ These findings from the survey suggest that exaggerated portrayals of narcolepsy in movies and television may contribute to misperceptions of the condition and its characteristic symptoms.

"On the heels of the inaugural World Narcolepsy Day, which took place on Sunday, September 22, 2019, we're pleased to see these continued efforts to raise critical awareness for narcolepsy," said Julie Flygare, J.D., president and CEO of Project Sleep. "These survey results reiterate that public understanding of narcolepsy is limited and often inaccurate and there is a need for the entire narcolepsy community, including patient advocacy organizations, researchers, clinicians, drug developers and local communities to continue working to help combat misperceptions about narcolepsy that are common among the general population in the U.S."

Of the people who reported they are familiar with the symptoms of narcolepsy, only 10% believe all people living with the condition have excessive daytime sleepiness (EDS),³ when in fact it is the essential symptom of narcolepsy – everyone with narcolepsy has EDS.⁴ Further, only half (51%) of people who reported they have heard of narcolepsy or are familiar with the symptoms considered EDS to be a potential indicator of narcolepsy and 73% had not heard of cataplexy³ – a symptom only people with narcolepsy experience, except in rare cases.⁵

Survey respondents were also asked about their level of sleepiness during the day. After being informed of the definition of EDS, the inability to stay awake and alert during the day resulting in drowsiness and unplanned lapses in sleep,^{1,6,7} 65% of respondents who noted they are familiar with EDS reported this is something they commonly experience and 15% reported this is something they sometimes experience.³

Being too tired may have an impact on day-to-day life for any population, both personally and professionally, which survey results also revealed. One-third of respondents reported driving a vehicle while drowsy and 11% reported being in a car accident as a result of being tired.³ At work, survey respondents reported inability to concentrate (38%), as well as lack of productivity (36%) and motivation (45%) due to being too tired.³ More than 30% reported needing to take a personal day because they were too tired to go to work, and approximately 20% reported making a mistake that resulted in personal injury or injury to someone else.³ Despite these serious issues, only 31% of the respondents had sought medical help for sleep or sleepiness issues.³

"At Jazz, we are committed to raising awareness of sleep disorders, like narcolepsy, and it's clear there is still work to be done to clarify misconceptions related to the condition and help people understand and identify its key symptoms," said Jed Black, M.D., senior vice president, Sleep and Neuroscience at Jazz Pharmaceuticals and adjunct professor, Stanford University Medical Center, Stanford Center for Sleep Sciences and Medicine. "Many people experiencing symptoms of narcolepsy, like EDS, don't realize that it could be the result of a serious, but treatable, neurological condition. We hope these survey results will encourage people to learn more about what narcolepsy is, and empower people experiencing symptoms of narcolepsy, like EDS or cataplexy, to talk with a doctor."

Jazz is committed to bringing more awareness to narcolepsy and other serious sleep disorders and helping people with these conditions at every stage of their journey – from education and diagnosis to treatment and patient assistance.

About the Survey

The Jazz Pharmaceuticals narcolepsy survey was conducted online by Toluna Analytics on behalf of Jazz Pharmaceuticals between August 23 and August 26, 2019 among a nationally representative sample of 1,300 adults ages 18 and older in the U.S.

About Narcolepsy

Narcolepsy is a chronic, debilitating neurological disorder characterized by EDS, and the inability to regulate sleep-wake cycles normally.⁶ It affects an estimated one in 2,000 people in the United States, with symptoms typically appearing in childhood. It is estimated that more than 50% of people with narcolepsy have not been diagnosed.² Studies have shown it may take 10 years or more for people with narcolepsy to receive a diagnosis.¹ Excessive daytime sleepiness is the primary symptom of narcolepsy and is present in all people with the disorder.⁸ EDS is characterized by the inability to stay awake and alert during the day resulting in drowsiness and unplanned lapses into sleep.^{2,8,9} There are five primary symptoms of narcolepsy, including EDS, cataplexy, disrupted nighttime sleep, sleep-related hallucinations, and sleep paralysis.¹⁰ While all people with narcolepsy experience EDS, not all individuals with narcolepsy experience all five symptoms.^{7,9}

About Cataplexy

Cataplexy, the most specific symptom of narcolepsy, is the sudden, generally brief (<2 minutes) loss of muscle tone with retained consciousness. It is usually triggered by strong emotions, such as laughter, surprise, or anger.^{7,9,11} Although many emotions can potentially lead to cataplexy, those associated with mirth are usually the most potent.⁷ Cataplexy occurs in about 70% of people with narcolepsy.¹¹ Presentation differs widely among people with narcolepsy, ranging from sporadic partial attacks triggered by laughter to frequent complete collapse brought about by a variety of emotions.^{7,9} Complete collapse is less common.⁹ More commonly, episodes of cataplexy involve only certain muscle groups, such as arms and legs (e.g., knees buckling), the head and neck (e.g., head drooping), or the face and jaw (e.g., sagging, slurred speech, eyelid drooping).^{7,9,11,12}

About Jazz Pharmaceuticals plc

Jazz Pharmaceuticals plc (Nasdaq: JAZZ), a global biopharmaceutical company, is dedicated to developing life-changing medicines for people with limited or no options. As a leader in sleep medicine and with a growing hematology/oncology portfolio, Jazz has a diverse portfolio of products and product candidates in development, and is focused on transforming biopharmaceutical discoveries into novel medicines. Jazz Pharmaceuticals markets Sunosi[®] (solriamfetol), Xyrem[®] (sodium oxybate) oral solution, Defitelio[®] (defibrotide sodium), Erwinaze[®] (asparaginase *Erwinia chrysanthemi*) and Vyxeos[®] (daunorubicin and cytarabine) liposome for injection in the U.S. and markets Defitelio[®] (defibrotide), Erwinaze[®] and Vyxeos[®] 44 mg/100 mg powder for concentrate for solution for infusion in countries outside the U.S. For country-specific product information, please visit www.jazzpharmaceuticals.com/medicines. For more information, please visit www.jazzpharmaceuticals.com and follow us on Twitter at [@JazzPharma](https://twitter.com/JazzPharma).

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