

New Research at SLEEP 2013 Demonstrates People with Narcolepsy Face Significant Health and Economic Burden and High Rates of Misdiagnosis

First U.S. study to highlight severe comorbidities and economic burden associated with narcolepsy

Survey indicates some sleep specialists may not be comfortable diagnosing narcolepsy

Patients' journeys survey shows narcolepsy diagnosis involves multiple physician visits and misdiagnoses

DUBLIN, June 5, 2013 /PRNewswire/ -- Researchers will present data today that demonstrate people with narcolepsy face significant personal health and economic burden. The Burden of Narcolepsy Disease (BOND) study, the largest of its kind and the first in the United States, found that patients with narcolepsy, with or without cataplexy, were more likely to suffer from a higher frequency of comorbidities such as mental illness, endocrine disorders, digestive disorders and cardiovascular disease, and had more than twice the mean annual medical costs compared with the general population. These data, supported by Jazz Pharmaceuticals plc (Nasdaq: JAZZ), will be presented at SLEEP 2013, the annual meeting of the Associated Professional Sleep Societies LLC (APSS) taking place this week in Baltimore, Md.

Additional results from two surveys presented at SLEEP characterize the impact that narcolepsy, as a currently misunderstood and underdiagnosed medical condition, has on patient care. The Awareness and Knowledge in Narcolepsy (AWAKEN) survey found that almost a quarter of 100 sleep specialists and more than half of 300 primary care physicians surveyed are not comfortable diagnosing narcolepsy. Results from the Patients' Journeys to a Narcolepsy Diagnosis survey of physicians characterize the many challenges patients must overcome and indicate that patients often go through multiple misdiagnoses and physician visits before reaching an accurate narcolepsy diagnosis.

"Jazz Pharmaceuticals plc continues to support ongoing narcolepsy research, such as BOND and AWAKEN, and hopes that awareness of the data presented at SLEEP will help sleep specialists, physicians and the general public better understand narcolepsy as a serious disabling medical condition," said Jed Black, M.D., Vice President, Sleep Medicine, Jazz Pharmaceuticals and Consulting Associate Professor, Stanford University Medical Center, Stanford Center for Sleep Sciences and Medicine.

The Burden of Narcolepsy Disease (BOND) Study

The purpose of the BOND study was to examine comorbidities associated with narcolepsy and the burden of these diseases on patients. As part of the protocol for the study, researchers evaluated the Truven Health Analytics MarketScan® Research Databases, which consist of more than 50 million patients across the United States, to identify a group of more than 9,000 narcolepsy patients each with at least five consecutive years of healthcare data, and matched these patients to more than 46,000 control patients. Jazz Pharmaceuticals sponsored the BOND study, but was not involved in the study design, analysis or scientific representation. The study investigators were not compensated by Jazz Pharmaceuticals.

Given the robust set of data from the BOND study, researchers reported the results in four abstracts presented at SLEEP, including:

- **High Rates of Psychiatric Comorbidity in Narcolepsy:** Patients with narcolepsy had significantly higher frequency of anxiety and mood disorders, and a higher rate of psychiatric medication usage compared with the non-narcolepsy population. [*Abstract/0904, Poster Board 244, June 3, 4:00 - 6:00 p.m.*]
- **High Rates of Medical Comorbidity in Narcolepsy:** Narcolepsy patients had significantly higher frequencies of respiratory, musculoskeletal, endocrine and circulatory conditions across the five-year period when compared with control subjects. [*Abstract/0723, Poster Board 158, June 5, 10:20 a.m. – 12:20 p.m.*]

- **Burden of Illness and Comorbidity in Narcolepsy with Cataplexy:** Patients who have narcolepsy with cataplexy showed significantly higher rates of healthcare utilization and higher frequencies of sleep apnea, cardiovascular disease and pulmonary conditions compared with the non-narcolepsy population. *[Abstract/0725, Poster Board 160, June 5, 10:20 a.m. – 12:20 p.m.]*
- **Healthcare Utilization and Costs in Narcolepsy:** Narcolepsy patients had approximately two-fold higher annual rates of hospital admissions and physician visits compared with control subjects. *[Abstract/0724, Poster Board 159, June 5, 10:20 a.m. – 12:20 p.m.]*

