# CRESCENDO: Results From a Survey of Symptom Burden and Quality of Life in Patients with Narcolepsy Type 1

Michael J Thorpy<sup>1</sup>; Amy Kant<sup>2</sup>; Keith Harper<sup>2</sup>; Eileen B Leary<sup>3</sup>; Gregory Parks<sup>3</sup>; Samantha Floam<sup>4</sup>; Herriot Tabuteau<sup>4</sup>

<sup>1</sup>Montefiore Medical Center, Sleep-Wake Disorders Center, Bronx, NY, United States; <sup>2</sup>Narcolepsy Network, Camas, WA, United States; <sup>3</sup>Formerly of Axsome Therapeutics, Inc., New York, NY, United States; <sup>4</sup>Axsome Therapeutics, Inc., New York, NY, United States



## **Key Objective**

To describe the patient journey, treatment experience, and unmet need in patients with narcolepsy type 1

#### Introduction

- Narcolepsy is a chronic, debilitating, neurological condition that dysregulates the sleep-wake cycle and is characterized clinically by excessive daytime sleepiness (EDS), cataplexy (narcolepsy type 1 [NT1] only; c. 70% of patients<sup>1</sup>), hypnagogic/hypnopompic hallucinations, sleep paralysis, and disrupted nocturnal sleep<sup>2,3</sup>
- Narcolepsy has a substantial impact on quality of life, impairing social, professional, and physical functioning<sup>4</sup>
- Patients with narcolepsy often require polypharmacy due to the burden of the multiple symptoms experienced<sup>5</sup>
- Narcolepsy is underrecognized and underdiagnosed, partially due to symptomatic overlap with more common sleep and psychiatric conditions such as sleep apnea and depression<sup>6</sup>

#### Methods

- To better understand the patient experience, burden of illness and unmet needs for patients with narcolepsy, the Characterizing Patient Perspectives on Unmet Needs in Narcolepsy (CRESCENDO) survey was conducted from October to December 2023, involving adults diagnosed with NT1 who were currently taking US FDA-approved medication for the condition
- The survey comprehensively assessed the patient experience, including comorbidities, current medication use, symptom burden and impact on quality of life
- Participants also completed assessments of subjective sleepiness (Epworth Sleepiness Scale; ESS), subjective cognitive function (British Columbia Cognitive Complaints Inventory; BC-CCI), and depression (Patient Health Questionnaire-8; PHQ-8)
- CRESCENDO was developed and executed in partnership with the patient advocacy organization Narcolepsy Network; a thirdparty research firm conducted the survey and ensured respondent privacy

#### References

- 1. Swick TJ. *Nat Sci Sleep*. 2015; 7: 159–169.
- American Academy of Sleep Medicine. ICSD-3-TR. Chicago, IL: 2023.
   España RA, Scammell TE. Sleep. 2011;34(7):845-858.
- 4. Tadrous R, et al. *J Sleep Res*. 2021 Dec;30(6):e13383.
- 5. Thorpy MJ, Hiller G. Am Health Drug Benefits. 2017 Jul;10(5):233-241.
- 6. Krahn LE, et al. *Adv Ther.* 2022; 39(1): 221-243.

#### Acknowledgments

This study was supported by Axsome Therapeutics, Inc. Under the direction of the authors, Jared Levine, PhD, of Axsome Therapeutics, Inc., provided medical writing and editorial support for this poster. The authors thank the participants who contributed data, personnel who collected data, and consultants who contributed to the design of the CRESCENDO Study.

#### Disclosures

MJT serves as a consultant to Axsome Therapeutics.

AK and KH are affiliated with Narcolepsy Network.

EBL and GP are former employee of Axsome Therapeutics.

