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Effectiveness and Satisfaction With Low-Sodium Oxybate as Described by Adults Living With Idiopathic Hypersomnia: LYRICAL Survey and Interview Findings

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Objective

- To characterize the real-world treatment experience with low-sodium oxybate (LXB) among US adults with idiopathic hypersomnia in the LYRICAL study, including treatment effectiveness and satisfaction assessed through participant surveys and qualitative interviews

Conclusions

- Final results from the real-world LYRICAL study showed that many individuals with idiopathic hypersomnia taking LXB experienced sustained improvements in quality of life (QoL) and multiple symptoms across the 24-hour period, including excessive daytime sleepiness and nighttime sleep quality, as well as high treatment satisfaction
- Limitations include the lack of a comparator group, potential selection and recall bias (participants had been taking LXB for ≥12 weeks at enrollment), and small sample sizes for some analyses
- Survey and qualitative insights revealed the meaningful and durable multi-dimensional impacts that LXB can have on nighttime and daytime symptoms and QoL in idiopathic hypersomnia

References: 1. Xywav® (calcium, magnesium, potassium, and sodium oxybates) oral solution, CIII [prescribing information]. Palo Alto, CA: Jazz Pharmaceuticals, Inc.

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Disclosures: C Drachenberg, M Whalen, JK Alexander, S Beaty, and **SC Markt** are full-time employees of Jazz Pharmaceuticals who, in the course of this employment, have received stock options exercisable for, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc. **M Farrell, J D'Souza, E Kim, M Lawrence,** and **CA Graham** are full-time employees of IQVIA, which received funding from Jazz Pharmaceuticals to conduct the study. **LB Herpel** is an Affiliate Assistant Professor at the Medical University of South Carolina; participates in clinical research for Alkermes, Avadel, Axsome Therapeutics, Eisai, Eli Lilly, Harmony Biosciences, Idorsia, Jazz Pharmaceuticals, LivaNova/OSPREY, Merck, Noctrix, Roche, Samsung, Sanofi, Suven, Takeda, and Vanda; serves as an advisor to Avadel, Axsome, Eli Lilly, Harmony Biosciences, and Jazz Pharmaceuticals; and serves on the speakers bureau for Avadel and Harmony Biosciences.

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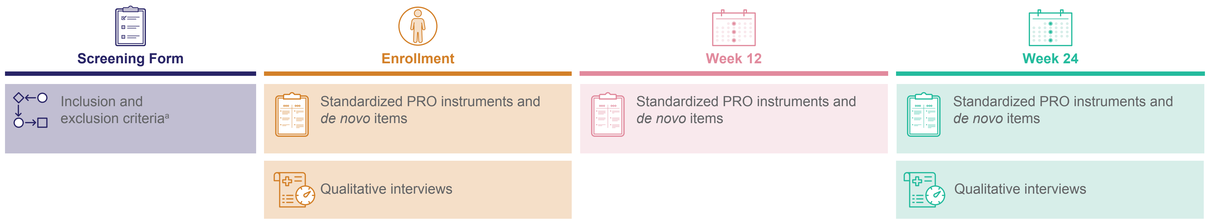
Introduction

- Low-sodium oxybate (LXB; Xywav®) is approved by the US Food and Drug Administration for the treatment of excessive daytime sleepiness (EDS) or cataplexy in patients aged ≥7 years with narcolepsy and for the treatment of idiopathic hypersomnia in adults[1]
- Since the approval of LXB, limited information triangulating longitudinal survey and qualitative insights has been published regarding patient-reported treatment satisfaction with LXB and overall effectiveness in real-world settings, particularly in idiopathic hypersomnia
- LYRICAL (**L**ongitudinal mixed methods stud**Y** of **R**eal-world patterns of use, effectiveness, and treatment satisfaction in adults with **I**diopathic hypersomnia and nar**C**olepsy t**A**king **L**ow-sodium oxybate) is a study to better understand the real-world experience of adults with narcolepsy or idiopathic hypersomnia receiving LXB treatment
  - This poster reports results on participant-reported effectiveness and treatment satisfaction for participants with idiopathic hypersomnia; results for the narcolepsy cohort are presented in **Poster 359**
  - **Posters 362** and **361** describe LXB individualized dosing for LYRICAL participants with narcolepsy and idiopathic hypersomnia, respectively; **Posters 534** and **535** explore associations between daytime and nighttime symptoms and quality-of-life (QoL) outcomes for LYRICAL participants with narcolepsy and idiopathic hypersomnia, respectively

Methods

- This longitudinal, mixed methods study collected quantitative (survey) and qualitative (interview) data from participants currently taking LXB at enrollment and over the 24-week study period