“While the medical community knows that narcolepsy is associated with significant medical comorbidities, BOND is the first study to use U.S. longitudinal patient data to validate the full scope of concomitant illness,” said Dr. Chad Ruoff, Clinical Assistant Professor, Stanford University Medical Center, Stanford Center for Sleep Sciences and Medicine. “The data provide further insight into the impact of narcolepsy on patients and our healthcare system, and suggest how important early diagnosis and regular screening are in reducing this burden.”

The AWAKEN Survey: Physician Knowledge and Diagnosis of Narcolepsy

[Abstract 0730, Poster 165, June 5, 10:20 a.m. – 12:20 p.m.]

This online survey of 1,000 adults, 300 primary care physicians (PCPs) and 100 sleep specialists conducted by Jazz Pharmaceuticals and Harris Interactive found that physicians struggle with narcolepsy symptom recognition and diagnosis. Only nine percent of PCPs and 42 percent of sleep specialists reported that they are comfortable diagnosing narcolepsy, and 22 percent of sleep specialists reported they are “not very or not at all comfortable” diagnosing the disorder.

Patients’ Journeys to a Narcolepsy Diagnosis

[Abstract 0738, Poster 173, June 5, 10:20 a.m. – 12:20 p.m.]

More than 75 expert neurologists, pulmonologists, psychiatrists and other board certified sleep specialists who treat at least five narcolepsy patients per month completed a survey using data from the charts of 252 narcolepsy patients. The survey aimed to provide insight into the patient’s journey to diagnosis for narcolepsy. Jazz Pharmaceuticals conducted the survey and found that 60 percent of patients had been misdiagnosed with other disorders, such as depression, insomnia and/or obstructive sleep apnea, before receiving the appropriate narcolepsy diagnosis, additionally 67 percent of patients saw multiple providers prior to receiving a narcolepsy diagnosis.

“Approximately half of the patients living with narcolepsy go undiagnosed or are misdiagnosed, and many live with the disorder for 10 years before they receive a correct diagnosis,” said Russell Rosenberg, PhD, primary author of AWAKEN, director and chief scientist at NeuroTrial Research and current chairman of the National Sleep Foundation. “Findings from the AWAKEN survey, and more research like this, will help us better understand current physician misperceptions that may contribute to a patient’s journey, and hopefully create more urgency around the need for enhanced narcolepsy screening and diagnosis.”

About Narcolepsy

Narcolepsy is a serious, chronic disorder of the central nervous system characterized by symptoms of excessive daytime sleepiness (EDS), muscle weakness (cataplexy), disrupted nighttime sleep, hypnagogic hallucinations and sleep paralysis. People with narcolepsy experience abrupt shifts between wakeful and REM-like states that are thought to be caused by a loss or impairment of hypocretin-producing neurons in the hypothalamus. The disorder affects approximately one in 2,000 Americans, yet approximately 50 percent of patients remain undiagnosed. Symptoms of narcolepsy often start between the ages of 15 and 25.

Jazz Pharmaceuticals Commitment to Narcolepsy

Jazz Pharmaceuticals is dedicated to working with patients, researchers, providers and advocacy organizations to further the awareness, understanding and improved diagnosis of narcolepsy, and to helping the narcolepsy community navigate the complexities associated with the disorder. As part of this commitment, Jazz Pharmaceuticals supports initiatives and research to improve narcolepsy awareness and to help the sleep community address the misunderstanding, misperceptions and misdiagnosis surrounding the disease.



About Jazz Pharmaceuticals

Jazz Pharmaceuticals plc is a specialty biopharmaceutical company focused on improving patients' lives by identifying, developing and commercializing innovative products that address unmet medical needs. The company has a diverse portfolio of products in the areas of narcolepsy, oncology, pain and psychiatry. For further information, see www.jazzpharmaceuticals.com.

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