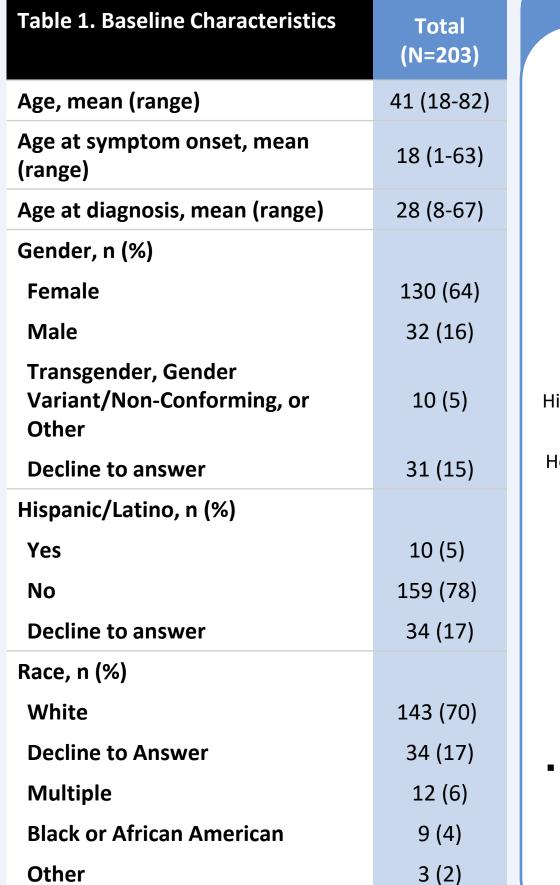
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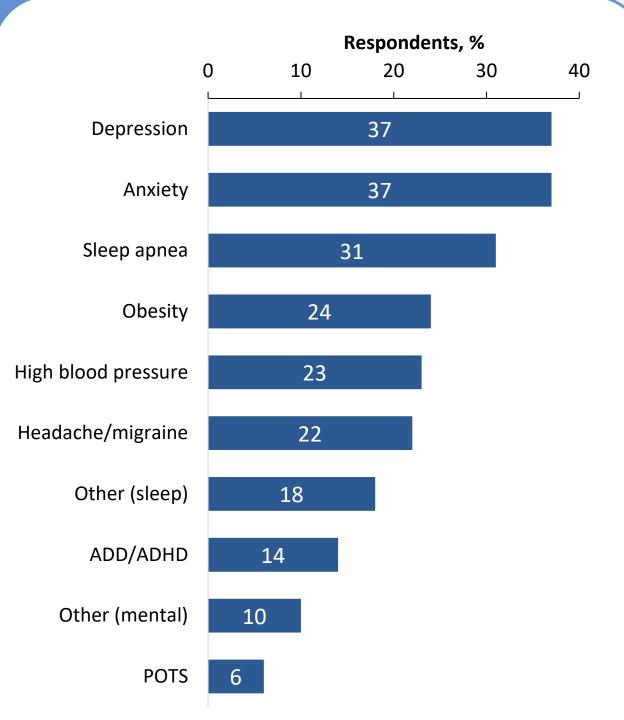
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### Results



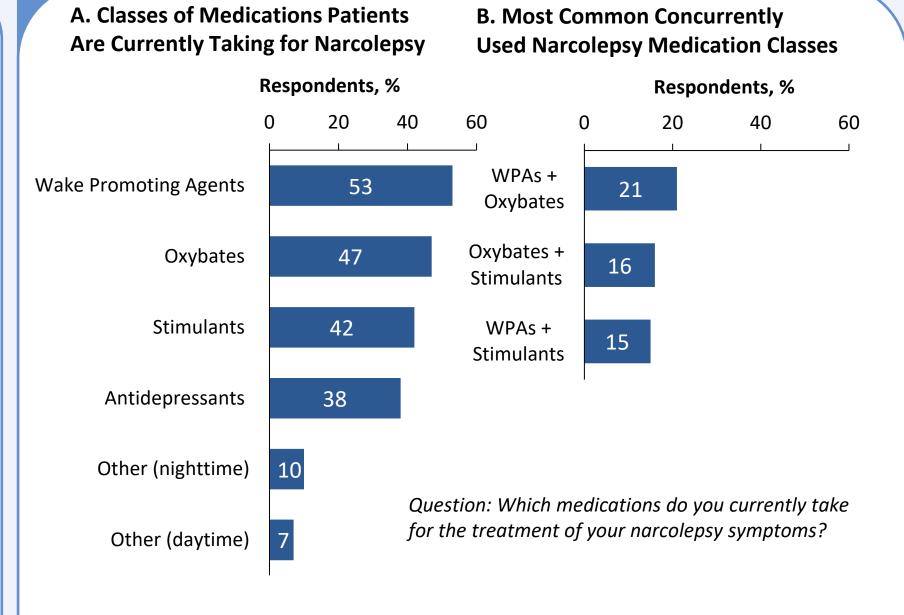
## Figure 1. Diagnosed Comorbidities Occurring in ≥5% of Participants



Depression and anxiety were the most commonly diagnosed comorbidities reported by respondents (**Figure 1**)

ADD/ADHD, Attention-Deficit Disorder/Attention-Deficit/Hyperactivity Disorder; POTS, Postural orthostatic tachycardia syndrome.

