



## **Jazz Pharmaceuticals and Hypersomnia Foundation Launch Campaign to Increase Understanding and Awareness of Idiopathic Hypersomnia**

March 18, 2021

**Initiative aims to generate awareness about idiopathic hypersomnia and encourage those who may be struggling with the sleep disorder to have effective discussions with their healthcare providers and supporters about their condition**  
**Survey of healthcare providers found a lack of knowledge about idiopathic hypersomnia among physicians, and that the disorder is often misdiagnosed**

DUBLIN, March 18, 2021 /PRNewswire/ -- Jazz Pharmaceuticals plc (Nasdaq: JAZZ) and the Hypersomnia Foundation today announced the launch of I Have IH, a disease awareness campaign that aims to increase understanding of the debilitating sleep disorder, idiopathic hypersomnia (IH), and empower patients to recognize their symptoms and improve conversations with their care teams.

Experience the interactive Multichannel News Release here: <https://www.multivu.com/players/English/8830051-jazz-pharmaceuticals-hypersomnia-foundation-i-have-ih/>

IH is an often debilitating neurologic sleep disorder characterized by chronic excessive daytime sleepiness (the inability to stay awake and alert during the day resulting in the irrepressible need to sleep or unplanned lapses into sleep or drowsiness). In addition to excessive daytime sleepiness, symptoms may include severe sleep inertia (prolonged difficulty waking with frequent reentries into sleep, confusion and irritability), a core symptom of IH, as well as prolonged, non-restorative nighttime sleep and long and unrefreshing naps.<sup>1,2,3,4</sup>

People living with IH face challenges in managing their condition as healthcare providers underdiagnose IH and there is a current lack of U.S. Food and Drug Administration (FDA)-approved therapies. Jazz and the Hypersomnia Foundation have partnered together on this campaign to help increase awareness and knowledge of IH within the health and larger sleep community and to activate people who have or may have IH to initiate insightful conversations with their physicians.

To better determine physicians' understanding of IH, as part of the campaign, Jazz and the Hypersomnia Foundation conducted a survey of 305 healthcare providers, measuring their perceptions and knowledge of IH.

The results from the online survey, conducted by Toluna Analytics, underscore the need for more education and awareness of IH among healthcare providers. Only 36% of physicians reported that they believe other healthcare providers have a sufficient understanding of IH, while more than 90% said that physicians need more education about the sleep disorder.<sup>5</sup>

Healthcare providers' low familiarity with IH may contribute to patients experiencing long delays in receiving an accurate diagnosis—up to 10 to 15 years in some cases.<sup>6,7</sup> Notably, 87% of the surveyed physicians stated that diagnosing IH can be challenging, with more than half of healthcare providers (57%) reporting that they have personally misdiagnosed IH as another condition before providing the correct diagnosis. Also, a strong majority of providers (86%) reported that they think that patients who have IH are often misdiagnosed with depression and/or anxiety.<sup>5</sup>

"I'm happy to see that Jazz and the Hypersomnia Foundation are committed to this community and working to help physicians and patients, as well as their supporters, better understand this debilitating neurologic sleep disorder, with the aim of strengthening dialogues between patients and their doctors," said Richard K. Bogan, MD, FCCP, FAASM, associate clinical professor at the University of South Carolina School of Medicine. "As a sleep specialist, the findings from this survey do not come as a shock. I am well aware that some specialties that often are the first to encounter IH patients don't have enough awareness of the sleep disorder or the diagnosing process to accurately diagnose them, often causing missed diagnoses."

Given the misdiagnosis and delay in diagnosis, more education and awareness of IH is needed within the sleep community. Nearly all healthcare providers (92%) said they agree that the negative impact of IH is significantly underestimated and that it deserves greater recognition among sleep disorders.<sup>5</sup>

"We're very pleased to be partnering with Jazz to raise awareness of idiopathic hypersomnia. We know that patients in the IH community face many challenges—and one of those challenges is that most physicians do not have a deep understanding of this sleep disorder," said Diane Powell, board chair and chief executive officer of the Hypersomnia Foundation. "The results of this survey make it clear that the understanding of IH is very limited. Thus, it is vital for the entire sleep community to continue working to increase awareness of IH, both among physicians and the general population."

