

Estimating the Prevalence of Diagnosed Idiopathic Hypersomnia in the Pediatric Population: A US Claims Analysis

Natalie Gavrielov-Yusim, PhD¹; Sarah C. Markt, ScD, MPH¹; Jerrod Nelms, PhD, MPH¹; Rakesh Bhattacharjee, MD²; Kiran Maski, MD, MPH³

¹Jazz Pharmaceuticals, Palo Alto, CA, USA; ²Department of Pediatrics, University of California San Diego School of Medicine, San Diego, CA, USA; ³Department of Neurology, Boston Children’s Hospital, Boston, MA, USA

Objective

- To estimate the prevalence of diagnosed idiopathic hypersomnia among the pediatric population in the United States (US) based on administrative claims data

Conclusions

- This claims-based analysis found that the US pediatric prevalence of diagnosed idiopathic hypersomnia in 2023 was 7.6 cases per 100,000 persons, or 0.008% of the pediatric population of the US
- The highest age-specific pediatric prevalence was observed in individuals aged 15 to <19 years; the mean age at first pediatric idiopathic hypersomnia diagnosis was approximately 12 years
- Most individuals with pediatric idiopathic hypersomnia had a sleep test claim within 6 months of their diagnosis
- Nearly one-quarter of pediatric individuals underwent sleep testing more than 6 months before receiving a diagnosis, underscoring the need to reduce diagnostic delays—especially in younger age groups—to ensure timely and effective symptom management

References: 1. Trotti LM. *Sleep Med Clin.* 2017;12(3):331-344. 2. American Academy of Sleep Medicine. *International Classification of Sleep Disorders – Third Edition, Text Revision.* Darien, IL: American Academy of Sleep Medicine; 2023. 3. Markt SC, et al. *Sleep Adv.* 2026;7(1):zpag011. 4. Saini P, Rye DB. *Sleep Med Clin.* 2017;12(1):47-60. 5. Plante DT, et al. *Neurology.* 2024;102(2):e207994. 6. ICD9Data.org. Organic sleep disorders. 2022. Available at: <http://www.icd9data.com/2015/Volume1/320-389/320-327/327/default.htm>. 7. ICD10Data.org. Sleep disorders. 2022. Available at: <https://www.icd10data.com/ICD10CM/Codes/G00-G99/G40-G47/G47->.

Support and Acknowledgments: This study was supported by Jazz Pharmaceuticals. Under the direction of the authors, Peloton Advantage, LLC (an OPEN Health company), employees Aeja Jackson, PhD, MS, and Eleanor Bush, MA, provided medical writing support and Katie Herman provided editorial support for this poster, which were funded by Jazz Pharmaceuticals.

Disclosures: N Gavrielov-Yusim 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. J Nelms is a contract worker for Jazz Pharmaceuticals. R Bhattacharjee has consulted for Avadel, Harmony Biosciences, and Jazz Pharmaceuticals. K Maski has consulted for Alkermes, Avadel, Harmony Biosciences, Jazz Pharmaceuticals, Synchronicity Pharmaceuticals, Takeda, Taysha Gene Therapies; received grant funding from Harmony Biosciences and Jazz Pharmaceuticals; and is a co-investigator in a clinical trial sponsored by Takeda.

Presented at SLEEP 2026, the 40th Annual Meeting of the Associated Professional Sleep Societies, LLC (APSS); June 14–17, 2026; Baltimore, MD, USA

Scan this code to access this poster online. This code is not for promotional purposes.

