



**IDIOPATHIC HYPERSOMNIA
AWARENESS WEEK®**

Media Release

August 20th 2019

Living with Idiopathic Hypersomnia is only part of my story

Hypersomnolence Australia will launch the seventh annual International Idiopathic Hypersomnia Awareness Week (#IHAW2019) on 2nd September, building on the success of previous years in raising public and medical awareness of the devastating neurological sleep wake disorder, Idiopathic Hypersomnia.

This year our focus is on the fact that Idiopathic Hypersomnia does have a huge impact on sufferers' lives, but it does NOT define who we are. We are parents, partners, hard working students, successful people and good friends and family.

Our longstanding belief is that the key to improving quality of life is by taking a holistic or “whole” approach to treatment. People with Idiopathic Hypersomnia can very easily neglect areas of their life, including work, relationships and also other health issues because the symptoms are so debilitating. This can set off a domino effect that often results in sufferers struggling to cope emotionally, psychologically, as well as physically.

Idiopathic Hypersomnia is a rare neurological sleep/wake disorder. Its cause is unknown. As you may expect this means treatments are limited and as they don't treat the cause they are not always effective. Medications can also have unpleasant side effects leaving some people with no treatment options at all. Symptoms include:

- A need for much more sleep than a normal person.
- Deep, undisturbed sleep and yet the sufferer wakes up feeling like they have had no sleep at all.
- Chronic daytime sleepiness.
- Extreme difficulty awakening from sleep, accompanied by confusion, disorientation, irritability and poor coordination with an uncontrollable desire to go back to sleep. It can also include automatic behaviour, ie: performing tasks without consciously knowing it and not remembering you have done them eg: turning off alarm clocks or answering your phone.

These symptoms have a devastating impact on the ability to work, socialise, stay healthy and live a normal life. Often, there is the view that sufferers are lazy, or they should just “try harder”, whereas the truth is people with Idiopathic Hypersomnia are constantly fighting to be the people who we want to be.

Michelle Chadwick, the founder of the IHAW, said “*The mission of the IHAW is to unite the international Idiopathic Hypersomnia community to raise awareness and to help improve the level of education among medical professionals and the general public.*”

The IHAW is a truly global event. We now have Project Coordinators in the UK, Japan and Australia and we work with ambassadors in parts of Europe and the Americas.”

Idiopathic Hypersomnia has recently come to the attention of the Australian Parliament and formed part of their seminal report on sleep and its issues, “[Bedtime Reading](#)”. The Parliamentary Committee expressed concern that many people with neurological sleep disorders such as Idiopathic Hypersomnia experience stigma as a result of their condition. It was acknowledged that this stems from a lack of understanding in the community. It was also recognised that illnesses such as Idiopathic Hypersomnia are poorly understood in the medical community and are difficult to diagnose leaving people suffering for many years without a diagnoses and treatment.

<https://www.hypersomnolenceaustralia.org.au/post/2019/05/27/time-for-a-good-nights-sleep>

Idiopathic Hypersomnia Awareness Week will run from 2-8 September 2019.

IHAW social media:

Facebook www.facebook.com/IHAwarenessWeek

Twitter www.twitter.com/IHAWeek @IHAWeek

Instagram www.instagram.com/ihaweek

We will be using the hashtags #livingwithidiopathichypersomnia and #IHAW2019

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About Hypersomnolence Australia and the Idiopathic Hypersomnia Awareness Week.

Hypersomnolence Australia (HA) is the only not for profit organisation in Australia and was the first in the world to specifically represent and support the neurological sleep wake disorder Idiopathic Hypersomnia (IH). HA started the worldwide Idiopathic Hypersomnia Awareness Week® (IHAW) in 2013. It is the mission of the IHAW to unite the international Idiopathic Hypersomnia community to raise awareness and to help improve the level of education of Idiopathic Hypersomnia among the general public, medical professionals and people living with Idiopathic Hypersomnia.

For further information about Idiopathic Hypersomnia:

Hypersomnolence Australia www.hypersomnolenceaustralia.com

Hypersomnia Foundation www.hypersomniafoundation.org

