

**Mr Aaron Schokman**

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***Submission to the Inquiry into Sleep Health Awareness in Australia***

**Background:** I was diagnosed with a rare neurological sleep disorder known as narcolepsy type 1 in early 2011. It is characterised by severe, irresistible daytime sleepiness and sudden loss of muscle tone brought on by emotion (cataplexy), and can be associated with sleep-onset or sleep-offset paralysis and hallucinations, frequent movement and awakening during sleep, and weight gain<sup>1</sup>. It is hypothesised to be an environmentally triggered genetic autoimmune disease, whereby the protein that controls an individual being awake and asleep is attacked by the bodies immune system. This is an unfathomable situation as sufferers continuously feel the need to sleep (which if ignored, will be forced upon the individual akin to a microsleep in a healthy yet sleep deprived subject) yet are unable to stay asleep (waking up multiple times a night). Upon accessing first-line treatment (available overseas yet unregistered here in Australia) late 2015 at great personal cost, I have been able to work full time, completed a masters in sleep research this year at the University of Sydney, published my first journal article in the Sleep Health Journal<sup>2</sup>, and am now pursuing a PhD in sleep disorder research. I have also advocated on behalf of others with narcolepsy, having had an online documentary/story created by the ABC and other media outlets focusing on experience, spoken at conferences as well as working with my federal parliament representative John Alexander OAM to improve access to treatment options for Australians suffering from narcolepsy.

- 1. The potential and known causes, impacts and costs (economic and social) of inadequate sleep and sleep disorders on the community;*

Many studies have looked at the implications and costs of narcolepsy. Most show a devastating effect on the ability to work, potential earnings and impaired social functionality. Unfortunately, there seems to be a disconnect between the established impact, cause and cost of narcolepsy and current government policy. One such example is that narcolepsy is not considered a disability in Australia and as such, precluded many from obtaining support through Centrelink and the NDIS. Another disconnect is the lack of mandatory reporting to state-based driving regulators. Narcolepsy by its very definition involves uncontrollable bouts of sleep occurring at inappropriate times, such as during driving. A Maintenance Wakefulness Test (MWT) is sometimes performed to ensure that the individual is capable of driving on their current disease. This reporting should be mandatory by all medical professionals once a diagnosis is made and an MWT completed before any driving.

2. *Access to, support and treatment available for individuals experiencing inadequate sleep and sleep disorders, including those who are: children and adolescents, from culturally and linguistically diverse backgrounds, living in rural, regional and remote areas, Aboriginal and Torres Strait Islander;*

Overall, support and treatment options for individuals suffering from narcolepsy is extremely poor and lacking in Australia. Xyrem (sodium oxybate) is the current first-line treatment for narcolepsy with cataplexy according to the British Medical Journal Best Practice. This medication was first available in 2003 in the United States to treat this narcolepsy, however, remains unregistered here in Australia, setting our current treatment options roughly 15 years behind the rest of the world.

As mentioned, I was diagnosed in 2011 and treated with high dosages of antidepressants and stimulant medication. While antidepressants are classified as the first-line treatment here in Australia, there is little to no evidence to support its use nor are the side-effects adequately investigated<sup>4</sup>. My personal experience on this course of treatment was both traumatic and dangerous. I became extremely introverted and depressed, with my weight ballooning from 70kgs to 140kgs over a year. The combined effect of sleep deprivation and antidepressants resulted in an overall numbness where I was unable to express or process emotion. This, along with visual and auditory hallucinations that accompany narcolepsy resulted in an extreme and rapid decline in my mental health, where I would black out and come to having written obscenities on the walls and engaging in dangerous and violent actions without any knowledge. The large dosages of stimulant medication caused extreme mood swings and aggression resulting in holes being punched in walls and my father being physically assaulted. I sought help at the time from a prominent sleep specialist at the Royal Prince Alfred hospital, however, was turned away from further treatment as it 'wasn't my local hospital'. I tried another hospital; however, sleep conditions are not classified as 'life-threatening' or a serious 'emergency' and was put on a 10-month wait list. Thankfully, I gained access to Xyrem in 2015, privately importing it through the TGA special access scheme. This was self-funded at almost \$25,000 a year and at the time did whatever I could to raise the necessary funds as I was terrified that if I continued on my treatment regime, [REDACTED]. Xyrem had an amazing effect on my narcolepsy, and within three months, enabled me to come off all antidepressants and reduce my stimulant dosage by 90%. My symptoms of the condition are managed, and I have been able to work full time, socialise and complete my studies.

Unfortunately, the price of Xyrem is a significant barrier for those suffering narcolepsy as the drug remains unregistered. A substantial amount of advocacy work has been done to try and get the drug registered (and thus an application to the PBS potentially made) however the pharmaceutical company has stated that the cost of registration outweighed the economic benefit. While this is a legitimate reason, the Orphan Drug scheme was changed in 2017 which removed the cost of registering narcolepsy treatments; however, the pharmaceutical company has remained silent with no plans to register the procedure. The drug is protected internationally by patent, yet what has developed is a situation whereby the pharmaceutical company has monopolised the market and can charge whatever they want for the drug privately, with no incentive or reason to register the medication. The underlying idea of pharmaceutical products being protected by a patent is to reward

research and development of new drugs and as a reward for their investment in developing the drug. What has occurred instead is a bastardisation of our laws and universal health care system and resulted in those with narcolepsy being left in limbo.

*3. Education, training and professional development available to healthcare workers in the diagnosis, treatment and management of individuals experiencing inadequate sleep and sleep disorders;*

My experience with health care workers, in particular, sleep specialists has been troubling. A recent study has shown that 91% of primary care doctors and 58% of sleep specialists are NOT COMFORTABLE diagnosing narcolepsy. Only 22% of sleep specialists could name all five significant symptoms. As a result, most remain undiagnosed on average between 8-12 years. A lack of education and professional development was again apparent when I sought access to Xyrem in 2015, with 9 out of 10 sleep physicians claiming that they had never heard of Xyrem before (yet it being used as a frontline treatment option, backed by significant evidence for almost 12 years overseas).

I believe that this has come about because of the combination of sleep medicine with that of respiratory medicine here in Australia. Most, if not all sleep physicians are focused on treating Obstructive Sleep Apnea (OSA) for whatever reason (possibly invested corporate interest). Professional development, therefore, takes the form of keeping up to date with the latest in the OSA field, with little focus given on anything else. This is emphasised in the Australasia Sleep Down Under annual conference which is attended each year by most sleep physicians and forms the core of their development requirements. This year the annual conference agenda was populated by more than 80% of research and material relating to OSA.

*4. Current national research and investment into sleep health and sleeping disorders.*

As a current early career researcher looking to pursue PhD projects in the field of sleep disorders, I have been unable to find any opportunities to study sleep disorders in Sydney. This is worrisome as most of our world-renowned universities with sleep laboratories are focused on a tiny field of sleep (mainly OSA). This was highlighted only last month by a sleep physician with whom I met with to potentially oversee my PhD. He commented that he would be shocked if I found anyone to oversee my project as no one is interested in anything other than OSA, and that respiratory sleep physicians are the ones that now control all the purse strings in regards to funding allotment. From a patient perspective, I believe that there should at least be a minimum requirement that funding for sleep-related research should be specific to sleep disorders (other than OSA) and investigating the overall nature of sleep.

Thank you for the opportunity to make a submission to this enquiry.

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