Figure 1. LYRICAL Study Design

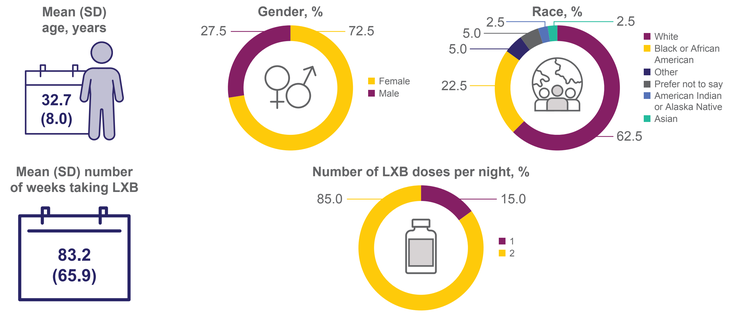


[a]Participants were eligible if they were ≥18 years of age at the time the screening form was completed, a US resident, diagnosed with narcolepsy or idiopathic hypersomnia, prescribed and currently taking LXB for narcolepsy or idiopathic hypersomnia, and had been taking LXB for ≥12 weeks prior to completing the screening form. All participants provided written or electronic informed consent.
LXB, low-sodium oxybate; PRO, patient-reported outcome.

- Online surveys were conducted between March 2024 and August 2025 via an IQVIA-hosted platform and comprised standardized patient-reported outcome instruments (eg, Patient Global Impression of Change [PGI-C], 9-item Treatment Satisfaction Questionnaire for Medication [TSQM-9]) and *de novo* questions; surveys were administered at enrollment, week 12, and week 24
- Virtual 45-minute interviews were conducted using semi-structured discussion guides with a subset of participants at enrollment (n=13) and week 24 (n=12)
  - Interviews were audio-recorded, transcribed, and coded and analyzed using MAXQDA (VERBI Software, 2021) and Microsoft Excel
- Descriptive analyses were conducted

Results

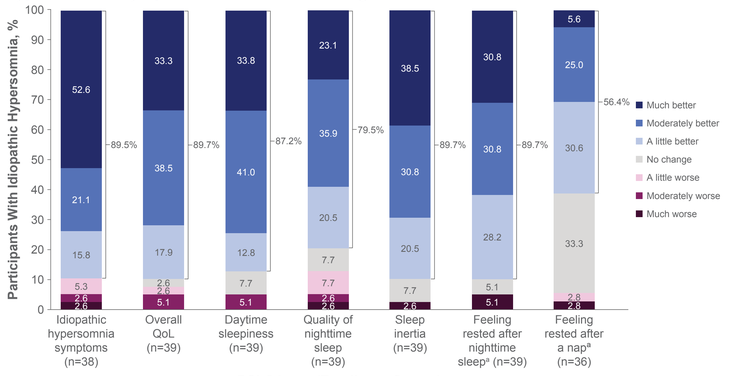
Figure 2. Characteristics of Participants With Idiopathic Hypersomnia[a]



[a]Per the enrollment survey.
LXB, low-sodium oxybate; SD, standard deviation.

- Among the 40 participants who completed the enrollment survey, most were female (72.5%), White (62.5%), and working full time (65.0%); mean (SD) age was 32.7 (8.0) years
- At enrollment, the mean (SD) duration of LXB treatment was 83.2 (65.9) weeks or approximately 19 months
- According to the enrollment survey, the proportion of participants taking alerting agents decreased from 72.5% to 55.0% after LXB initiation
- Additional demographic and clinical characteristics are available in the Supplement, accessed via the QR code

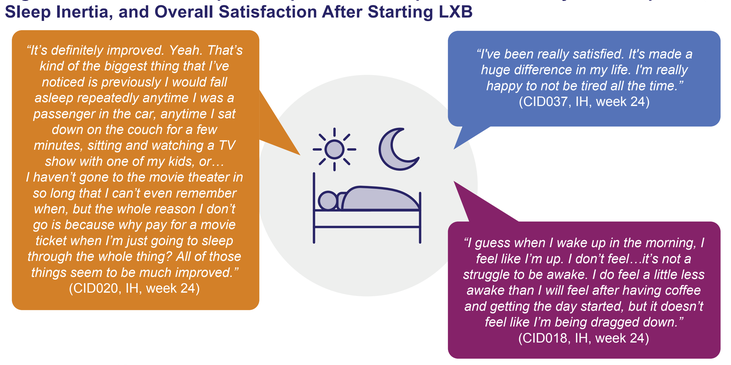
Figure 3. At Enrollment, Participants Reported Improvements in Idiopathic Hypersomnia Symptoms and QoL Following LXB Initiation



Numbers may not add to 100% due to rounding.
[a]Response options were "Much more refreshed," "Moderately more refreshed," "A little more refreshed," "No change," "A little less refreshed," "Moderately less refreshed," and "Much less refreshed."
LXB, low-sodium oxybate; PGI-C, Patient Global Impression of Change; QoL, quality of life.