### Figure 2. Medication Usage Patterns

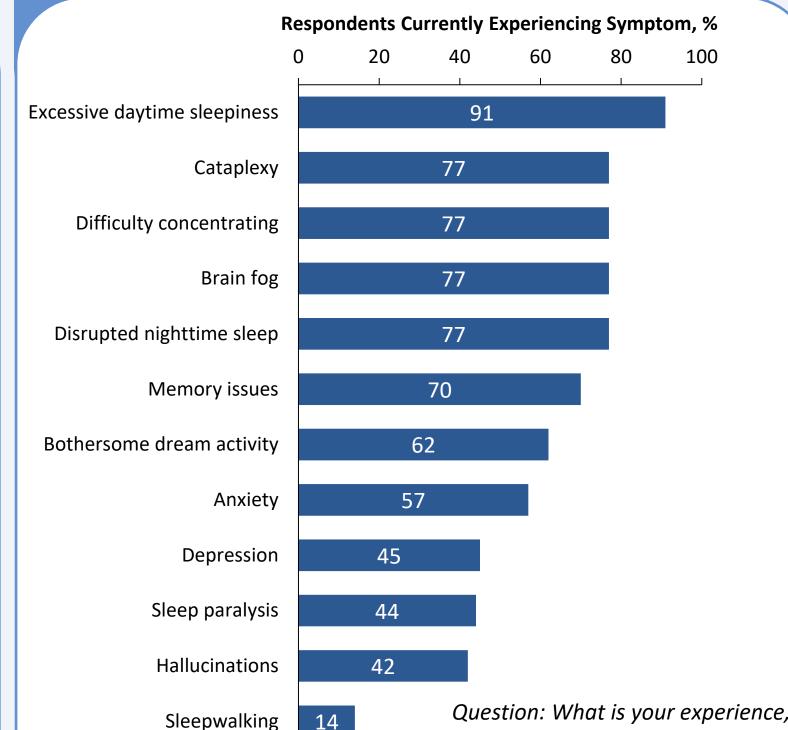


- The most common treatments were wake-promoting agents (53%), oxybates (47%), and stimulants (42%) (Figure 2A)
- Polypharmacy for narcolepsy was common (Figure 2B; most frequently reported): overall,
   30% of respondents reported taking medications from 2 classes, while 30.6% reported taking
   3 or more classes
- Almost all (93%) respondents reported discontinuing at least one medication, with lack of desired efficacy (51%), too many side effects (42%), and recommendation of new treatment by healthcare provider (34%) as the most commonly cited reasons

\*Wake promoting agents (WPAs): armodafinil, modafinil, pitolisant, and solriamfetol.

EDS (11+)

# Figure 3. Prevalence of Breakthrough Symptoms Experienced Despite Treatment



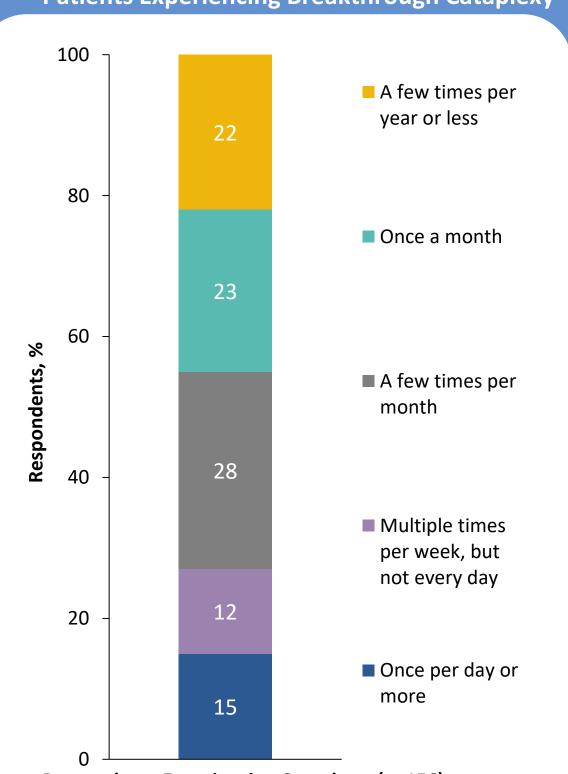
 EDS was the most prevalent breakthrough symptom experienced by participants while taking their current treatment regime (91%); cataplexy, difficulty concentrating, brain fog, and disrupted nighttime sleep were the next most experienced (77% each) (Figure 3)

