

“Idiopathic hypersomnia feels like going under general anesthesia. It’s like being drugged. No matter how much sleep I get, I’m always desperately wanting more sleep, yet hating it with a passion.”



What Is Hypersomnia?

Hypersomnia refers to specific sleep disorders, which include **idiopathic hypersomnia** and the related disorders:

- Narcolepsy type 1
- Narcolepsy type 2
- Kleine-Levin syndrome (KLS)
- Hypersomnia associated with certain disorders, such as myotonic dystrophy and Parkinson’s disease

Because current treatments for these disorders are very similar and current research indicates that there may also be significant overlap among them, it is important to address and research them together.

About Us



The Hypersomnia Foundation is a **501(c)(3) nonprofit** organization. **Our mission** is to improve the lives of people with idiopathic hypersomnia and related disorders by advocating on their behalf, providing support, educating the public and healthcare professionals, raising awareness, and funding research into effective treatments, better diagnostic tools, and, ultimately, a cure for these debilitating conditions.

Donate Now

As a nonprofit, we rely 100% on the support of generous donors like you to carry out our mission.

Stay Connected

Sign up for our monthly e-newsletter, *SomnusNooze*, at hypersomniafoundation.org.

Attend our events. #HFConf   

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Do you sleep too much or have difficulty waking up or staying awake?



It Could Be Idiopathic Hypersomnia (IH)

IH is a chronic and often debilitating neurologic disorder

hypersomnia
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Symptoms

The main symptom of IH is excessive daytime sleepiness despite adequate, or, more typically, extraordinary sleep amounts (e.g., 11 or more hours per night). Additional symptoms commonly include:

- Inability to stay awake during the day, resulting in unintended lapses of drowsiness or sleep
- Daytime naps that are usually more than one hour and unrefreshing
- Talking or moving without awareness or recollection while sleeping (i.e., automatic behavior)
- Extreme and prolonged difficulty fully awakening, along with an uncontrollable desire to return to sleep, disorientation, confusion, irritability, and poor coordination (aka sleep drunkenness)
- Cognitive dysfunction: deficits in memory, attention, and concentration (sometimes informally referred to as “brain fog”)

Diagnosis

Proper diagnosis of idiopathic hypersomnia is key to establishing beneficial treatment strategies and includes:

- Presence of excessive daytime sleepiness for at least 3 months
- Excluding prescribed medications as a cause
- A comprehensive medical history, physical examination, and medical tests to rule out other conditions as a cause
- Excluding disturbances in sleep rhythms (e.g., circadian sleep disorders) and insufficient sleep (usually assessed via a ‘sleep diary’ in combination with a wearable sensor called an actigraph)
- An overnight sleep test or polysomnography (PSG), followed immediately by a daytime Multiple Sleep Latency Test (MSLT), ideally performed in an accredited sleep laboratory

Treatment & Research

There are no drugs or treatments approved for IH. In the US, doctors can prescribe medications for IH “off-label” (i.e., FDA-approved medications for other conditions), but effectiveness varies.

Researchers continue to test medications approved for other disorders, as well as novel treatments, for IH. Some patients with IH have found that Cognitive Behavioral Therapy (CBT) can also be helpful for learning skills to cope with IH.

Help Research Hypersomnias

The Hypersomnia Foundation is proud to partner with CoRDS (Coordination of Rare Diseases at Sanford), on a hypersomnia specific registry.

Help researchers learn more about IH and the related disorders. Go to this link to complete the CoRDS registry today!

hypersomniafoundation.org/registry

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