- Following LXB initiation, most participants reported improvement (ie, "a little better," "moderately better," or "much better") in overall idiopathic hypersomnia symptoms (89.5%) and QoL (89.7%)
- PGI-C symptom-specific items reflected improvements in daytime sleepiness (87.2%), nighttime sleep quality (79.5%), sleep inertia (89.7%), and feeling rested after nighttime sleep (89.7%)
- Patient Global Impression of Severity ratings at weeks 12 and 24 suggest that improvements were generally maintained over the study period (data not shown)
- Daytime sleepiness also remained stable over follow-up, with mean (SD) Epworth Sleepiness Scale scores of 10.7 (5.3) at enrollment and 9.3 (4.9) at week 24

Figure 5. Interview Participants Report Marked Improvements in Daytime Sleepiness, Sleep Inertia, and Overall Satisfaction After Starting LXB

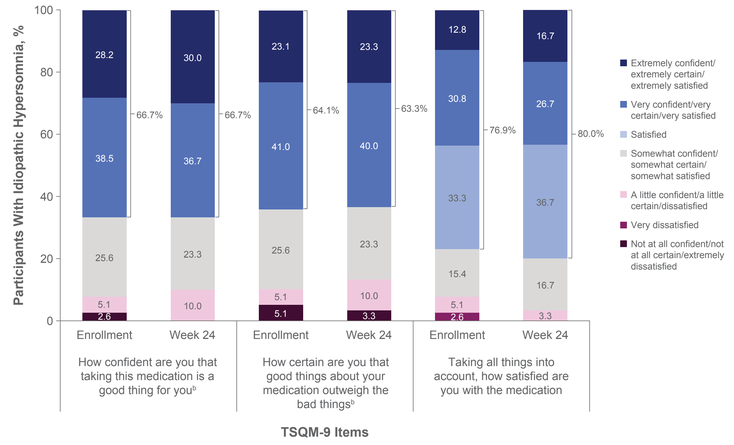


IH, idiopathic hypersomnia; LXB, low-sodium oxybate.

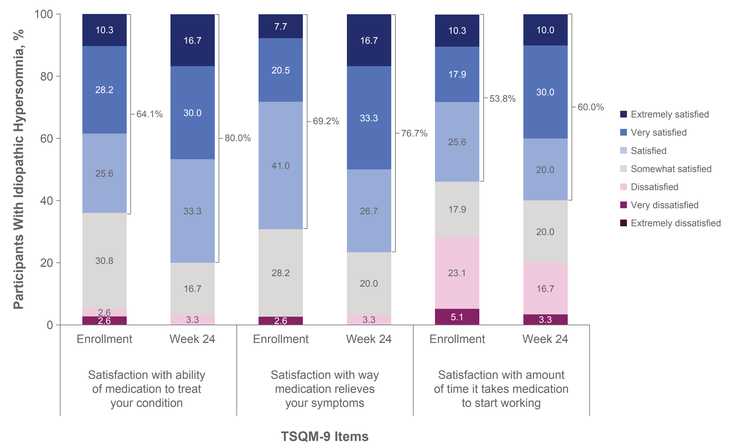
- Among interview participants at enrollment (n=13), most described feeling more awake/refreshed (10/13; 76.9%) and improved sleep quality (8/13; 61.5%) after starting LXB
  - All interview participants who reported EDS (12/12) described improvement or complete resolution after LXB initiation
- More than half (8/13; 61.5%) of participants described ineffectiveness of prior treatments as a reason for initiating LXB
- All interview participants (100%) reported being "satisfied" or "very satisfied" with LXB and indicated they were very likely to continue treatment
- These qualitative findings were consistent with and supported the survey results

Figure 4. Participants Reported High Global Satisfaction and Effectiveness at Enrollment and Through 24 Weeks of Follow-up[a,b]