### Conclusions

- The CRESCENDO survey provides valuable patient-generated insights into the burden of illness in persons with NT1
- Despite ongoing treatment, patients reported a wide range of persistent symptoms including cataplexy, EDS, and impaired cognition
- Breakthrough cataplexy was reported by most patients, substantially impacting their quality of life
- The majority of patients reported impacts on their work, home, and social lives from cognitive complaints and depressive symptoms
- These results highlight the significant unmet treatment needs of this patient population

# Figure 4. Frequency of Cataplexy Attacks in Patients Experiencing Breakthrough Cataplexy

2 (1)



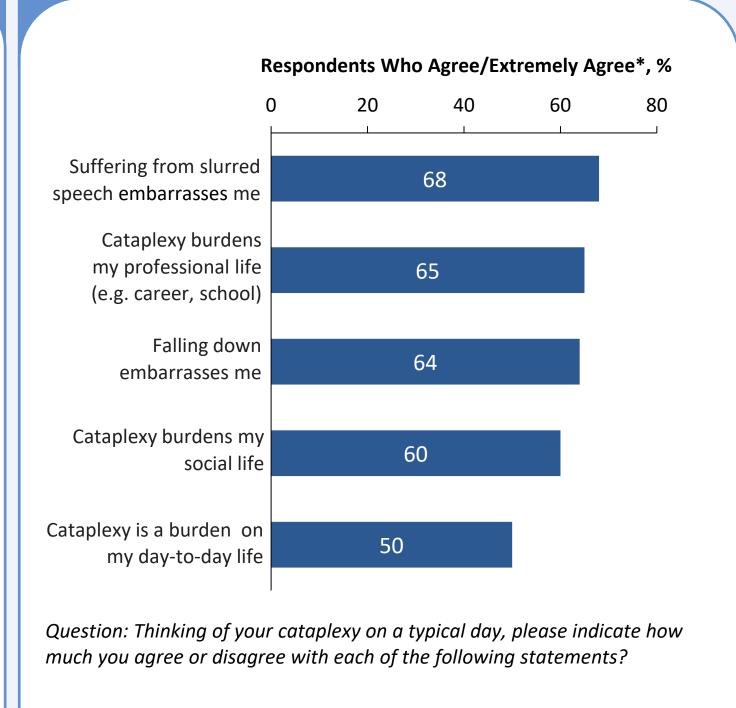
Respondents Experiencing Cataplexy (n=156)

Of the respondents reporting breakthrough cataplexy, 43%

(Figure 4)

reported experiencing it daily or multiple times per week

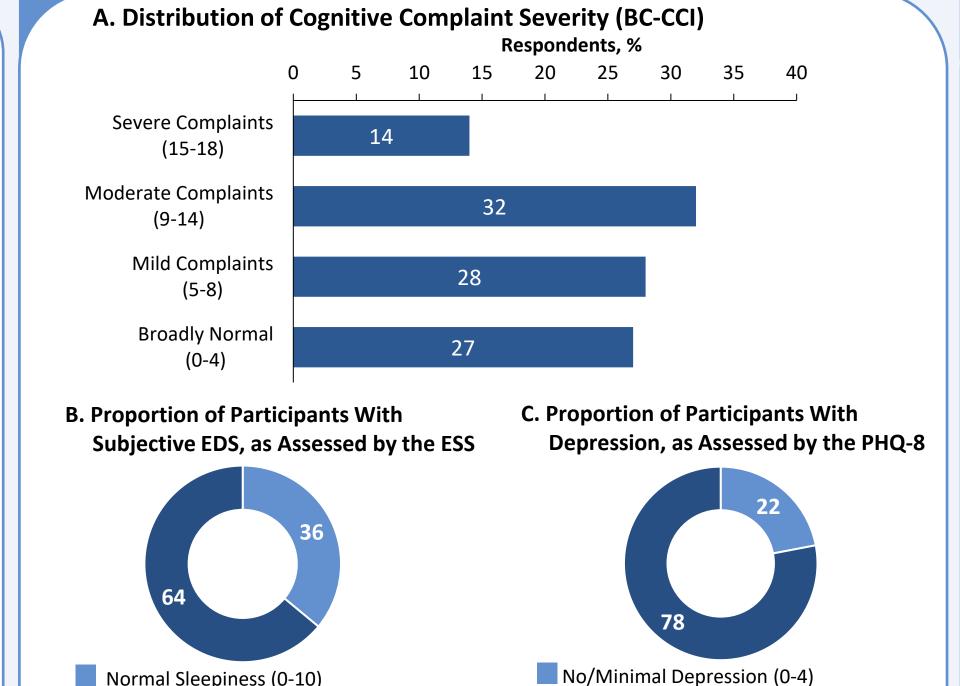
### Figure 5. Impacts of Cataplexy on Quality of Life



