

“ 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.

Help Research Hypersomnias

The Hypersomnia Foundation is proud to partner with CoRDS (Coordination of Rare Diseases at Sanford), on an international 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



About Us

The Hypersomnia Foundation is a **501(c)(3)** nonprofit organization. **Our mission** is to engage, inform and champion our global community to improve the lives of people with idiopathic hypersomnia and related sleep disorders.

Donate Now

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

Stay in Touch with HF

Sign up to stay up to date with the latest news and upcoming events:

hypersomniafoundation.org/stay-in-touch

Follow us on social media   
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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

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”)

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

There are three major classes of medications commonly used in the treatment of idiopathic hypersomnia: stimulant medications, non-stimulant wake-promoting medications, and medications taken at nighttime to promote deep sleep.

Detailed information about specific medications in each of these categories can be found at hypersomnifoundation.org/treatment. It may be necessary to try several medications or combinations of medications to determine what works best with the fewest side effects. Some people with IH are treatment-resistant and may not achieve adequate control of symptoms with currently available medications. Some people with IH have found that Cognitive Behavioral Therapy (CBT) and other behavioral treatments can also be helpful for learning skills to cope with IH.

Clinical trials are underway across the globe to find better treatments for IH and obtain approval of regulatory bodies in different countries. If you are interested in volunteering, please visit hypersomnifoundation.org/research-studies.

