

## National Lieutenant Governors Association

## Resolution In Support of Narcolepsy Education and Support for Patients with the Disease

**WHEREAS,** narcolepsy is a chronic, neurological sleep disorder caused by the brain's inability to regulate sleep-wake cycles, and

WHEREAS, narcolepsy affects an estimated 1 in every 2,000 Americans<sup>i</sup>, and

WHEREAS, narcolepsy is an under-recognized and under diagnosed condition, and

**WHEREAS,** the symptoms of narcolepsy, especially when undiagnosed, can lead to accidents, injuries, and problems with learning, and working, and

WHEREAS, narcolepsy affects people neurologically, socially, and emotionally, and

WHEREAS, narcolepsy affects people of all ages, with onset typically in childhood or adolescence", and

**WHEREAS,** on average, it takes a patient up to 10<sup>iii</sup> years to be diagnosed with narcolepsy after first experiencing symptoms, and

**WHEREAS,** research shows that narcolepsy patients have an increased prevalence of high blood pressure, heart attack, stroke, heart failure and diabetes<sup>iv</sup>, and

**WHEREAS,** narcolepsy patients need trained providers to address their comorbidities and treat additional underlying health concerns.

**NOW, THEREFORE, BE IT RESOLVED** that the National Lieutenant Governors Association supports additional efforts in the states/territories to research and learn more about narcolepsy and its impact on patients.

ADOPTED, this day, the 16<sup>th</sup> of August, 2023.

Co-Sponsors: TBD

Proposed for the docket by: Jazz Pharmaceuticals, NLGA Partner

<sup>&</sup>lt;sup>1</sup> 1. Narcolepsy: MedlinePlus Genetics. medlineplus.gov. https://medlineplus.gov/genetics/condition/narcolepsy/#frequency

<sup>&</sup>lt;sup>11</sup> 2. Thorpy MJ, Krieger AC. Delayed diagnosis of narcolepsy: characterization and impact. *Sleep Med*. 2014;15(5):502-507.

- iii 2. Thorpy M, Krieger A. Delayed diagnosis of narcolepsy: characterization and impact. Sleep Med. 2014;15(5):502–507
- 3. Morrish E, King M, et al. Factors associated with a delay in the diagnosis of narcolepsy. Sleep Med. 2004;5(1):37-41.
- iv 4. Ben-Joseph RH, Saad R, Black J, et al. Cardiovascular burden of narcolepsy disease (CV-BOND): a real-world evidence study. Presented at: 2022 AAN Annual Meeting; April 2-7; Seattle, Washington. Poster 1203
- 5. Black J, Reaven NL, Funk SE, et al. Medical comorbidity in narcolepsy: findings from the Burden of Narcolepsy Disease (BOND) study. *Sleep Med*. 2017;33:13-18.
- 6. Ohayon MM, Black J, Lai C, et al. Increased mortality in narcolepsy. Sleep. 2014;37(3):439-444.
- 7. Ohayon MM. Narcolepsy is complicated by high medical and psychiatric comorbidities: a comparison with the general population. *Sleep Med*. 2013;14(6):488-492.