Introduction

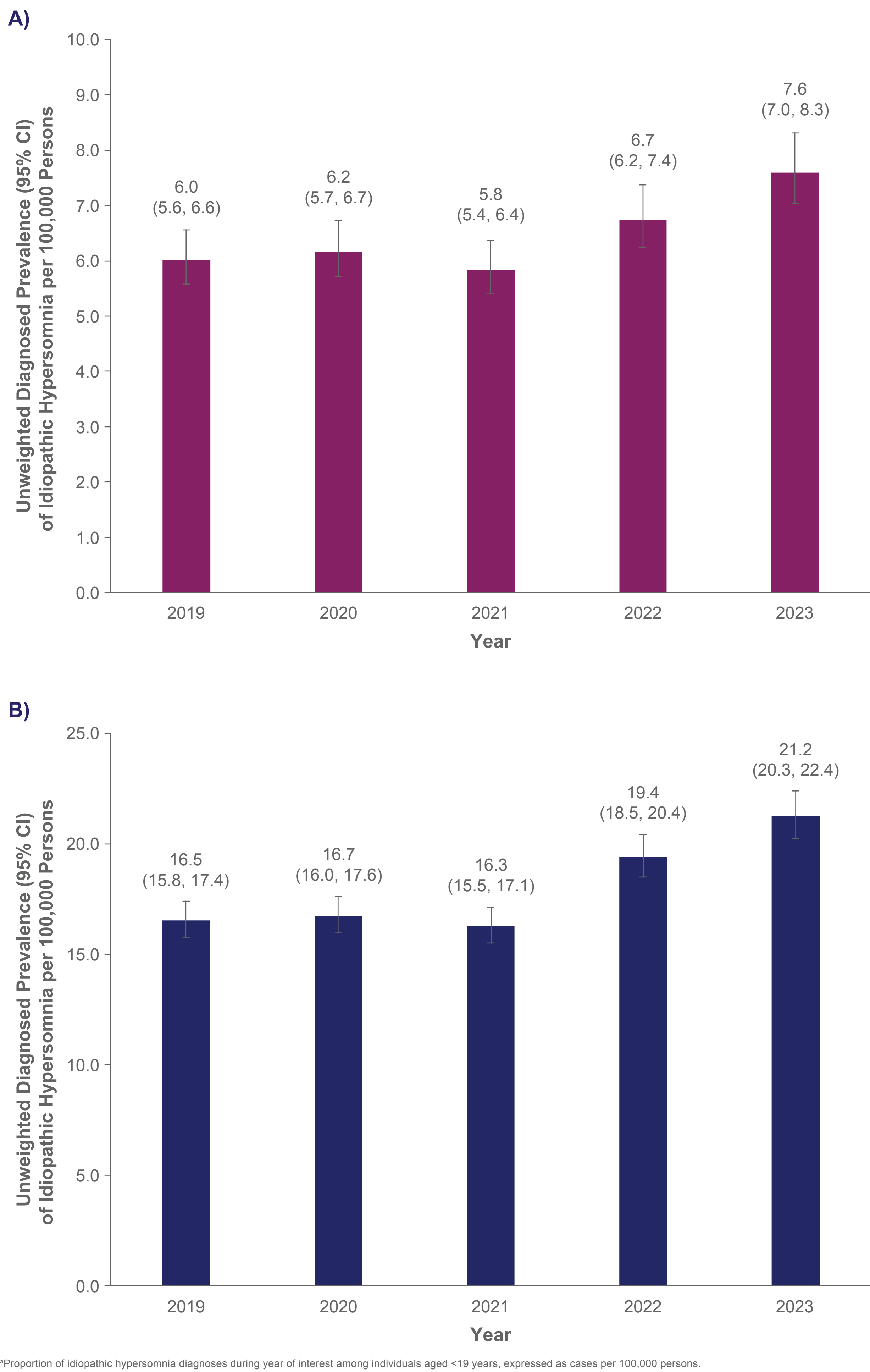
- Idiopathic hypersomnia is a rare neurologic sleep disorder with potentially debilitating symptoms, including excessive daytime sleepiness; severe sleep inertia; nonrestorative nighttime sleep; prolonged, unrefreshing naps; dysautonomia (eg, headache, orthostatic disturbance, temperature dysregulation); and fatigue^{1,2}
- The prevalence of idiopathic hypersomnia in the US adult population has been estimated within the broad range of 0.002% and 1.5%³⁻⁵
- There is little published literature evaluating the prevalence of idiopathic hypersomnia in the pediatric population