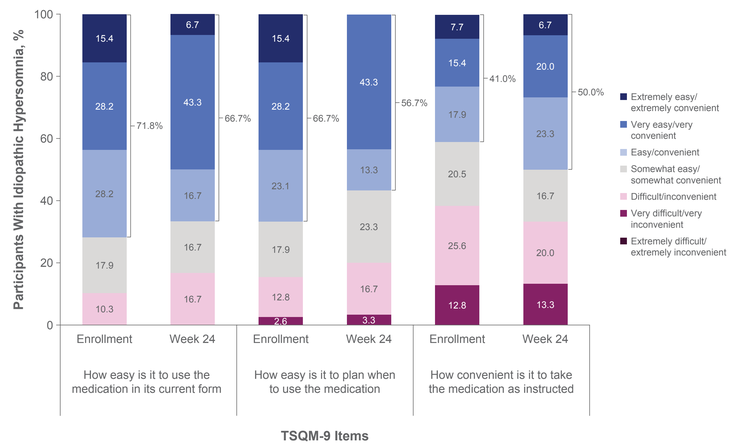
A) Global Satisfaction Domain



B) Effectiveness Domain



C) Convenience Domain



Numbers may not add to 100% due to rounding. Week 12 data are not shown.
[a]The TSQM-9 yields 3 domain scores: effectiveness, convenience, and global satisfaction. Most items are rated on a 7-point Likert-type scale ranging from "extremely dissatisfied/inconvenient/difficult" to "extremely satisfied/convenient/easy," which are transformed into domain scores ranging from 0 to 100. Higher scores indicate greater satisfaction. [b]Item rated on a 5-point scale, with response options: "extremely," "very," "somewhat," "a little," and "not at all."
LXB, low-sodium oxybate; TSQM-9, 9-item Treatment Satisfaction Questionnaire for Medication.

- High global satisfaction with LXB was reported at enrollment and week 24, with mean (SD) TSQM-9 global satisfaction domain scores of 70.0 (20.9) and 71.0 (20.2), respectively; 80.0% of participants reported that taking all things into account, they were "satisfied," "very satisfied," or "extremely satisfied" with LXB at week 24
- Mean (SD) TSQM-9 effectiveness domain scores at enrollment and week 24 were 64.7 (16.5) and 70.4 (17.8), respectively, with 76.7% of participants reporting that they were "satisfied," "very satisfied," or "extremely satisfied" with symptom relief provided by LXB at week 24
- Mean (SD) TSQM-9 convenience domain scores at enrollment and week 24 were 63.8 (19.8) and 62.2 (19.6), respectively, with 66.7% of participants reporting that LXB was "easy," "very easy," or "extremely easy" to use in its current form at week 24
- TSQM-9 domain scores at enrollment were maintained through week 24, suggesting stable treatment satisfaction over the study period

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Supplemental Results

Supplemental Table S1. Full Details on Participant Characteristics

Characteristic	Participants With Idiopathic Hypersomnia (N=40)
Age (years)	
Mean (SD)	32.7 (8.0)
Median (range)	30.5 (21, 53)
Gender, n (%)	
Female	29 (72.5)
Male	11 (27.5)
Race, n (%)	
White	25 (62.5)
Black or African American	9 (22.5)
American Indian or Alaska Native	1 (2.5)
Asian	1 (2.5)
Other	2 (5.0)
Prefer not to say	2 (5.0)
Employment, n (%)[a]	
Working full-time	26 (65.0)
Student	6 (15.0)
Seeking work opportunities	2 (5.0)
Working part-time	6 (15.0)
Homemaker	3 (7.5)
Unable to work	3 (7.5)
Number of LXB doses per night, n (%)	
1	6 (15.0)
2	34 (85.0)
Number of weeks taking LXB	
Mean (SD)	83.2 (65.9)
ESS score	
Mean (SD)	10.7 (5.3)
Other current comorbid diagnoses, n (%)[a]	
Attention deficit disorder/attention deficit hyperactivity disorder	6 (15.0)
Anxiety	18 (45.0)
Depression	12 (30.0)
Hypertension	1 (2.5)
Obesity	3 (12.5)
Obstructive sleep apnea	5 (12.5)
Periodic limb movement disorder	2 (5.0)
Restless legs syndrome	1 (2.5)
Current concomitant treatments, n (%)[a]	
Amphetamine	10 (25.0)
Armodafinil	1 (2.5)
Fluoxetine	4 (10.0)
Methylphenidate	7 (17.5)
Modafinil	3 (7.5)
Pitolisant	1 (2.5)
Sertraline	2 (5.0)
Solriamfetol	5 (12.5)
Other current treatment	4 (10.0)
None of the above[b]	16 (40.0)

[a]Response options are not mutually exclusive. [b]"None of the above" indicates participants were not taking any of the medications listed in this table; however, they may have been taking other concomitant medications.
ESS, Epworth Sleepiness Scale; LXB, low-sodium oxybate; max, maximum; min, minimum; SD, standard deviation.