

**Strategic Research Grant on Hypersomnolence Update**

*Prepared for Wake Up Narcolepsy on October 30, 2024*

As a result of this ongoing partnership, the AASM Foundation’s Board of Directors recently approved a \$100,000 Strategic Research Grant to investigator Aaron Schokman, Bsc, Mphil, PhD, at the University of Sydney. This grant was funded in collaboration with Wake Up Narcolepsy. His topic is *Co-production and Psychometric Validation of a Patient Reported Outcome Measure of the Impact Narcolepsy has on the Daily Life of Adult Persons Living with Narcolepsy Type 1 and 2*.

Few self-reported questionnaires used in narcolepsy are adequately validated, fit for purpose, or capture the broad impact narcolepsy has on daily life. This study intends to use best-practice methodology in psychometrics and questionnaire design to create a “one-stop-shop” patient-reported outcome measure that will capture all domains considered meaningful to those living with narcolepsy, using the language and terminology they use. The questionnaire will be a validated means to assess the impact of narcolepsy and treatment efficacy.

The Central Disorders of Hypersomnolence Research funding opportunities are open to

- Basic and Transitional Studies for Understanding Central Disorders of Hypersomnolence
- Improvement of Diagnosis for Central Disorders of Hypersomnolence
- Pharmacologic Treatments for Central Disorders of Hypersomnolence
- Patient-centered Outcome Measures for Central Disorders of Hypersomnolence
- Behavioral and Psychological Treatments for Central Disorders of Hypersomnolence

As a partner supporting the AASM Foundation’s Strategic Research Grant program, Wake Up Narcolepsy appointed representatives to participate in the peer-review process, and the organization agreed to co-fund a portion of the grant once approved by the AASM Foundation’s Board of Directors

The AASM Foundation has distributed more than \$1.7 million in hypersomnolence research since 2022, and we are proud to continue to partner with organizations like Wake Up Narcolepsy as we work together to improve the sleep health of all people.



**2024 Strategic Research Grant/Central Disorders of Hypersomnolence Research Recipient**

**Aaron Schokman, Bsc, Mphil, PhD**