

EXPLORING PHYSICIAN PERSPECTIVES OF

Idiopathic Hypersomnia

Results of a national survey from Jazz Pharmaceuticals and the Hypersomnia Foundation.

The survey findings underscore the need for more education and awareness of idiopathic hypersomnia among healthcare providers.



This survey was conducted online by Toluna Analytics on behalf of Jazz Pharmaceuticals and the Hypersomnia Foundation between February 5 and February 12, 2021 among a nationally representative sample of 305 healthcare providers, including self-identified sleep specialists (n=4), neurologists (n=67), psychiatrists (n=82), pulmonologists (n=90) and primary care physicians (n=62). About half of the sample (49%) are board certified in sleep medicine; thus, there were 148 sleep doctors and 157 non-sleep doctors among the neurologists, psychiatrists, pulmonologists, and primary care physicians who responded to the survey.

What is Idiopathic Hypersomnia (IH)?

IH is an often debilitating neurologic sleep disorder characterized by chronic excessive daytime sleepiness, which is the inability to stay awake and alert during the day, resulting in the irreversible need to sleep or unplanned lapses into sleep or drowsiness.^{1,2}

People with IH can struggle in their daily lives, as the disorder can significantly affect their social, school and occupational functioning.^{3,4}

The survey found a lack of knowledge about IH among physicians.⁵

Only 36% of respondents reported that they believe other physicians have a sufficient understanding of IH.

The 36% represents 110 of 305 total respondents.



Distinguishing Idiopathic Hypersomnia from Other Medical, Behavioral or Psychiatric Conditions

The results of the survey suggest that IH can be challenging to diagnosis and patients may go undiagnosed or misdiagnosed for years.⁵



57% of respondents said they have personally misdiagnosed IH.*

The 57% represents 173 of 305 total respondents.



90% of respondents reported that IH is misdiagnosed as another condition before receiving the correct diagnosis.*

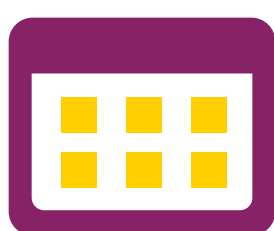
86% of respondents said that they think that patients who have IH are often misdiagnosed with depression and/or anxiety.*

The 90% represents 276 of 305 total respondents and the 86% represents 261 of 305 total respondents.

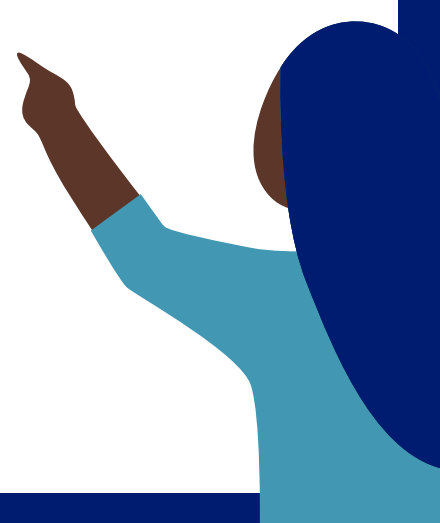


87% of respondents said that diagnosing IH is challenging.*

The 87% represents 264 of 305 total respondents.



39% of respondents reported that they believe it can take between **2-5 years** to receive an accurate diagnosis of IH. However, evidence shows a delay in diagnosis of between **10-15 years.**⁶



Increasing Awareness and Improving Patient Outcomes

Given the misdiagnosis and delays in diagnosis, healthcare providers agree that more education and awareness of IH is needed. Currently, respondents stated that people living with the disorder feel misunderstood, and may not be able to access appropriate care.⁵



92% of respondents said they agree that the negative impact of IH on people's lives is significantly underestimated.*

The 92% represents 281 of 305 total respondents.



93% of respondents said that more education is needed for IH.*

The 93% represents 283 of 305 total respondents.



87% of respondents said people living with IH are frustrated with their healthcare community, and **95%** said those living with IH are frustrated with their disease management.†

The 87% represents 266 of 305 total respondents and the 95% represents 289 of 305 total respondents.



66% of respondents said people with IH do not feel understood by the general public.‡

The 66% represents 201 of 305 total respondents.

* Percentage represents physicians that reported they "strongly agree" or "somewhat agree" with statement
 † Percentage represents physicians that reported patients are "extremely", "very", and "somewhat" frustrated
 ‡ Percentage represents physicians that reported patients feel "not very" and "not at all" understood

Sources:
 1. Trotti LM. Idiopathic Hypersomnia. Sleep Med Clin. 2017;12(3):331-344.
 2. American Academy of Sleep Medicine. The International Classification of Sleep Disorders. Third Edition (ICSD-3). 2014.
 3. Evangelista E, Lopez R, Dauvilliers Y. Update on treatment for idiopathic hypersomnia. Expert Opin Investig Drugs. 2018 Feb;27(2):187-192.
 4. Ozaki A, Inoue Y, Hayashida K, Nakajima T, Honda M, Usui A, Komada Y, Kobayashi M, Takahashi K. Quality of life in patients with narcolepsy with cataplexy, narcolepsy without cataplexy, and idiopathic hypersomnia without long sleep time: comparison between patients on psychostimulants, drug-naïve patients and the general Japanese population. Sleep Med. 2012 Feb;13(2):200-6.
 5. Idiopathic Hypersomnia Survey. Conducted by Toluna Analytics for Jazz Pharmaceuticals and the Hypersomnia Foundation, February 2021.
 6. Masri TJ, Gonzales CG, Kushida CA. Idiopathic Hypersomnia. Sleep Med Clin. 2012 June;7(2):283-289.