



## "AWAKEN" Survey Finds Only 50 Percent of Americans Understand Significant Health Impact of Narcolepsy, and Many Physicians Not Comfortable Diagnosing the Sleep Disorder

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**- Despite serious nature of narcolepsy, Americans also misperceive its severity compared to other diseases of similar health concern or prevalence -**

DUBLIN, June 11, 2012 /PRNewswire/ -- A survey of narcolepsy awareness conducted in the United States and released today by Jazz Pharmaceuticals (Nasdaq: JAZZ) confirms that while the majority of Americans view sleep as highly important, only half (50%) believe narcolepsy can significantly impact overall health, despite evidence that symptoms of this serious sleep disorder can be severe enough to disrupt a person's social, personal and professional life and limit their activities.(1) Findings further reveal that compared to a set of other diseases of similar concern or prevalence, such as Parkinson's and multiple sclerosis, narcolepsy was rated among the lowest in severity, and only 55% of adults who had heard of the disease considered it to be "very or extremely serious."

Results from the "AWAKEN Survey: Awareness and Knowledge of Narcolepsy" also reveal similar perceptions within the medical community, with primary care physicians (PCPs) and sleep specialists rating narcolepsy among the lowest in severity compared to other diseases (75% and 82%, respectively, considered it to be "very or extremely serious"). Physicians also struggle with narcolepsy symptom recognition and diagnosis, with only 9% of PCPs and 42% of sleep specialists admitting they are comfortable diagnosing the disorder. According to current figures, less than half of the estimated 125,000-200,000 people living with narcolepsy have been properly diagnosed,(2) and many are not definitively diagnosed until approximately 10-15 years after the first symptoms appear.(3)

AWAKEN was developed with input from representatives of the narcolepsy community, including leaders of the Narcolepsy Network, Wake Up Narcolepsy and the National Sleep Foundation. Harris Interactive conducted the online survey among 1,000 adults, 300 primary care physicians and 100 sleep specialists in May 2012 to assess the current level of narcolepsy awareness and identify gaps in disease education.

"The AWAKEN findings suggest that serious sleep disorders such as narcolepsy can be easily overlooked by patients and physicians as a result of low awareness or misunderstanding of disease severity," said Russell Rosenberg, PhD, director of The Atlanta School of Sleep Medicine and Technology and current chairman of the National Sleep Foundation. "These data reinforce the need for additional narcolepsy education and support resources to help bridge knowledge gaps and enhance patient care."

"Narcolepsy can be quite debilitating and impact education, employment opportunities and the personal lives of those who live with it, yet knowledge of the disorder has not kept pace with other chronic conditions of comparable health concern," said Sara Kowalczyk, MA, MPH, president of the Narcolepsy Network. "What's more is that physicians struggle with narcolepsy symptom recognition and therefore may not be initiating important discussions about sleep with their patients."

Specific findings from the AWAKEN Survey reveal:

- Seventy percent (70%) of adults have heard of narcolepsy – the lowest percentage among a range of diseases, including diabetes, sleep apnea, Alzheimer's, Parkinson's, multiple sclerosis, schizophrenia, restless leg syndrome and cystic fibrosis.
- Of those adults who have heard of narcolepsy, only 7% consider themselves "very or extremely knowledgeable" about the disorder.
- Similarly, only a quarter (24%) of PCPs and nearly two-thirds (62%) of sleep specialists consider themselves "very or extremely knowledgeable" about narcolepsy compared to the other diseases.
- Even sleep specialists may not fully recognize the symptoms of narcolepsy, with only a fifth (22%) identifying all five symptoms of the disease – excessive daytime sleepiness, cataplexy (sudden loss of muscle tone), sleep paralysis, hypnagogic hallucinations and disruptive nocturnal sleep.
- Additionally, 22% of sleep specialists report they are "not very or not at all comfortable" diagnosing narcolepsy.
- Among PCPs and sleep specialists who see three or more narcolepsy patients a month, narcolepsy is still one of the least discussed topics compared to other sleep-related disorders – higher only than sleep paralysis. Other sleep-related conditions surveyed include insomnia, obstructive sleep apnea, excessive daytime sleepiness, restless leg syndrome/periodic limb movement disorders and hypersomnia.

