

Today I saw an organization meant for educating medical professionals' tweet to their nearly 3k followers that Idiopathic Hypersomnia is "yet another invented illness" with a link to the New York Times article.

Another doctor tweeted that this was a weak approval for a "hyperinsomnia" drug.

This was my biggest fear when this article broke- that the stigma would make its way into the medical community when many of us were already facing it from our own doctors. Some were already, for example, afraid to ask our doctors about different treatments or to increase dosages for fear of coming off as a drug-seeker. I've been biting my tongue for over a year about my meds which aren't getting me through the day.

If I was nervous to discuss xywav with my doctor before, I'm absolutely terrified now. It might take another year for me to find the courage to even tell my doctor that my current meds aren't enough.

The longer this article stays up the way it is the more nervous I get. I am terrified of reliving the professional humiliation that I have experienced in the past. I will never ever ever ever under NO condition feel comfortable disclosing my diagnosis (in order to obtain reasonable accommodations) to an employer who is just going to google it, see this headline, and assume that they've just hired someone who takes a date-rape drug for an illness of which New York Times has grossly downplayed the severity and seriousness of.

Written by MP, USA.

These are MP's thoughts on a New York Times article published in August 2021. The intention of the article was supposedly to announce the FDA's approval of Jazz Pharmaceutical's Xywav (a low sodium version of Xyrem) for Idiopathic Hypersomnia. The author of the article however chose to incorrectly refer to Xywav as a 'date rape' drug. Indeed the New York Times chose it as their headline. The article also lacked balance and failed to make some important points not least of all that Xyrem has been used safely in narcolepsy for at least 20 years. There is literally no history of abuse or addiction so there was no need to put so much emphasis on this "risk". The way the article was written resulted in a number of ignorant comments including (as MP mentioned above) those from the medical community (this was naturally very disappointing).

We would like to show readers what sleep doctors who actually treat people with idiopathic hypersomnia and narcolepsy think of the New York Times article. We would also like to thank them for speaking out against it. If only we could all have doctors like this....

"Appalled by the New York Times "click bait" headline. Those living with narcolepsy and idiopathic hypersomnia face stigma and endure repeated empiric medication trials to feel better. Sensationalistic reporting is a pile-on #DoBetter @virginiahughes" Dr Katie Sharkey MD PhD Asst Dean, Women in Medicine & Science, Brown University.

"That headline really deserves a correction/retraction. These medications are not the same as GHB and cannot practically be used as agents of date rape. As a New York Times subscriber, I'm ashamed of the shoddy journalism of this article." Dr Brandon Peters MD, Board-certified sleep medicine physician and neurologist.

"Idiopathic hypersomnia is real. It's serious and disabling even if it's rare and most doctors haven't heard of it.... This article - not just the headline is hot garbage."  
Dr Spencer Dawson, PhD. Sleep scientist and clinical psychologist.

"Appalling. This story is very disappointing for the New York Times - clearly below their standard". Dr David Neubauer, sleep specialist and psychiatrist.

"When news outlets care more for views than news .. totally wrong.. NY times should retract or correct it.." Dr Saroj Prakash Kandel, pulmonologist and sleep physician

"Deflated by such a reputable media outlet not filtering this sensational and low grade "not researched "reporting" Sleep Specialist Indianapolis, USA.

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Idiopathic Hypersomnia Awareness Week 2021



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