Methods

- Merative™ MarketScan® claims data through 12/31/2023 were analyzed among individuals aged <19 years for each year from 2019 to 2023
- Idiopathic hypersomnia was defined as ≥2 claims ≥30 days apart with an idiopathic hypersomnia diagnosis code (ICD-9-CM, 327.11, 327.12; ICD-10-CM, G47.11, G47.12) in the primary or secondary position occurring in cumulative available data from 1/1/2013 through each year of interest^{6,7}
 - In a sensitivity analysis, idiopathic hypersomnia was defined using ≥1 claim with an idiopathic hypersomnia diagnosis code
 - Additional outcomes included age-specific prevalence estimates for 2023, age at first qualifying idiopathic hypersomnia diagnosis, and distribution of sleep-testing (polysomnography [PSG] and Multiple Sleep Latency Test [MSLT]) claims before and after pediatric idiopathic hypersomnia diagnosis

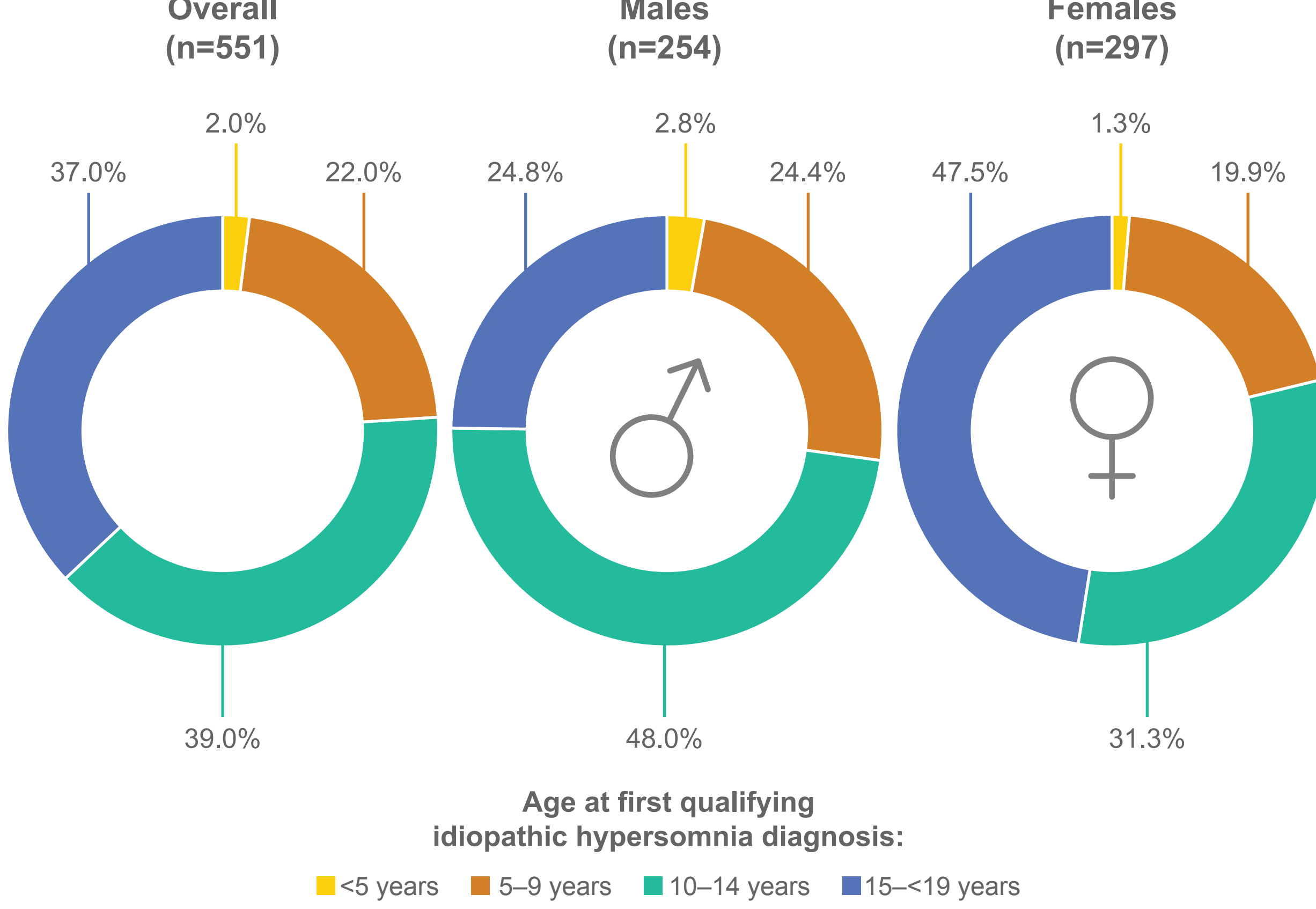
Results

Figure 1. Annual Pediatric Prevalence* of Diagnosed Idiopathic Hypersomnia Using (A) Two-claim and (B) One-claim Definitions



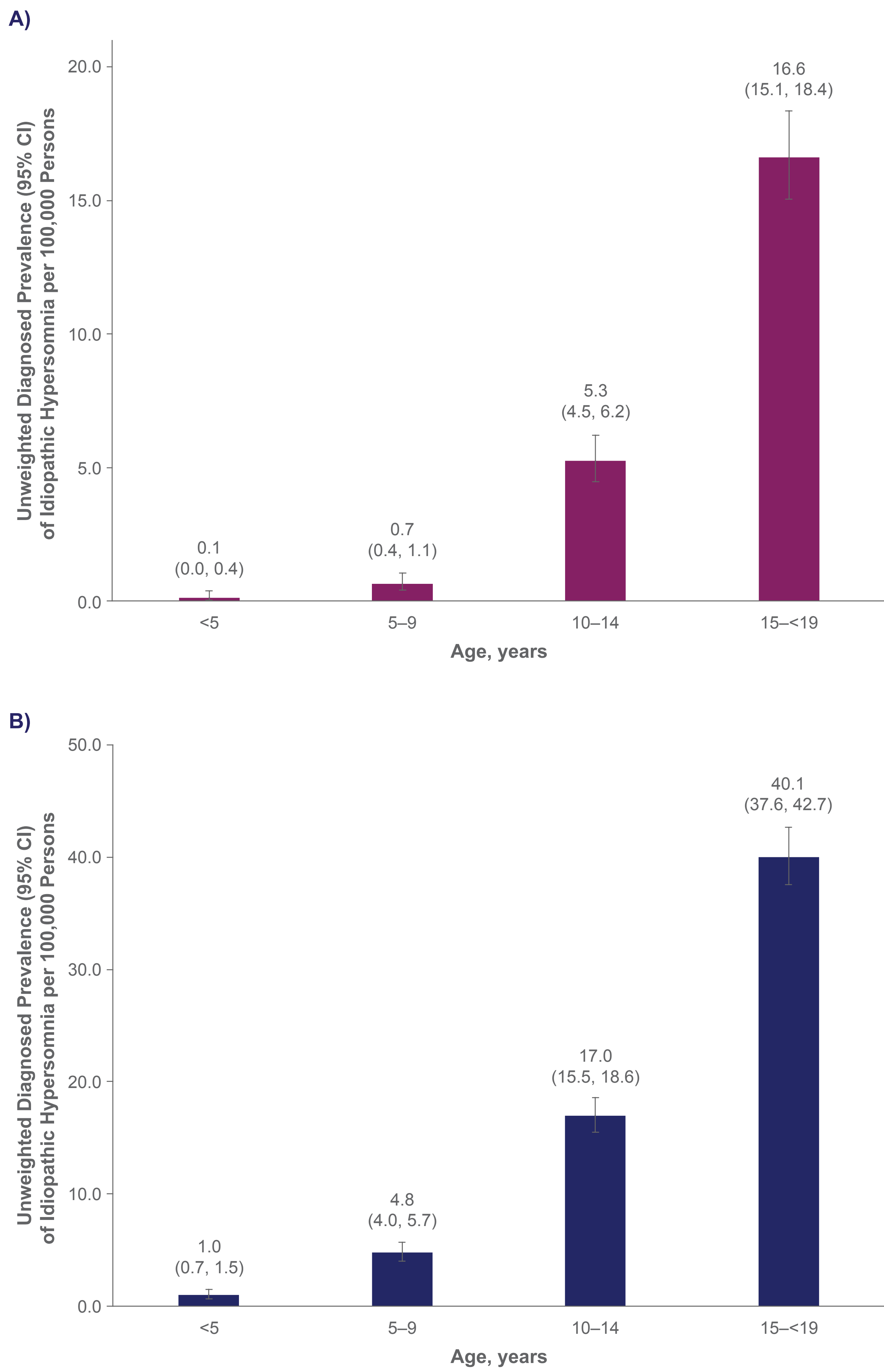
- In the primary analysis, 573, 575, 567, 546, and 551 pediatric individuals had ≥2 diagnostic claims for idiopathic hypersomnia between 2013 and each respective year of interest from 2019 to 2023
- Using the ≥2-claims definition, the unweighted pediatric prevalence (95% confidence interval [CI]) of diagnosed idiopathic hypersomnia, expressed per 100,000 persons, was 6.0 (5.6–6.6) in 2019, 6.2 (5.7–6.7) in 2020, 5.8 (5.4–6.4) in 2021, 6.7 (6.2–7.4) in 2022, and 7.6 (7.0–8.3) in 2023
- Using the ≥1-claim definition, the unweighted pediatric prevalence (95% CI) per 100,000 persons was 16.5 (15.8–17.4) in 2019, 16.7 (16.0–17.6) in 2020, 16.3 (15.5–17.1) in 2021, 19.4 (18.5–20.4) in 2022, and 21.2 (20.3–22.4) in 2023