Survey respondents were also asked about their patients' perceptions, with a strong majority of healthcare providers saying that people living with IH are frustrated with the healthcare community (87%) and their disease management (95%). They also said patients feel their condition is not understood by the general public (66%).<sup>5</sup>

"As a person living with IH, I can't stress enough how important it is that physicians and the greater public understand the disorder," said Meghan M. "I went nearly 5 years without a definitive diagnosis of what was causing my relentless need for sleep and extreme difficulty waking up, but when I was finally told by my doctor that I had IH, I felt a sense of relief. There needs to be more education and awareness of the disorder so other people who are living with it don't have to struggle as long as I did to receive a diagnosis."

Jazz and the Hypersomnia Foundation will continue to seek different perspectives within the IH community and will survey people living with this disorder and their supporters in the future as part of the I Have IH campaign.

"At Jazz, we are committed to raising awareness of IH and are proud to be partnering with the Hypersomnia Foundation on this initiative," said Robert Iannone, executive vice president, R&D and chief medical officer, Jazz Pharmaceuticals. "The Hypersomnia Foundation gives voice to patients and their unmet needs, making them the ideal partner for the I Have IH campaign. Based on results from this survey, it's clear that work needs to be done to help ensure prompt and accurate diagnosis of this serious condition. We hope these survey results will encourage people to learn more about what IH is, and empower people experiencing symptoms to talk with a doctor."

Jazz and the Hypersomnia Foundation are committed to bringing more awareness to IH and other serious sleep disorders and helping people with these conditions at every stage of their journey—from education and diagnosis to treatment and patient assistance.

#### **About the Survey**

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. The survey is a part of the I Have IH campaign, a partnership between Jazz Pharmaceuticals and the Hypersomnia Foundation, which aims to raise awareness of idiopathic hypersomnia within the sleep community. As a part of the campaign, Jazz and the Hypersomnia Foundation will continue to explore perspectives within the idiopathic hypersomnia community and will survey patients and their supporters and/or caregivers.

#### **About Idiopathic Hypersomnia**

Idiopathic hypersomnia is an often debilitating neurologic sleep disorder characterized by chronic excessive daytime sleepiness (the inability to stay awake and alert during the day resulting in the irrepressible need to sleep or unplanned lapses into sleep or drowsiness) that is not caused by other medical, behavioral or psychiatric conditions.<sup>1,2,3,4</sup> Symptoms may also include a prolonged main sleep episode of more than 9 hours or a sleep duration of 11 hours or longer over a 24-hour period, prolonged, non-restorative nighttime sleep and long and unrefreshing naps, and severe sleep inertia (prolonged difficulty waking, with frequent reentries into sleep, confusion and irritability).<sup>1,2,3,4</sup> Although there are overlapping clinical features with narcolepsy, idiopathic hypersomnia is a condition with its own specific diagnostic criteria.<sup>1,2,8</sup> Idiopathic hypersomnia is a debilitating illness that can significantly affect social, school and occupational functioning.<sup>9,10,11,12</sup> Insurance claims data suggest the number of people diagnosed with idiopathic hypersomnia and actively seeking healthcare is 37,000 patients in the U.S.; however, given that idiopathic hypersomnia is often misdiagnosed, in addition to the lack of an FDA-approved treatment, many people with idiopathic hypersomnia remain undiagnosed indicating that the unmet need may be significantly greater.<sup>6,7,8,12,13</sup>

#### **About Hypersomnia Foundation**

The Hypersomnia Foundation engages, informs and champions our global community to improve the lives of people with idiopathic hypersomnia and related sleep disorders.

To find out more about idiopathic hypersomnia and related disorders, please visit <https://www.hypersomniafoundation.org> or follow us on Twitter, Instagram or Facebook.

