While the majority of Americans agree sleep is highly important to overall health (89%), only half (50%) believe narcolepsy can significantly impact health. Americans also misperceive the severity of narcolepsy compared to other diseases of similar health concern or prevalence, and many physicians are not comfortable diagnosing.

**Fact Sheet**

**AWAKEN Survey: Awareness and Knowledge of Narcolepsy**

**About AWAKEN**
- AWAKEN is a national survey designed to quantify public and physician knowledge and misperceptions of narcolepsy and its severity.
- The survey was commissioned by Jazz Pharmaceuticals, designed with input from representatives of the narcolepsy community, including the Narcolepsy Network, Wake Up Narcolepsy and the National Sleep Foundation, and conducted online by Harris Interactive in May 2012.
- AWAKEN surveyed 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 who are board-certified in sleep medicine).

**Key Survey Findings**

**Awareness and knowledge of narcolepsy is low**
Compared to eight other diseases of similar health concern or prevalence:
- Seventy percent (70%) of adults have heard of narcolepsy – the lowest percentage among the range of diseases. (Chart right)
- 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 considered themselves “very or extremely knowledgeable” about narcolepsy.

**The severity of narcolepsy is misunderstood**
Compared to the same diseases:
- Narcolepsy was rated among the lowest in disease severity across all respondent groups. Only 55% of adults*, 75% of PCPs and 82% of sleep specialists believe narcolepsy is “very or extremely serious.” (Chart below)
- Only a third of adults* (32%) and half of PCPs (46%) and sleep specialists (50%) consider narcolepsy to be a significant public health concern.
  - Narcolepsy is considered a low research priority across all respondent groups, with respect to requiring more research and scientific understanding.
  - The perceived economic burden of narcolepsy is also low. A quarter of adults* (24%), slightly more than a third of PCPs (38%) and half of sleep specialists (52%) believe the sleep disorder poses an economic burden.

(Based on respondents who have heard of each condition)
Recognition of narcolepsy symptoms and comfort in diagnosis remains an issue, even among sleep specialists

- Symptoms associated with narcolepsy are not clearly recognized, which may contribute to under- or misdiagnosis of the disorder.
  - Even sleep specialists do not fully recognize all 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.

- Physician comfort in diagnosing narcolepsy is low.
  - Only 9% of PCPs and 42% of sleep specialists are “very or extremely comfortable” diagnosing the disorder.
  - Additionally, 22% of sleep specialists report they are “not very or not at all comfortable” diagnosing narcolepsy.

- Physicians may not be initiating discussions about narcolepsy with their patients.
  - 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.

* Based on general population who indicated they have heard of narcolepsy.