



Let's Fill the Seats

The Hypersomnia Foundation's annual conference provides opportunities to learn about the latest in hypersomnia research and treatments. In addition, our conference offers a forum for professionals and others interested in hypersomnia to interact and connect. To find out more about past and upcoming conferences, please visit the Hypersomnia Foundation's web site at www.hypersomniafoundation.org

About the Hypersomnia Foundation

In 2014, the Hypersomnia Foundation was incorporated as a 501(c)(3) nonprofit organization to advocate, educate, and provide resources for research on behalf of people affected by hypersomnia.

The Foundation will fulfill this mission by

1. Providing education for people with hypersomnia, medical professionals, and scientists.
2. Representing people with hypersomnia worldwide at medical meetings, pharmaceutical companies, sleep-related organizations, and extramural funding agencies such as foundations and government institutes and councils.
3. Hosting an annual conference.
4. Establishing a hypersomnia patient registry.
5. Funding research to identify the cause of and effective treatments for hypersomnia.

Won't you help? Your donation to the Hypersomnia Foundation will help to achieve these goals and ensure a better life for people with hypersomnia. Please donate online at www.hypersomniafoundation.org.



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

To receive the latest information from the Hypersomnia Foundation, sign up for our free electronic newsletter Hypersomnia News at www.hypersomniafoundation.org. Like us on Facebook or follow us on Twitter @HypersomniaNews. We can also be reached at info@hypersomniafoundation.org or 5885 Cumming Hwy Suite 108-255, Sugar Hill, GA, 30518



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It Could Be
Hypersomnia



Waking up is the hardest thing I do every day. After I finally do wake up, I feel as if I am walking around in a fog.

About Hypersomnia

The lack of reliable tools and biomarkers to diagnose hypersomnia limits its recognition. Wake-promoting medications have emerged as the default mainstays of treatment. Advancing recognition, diagnostic accuracy, and treatment benefits for hypersomnia will come by way of novel diagnostics and treatments informed by new knowledge of hypersomnia's biologic bases.

David Rye, MD, PhD

Some people with hypersomnia set several alarms, hoping to hear even one. Still others rely on someone to drag them out of bed. When finally “awake,” many stumble through the first minutes or hours of their day in a state of “sleep drunkenness” and rely on caffeine or stimulant medication to function in the few hours that they are awake. Surprisingly, people with hypersomnia have been documented to sleep for 50, 60, or even 70 hours at a stretch.

HYPERSOMNIA SYMPTOMS

- Sleeping for at least 11 out of 24 hours, including naps and a long stretch of sleep
- Sleep drunkenness (or confusional arousal) when trying to wake up
- Excessive daytime sleepiness
- Automatic behavior (talking or moving without awareness or recollection)
- Mental dullness or “brain fog”
- Trouble concentrating or cognitive dysfunction

CONDITIONS IN WHICH HYPERSOMNIA SYMPTOMS ARE CORE FEATURES

- Idiopathic hypersomnia/major somnolence disorder
- Type 2 narcolepsy (without cataplexy)
- Kleine-Levin syndrome

CONDITIONS IN WHICH HYPERSOMNIA SYMPTOMS ARE THOUGHT TO OCCUR

- Iron deficiency
- Hypothyroidism
- Adrenal insufficiency
- Carnitine deficiency
- Chronic fatigue syndrome
- Attention deficit disorder
- Ehlers-Danlos syndrome
- As a side effect of commonly prescribed or over-the-counter medication

DIAGNOSIS

Overnight polysomnography, followed by a Multiple Sleep Latency Test (MSLT), is sensitive in diagnosing potential causes of sleepiness such as sleep apnea and Type 1 narcolepsy. This testing, however, could be nondiagnostic for other people with hypersomnia, and identifying alternative methods for diagnosing hypersomnia is an unmet need. Laboratory tests or brain imaging studies may be necessary and are determined on a case-by-case basis.

Proper diagnosis is critical to successful treatment

TREATMENT

The US Food and Drug Administration has not approved any treatments for hypersomnia. All medications are therefore prescribed “off label” for idiopathic hypersomnia. The search is on for effective treatments for this often-debilitating condition.