#### **About Jazz Pharmaceuticals plc**

Jazz Pharmaceuticals plc (Nasdaq: JAZZ) is a global biopharmaceutical company dedicated to developing life-changing medicines for people with serious diseases — often with limited or no options. We have a diverse portfolio of marketed medicines and novel product candidates, from early- to late-stage development, in key therapeutic areas. Our focus is in neuroscience, including sleep medicine and movement disorders, and in oncology, including hematologic malignancies and solid tumors. We actively explore new options for patients including novel compounds, small molecule advancements, biologics and innovative delivery technologies. Jazz is headquartered in Dublin, Ireland and has employees around the globe, serving patients in more than 90 countries. For more information, please visit [www.jazzpharmaceuticals.com](http://www.jazzpharmaceuticals.com) and follow @JazzPharma on Twitter.

#### **Media Contact:**

Jacqueline Kirby, Vice President, Corporate Affairs & Government Relations  
Ireland +353 1 697 2141 U.S. +1 215 867 4910

#### **Investor Contact:**

Andrea N. Flynn, Ph.D., Vice President, Head, Investor Relations  
Ireland +353 1 634 7887 U.S. +1 650 496 2717

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My name is Meghan. I look like a typical 26-year-old but, as the saying goes, looks can be deceiving. In reality, my life is anything but typical. I sleep up to 20 hours a day, yet I constantly feel exhausted. Sleep does not refresh or restore me. I had to leave college because I couldn't stay awake for classes, working part-time is a challenge, daily tasks are a struggle, and it feels impossible to maintain a social life. It took five years for doctors to diagnose what caused my debilitating need for sleep. I have IH – idiopathic hypersomnia, an invisible disease most people don't recognize or understand. My IH changed life as I knew it. It continues to be an everyday struggle, but I refuse to let it define me. This is my story.

**- Meghan M.**



*I Have*  **IDIOPATHIC  
HYPERSONNIA**

 **hypersomnia**  
foundation.org

 **Jazz Pharmaceuticals**

# EXPLORING PHYSICIAN PERSPECTIVES OF IDIOPATHIC HYPERMOMNIA

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 9 and February 12, 2021 among a nationally representative sample of 305 healthcare providers, including self-identified sleep specialists (n=4), neurologists (n=23), psychiatrists (n=2), pulmonologists (n=50) and primary care physicians (n=25). 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 HYPERMOMNIA (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 irrepensible need to sleep or unplanned lapses into sleep or drowsiness.<sup>1,2</sup>

People with IH can struggle in their daily lives, as the disorder can significantly affect their social, school and occupational functioning.<sup>3,4</sup>

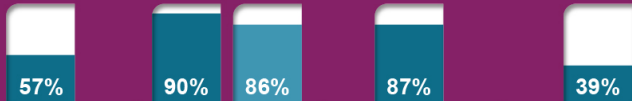
**The survey found a lack of knowledge about IH among physicians.<sup>5</sup>**

**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 HYPERMOMNIA 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.<sup>5</sup>



**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 86% represents 276 of 305 total respondents and the 80% represents 201 of 305 total respondents.

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

The 87% represents 204 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.<sup>6</sup>

The 39% represents 119 of 305 total respondents.

## 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.<sup>5</sup>



**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 269 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.

# I Have to sleep my life away because of IH.

People with Idiopathic Hypersomnia often take long naps, but wake up feeling no better than when they fell asleep.

Source: Hypersomnia Foundation



#IHAVEIH

## Symptoms of Idiopathic Hypersomnia (IH) may include-



**Chronic excessive daytime sleepiness (EDS):** sleepiness that makes it difficult to perform normal daily activities



**Prolonged nighttime sleep:** sleeping 9 hours or more every night without feeling refreshed upon waking



**Daytime napping:** despite plenty of nighttime sleep, having an irrefragable need for long daytime naps, which are typically unrefreshing



**Severe sleep inertia:** extreme difficulty waking, often with confusion, irritability, and frequent reentries into sleep



**Brain fog:** experiencing problems with memory, attention, and concentration



Source: NIH



View original content: <http://www.prnewswire.com/news-releases/jazz-pharmaceuticals-and-hypersomnia-foundation-launch-campaign-to-increase-understanding-and-awareness-of-idiopathic-hypersomnia-301249940.html>

SOURCE Jazz Pharmaceuticals plc; Hypersomnia Foundation