Figure 3. Age at First Pediatric Idiopathic Hypersomnia Diagnosis for 2023, Overall and Stratified by Sex*



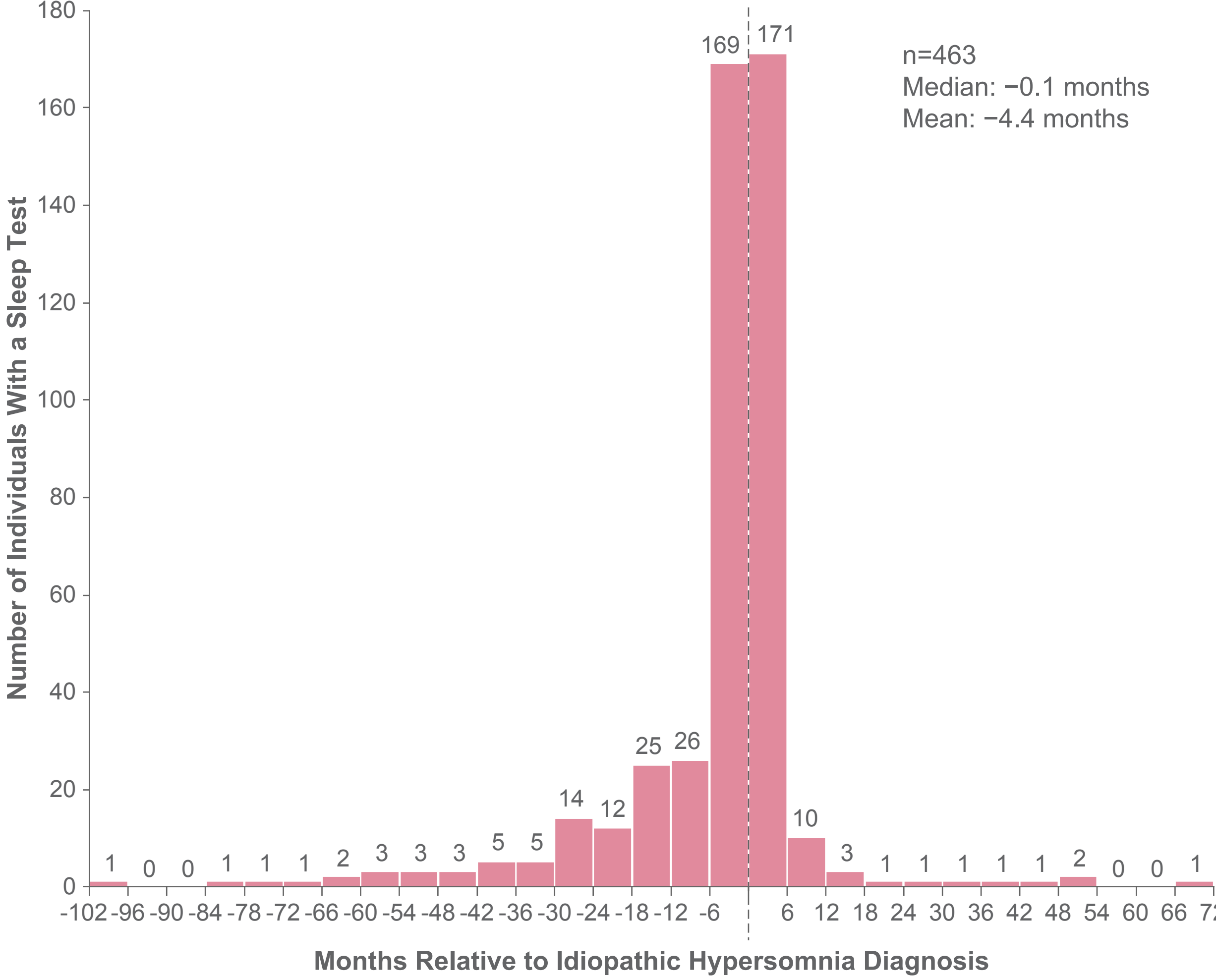
- Mean (SD) age at first idiopathic hypersomnia diagnosis was 12.5 (4.0) years
 - Median age (IQR) was 13.0 (10.0–16.0)
- Males most commonly received their first qualifying diagnosis at 10 to 14 years of age, while females were most commonly first diagnosed at 15 to <19 years

Figure 2. Pediatric Prevalence of Diagnosed Idiopathic Hypersomnia in 2023, Stratified by Age Using (A) Two-claim and (B) One-claim Definitions



- In 2023, age-specific pediatric prevalence per 100,000 persons for the primary ≥2-claims definition was 0.1 (<5 years), 0.7 (5 to 9 years), 5.3 (10 to 14 years), and 16.6 (15 to <19 years)
- Sensitivity analysis estimates of age-specific pediatric prevalence using the ≥1-claim definition were consistently higher than those using the primary ≥2-claims definition

Figure 4. Distribution of Sleep-Testing Claims Before and After Pediatric Idiopathic Hypersomnia Diagnosis*



- In 2023, 84.0% (463/551) of individuals with pediatric idiopathic hypersomnia had claims for sleep testing (PSG or MSLT) before or after their qualifying idiopathic hypersomnia diagnosis, with the majority (73.4%) of these occurring within 6 months
- Among those with sleep-testing claims, 22.0% occurred more than 6 months prior to idiopathic hypersomnia diagnosis, suggesting a gap between symptom investigation and diagnosis