

Media Release

August 10th 2020

Worldwide Awareness for Idiopathic Hypersomnia

Hypersomnolence Australia will launch the eighth annual Worldwide Idiopathic Hypersomnia Awareness Week (#IHAW2020) on 7th September. It is the goal of the IHAW to raise global public and medical awareness of the debilitating neurological sleep wake disorder, Idiopathic Hypersomnia.

Our longstanding belief is that the key to improving quality of life for people with Idiopathic Hypersomnia (IH) is by taking a holistic or "whole" approach to treatment. People with IH 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. 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 of IH include:

- A desperate 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.
- Cognitive dysfunction (commonly referred to as 'brain fog'): problems with memory, automatic behaviour, concentration and attention.

These symptoms have a devastating impact on the ability to work, socialise, stay healthy and live a normal life. Many sufferers are told they are lazy, or that they should just "try harder", whereas the truth is people with Idiopathic Hypersomnia are constantly fighting to be involved in life and are devastated at how much they miss out on.

Michelle Chadwick, the founder of the IHAW, said "The mission of the IHAW is to unite the worldwide Idiopathic Hypersomnia community to raise awareness and to help improve the level of education among medical professionals and the general public. It is encouraging to see more and more people from all over the world joining us in this very important annual event."

Idiopathic Hypersomnia Awareness Week will run from 7-13 September 2019.

IHAW social media:

<u>Facebook</u> <u>www.facebook.com/IHAwarenessWeek</u>
<u>Twitter</u> <u>www.twitter.com/IHAWeek</u> @IHAWeek
<u>Instagram</u> <u>www.instagram.com/ihaweek</u>

We will be using the hashtags #LivingWithIdiopathicHypersomnia and #IHAW2020

All media enquiries: Michelle Chadwick ihaweek@gmail.com

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 <u>www.hypersomnolenceaustralia.com</u> Hypersomnia Foundation www.hypersomniafoundation.org