"The AWAKEN findings show just how in the dark many Americans still are about the severity of narcolepsy and will certainly inform our organization's ongoing disease education initiatives," said Kevin Cosgrove, president of Wake Up Narcolepsy. "We're constantly striving to advance narcolepsy awareness to help ensure patients receive accurate diagnosis and access to effective treatment and support systems."

Narcolepsy is a chronic neurologic brain disorder caused by the brain's inability to regulate sleep-wake cycles normally, and can affect all aspects of a person's life, emotionally, physically, socially and academically. Contrary to common belief, people with narcolepsy do not spend more of their time asleep during a 24-hour period. In addition to suffering from excessive daytime sleepiness (EDS) and uncontrollable sleep episodes, many individuals also experience poor sleep quality that can involve frequent awakenings during nighttime sleep and other sleep disorders.(4)

### Leadership in the Narcolepsy Community

Jazz Pharmaceuticals is dedicated to working with patients, providers and advocacy organizations to further the understanding of narcolepsy and help

the community navigate the complexities associated with the disorder.

"As part of our enduring commitment to patients with narcolepsy, we're dedicated to improving awareness of this serious disorder and helping the sleep community tackle misunderstanding, misperceptions and misdiagnosis," said Bruce Cozadd, chairman and chief executive officer of Jazz Pharmaceuticals.

The company also supports a variety of patient and medical education initiatives to help improve awareness of narcolepsy, its diagnosis and treatment. As part of SLEEP 2012, the 26th Annual Meeting of the Associated Professional Sleep Societies (APSS) in Boston, Jazz Pharmaceuticals provided an educational grant for a continuing medical education roundtable titled "Optimizing Care for the Narcolepsy Patient," where experts discussed the clinical features and diagnosis of narcolepsy and challenges in patient care.

#### **About AWAKEN**

The AWAKEN Survey: Awareness and Knowledge of Narcolepsy is a national online survey commissioned by Jazz Pharmaceuticals and conducted by Harris Interactive in May 2012. The survey was conducted among 1,000 adults (general public, 18+), 300 primary care physicians (general practice, family practice and internal medicine) and 100 sleep specialists (neurologists, psychiatrists, pulmonologists and PCPs) to discern the level of public and physician knowledge of narcolepsy. All physician respondents have practiced 2-30 years, spend at least 75% of their professional time in direct patient care and treat at least 50 patients per month for any condition. Sleep specialist respondents are neurologists, psychiatrists or pulmonologists who treat at least 30 patients a month for sleep disorders, or are primary care physicians who treat at least 30 patients a month for sleep disorders and are board-certified in sleep medicine.

#### **About Jazz Pharmaceuticals**

Jazz Pharmaceuticals plc is a specialty biopharmaceutical company focused on improving patients' lives by identifying, developing and commercializing products that address unmet medical needs. The company has a diverse portfolio of products in the areas of narcolepsy, chronic pain, psychiatry and women's health.

#### **References:**

- (1) "Facts About Narcolepsy." National Institute of Health. National Heart, Lung and Blood Institute. NIH publication no. 96-3649. Oct. 1996. <http://www.nhlbi.nih.gov/health/public/sleep/narcolep.pdf>. Accessed June 1, 2012.
- (2) "Narcolepsy." American Sleep Association Website. <http://sleepassociation.org/index.php?p=aboutnarcolepsy>. Accessed June 1, 2012.
- (3) Morrish et al. "Factors associated with a delay in the diagnosis of narcolepsy." *Sleep Medicine*. 2004; 5:37-41.
- (4) "Narcolepsy Fact Sheet." National Institute of Neurological Disorders and Stroke website. [http://www.ninds.nih.gov/disorders/narcolepsy/detail\\_narcolepsy.htm](http://www.ninds.nih.gov/disorders/narcolepsy/detail_narcolepsy.htm). Accessed June 1, 2012.

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