 When asked about their typical day, a majority of respondents currently experiencing cataplexy despite receiving treatment felt that this symptom caused them embarrassment and impacted their professional and social life (Figure 5)

\*Of the 156 currently experiencing cataplexy.

# Figure 6. Assessment of Cognitive Complaints, Sleepiness, and Depression



Cognitive impairment (BC-CCI scores ≥5), was observed in 73% of respondents (Figure 6A)
 Neary two-thirds (64%) of respondents experienced EDS, as measured by the ESS, despite receiving

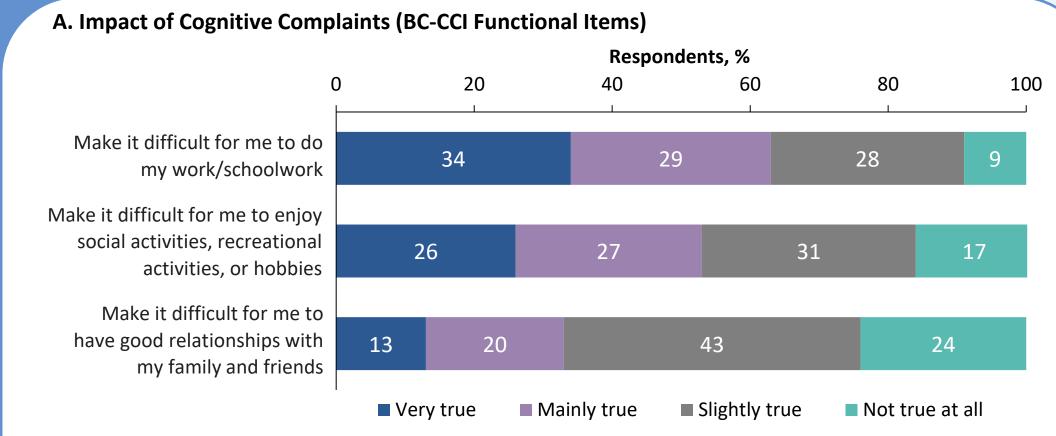
Depression (5+)

treatment (Figure 6B)
 More than 75% of respondents presented with depression, as assessed by the PHQ-8 (Figure 6C)
 BC-CCI, British Columbia Cognitive Complaints Inventory; EDS, excessive daytime sleepiness;

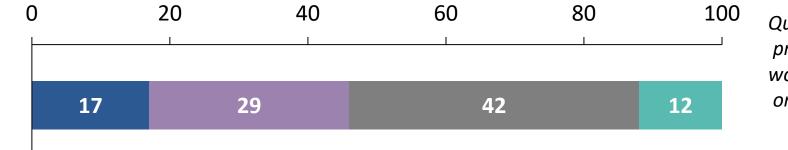
ESS, Epworth Sleepiness Scale; PHQ-8, Patient Health Questionnaire-8.



if any, with each of the following?







Question: How difficult have these problems made it for you to do work, take care of things at home, or get along with other people?

- Extremely difficult Very difficult Somewhat difficult Not difficult
- A large majority of respondents reported that cognitive complaints impaired their professional/scholastic lives (very/mainly/slightly true; 91%); their enjoyment of recreational pursuits (83%); and their ability to have good social relationships (76%) (Figure 7A)
- Most respondents reported that symptoms associated with depression were associated with difficulties in their professional, home, and social lives (extremely/very/somewhat difficult; 88%) (Figure 7B)

BC-CCI, British Columbia Cognitive Complaints Inventory; PHQ-8, Patient Health Questionnaire-8.