

This is what I'd like to tell the New York Times about their horrible article:

The New York Times published an article by Virginia Hughes on August 12th. And I've never been so disappointed by something that acknowledges my condition. I know that unbiased reporting is, realistically, difficult to do....but surely Virginia could have tried a touch harder?

It starts with that leading title, which implies that the prescription and the street drug are one and the same. And at no point in the article does she correct that statement. Two minutes on Google finds multiple sites that explain the purity differences. Calling it the "date rape drug" and having the first line be about how much money the drug has brought in for Jazz certain pulls the reader towards "FDA let's big pharma put dangerous drugs on the streets".

Two thirds of the article is negative against Xywav, with the only positive quotes coming from the pharmaceutical company itself for more than half of the article. You don't see anything from outside the profit-makers until the last stretch. And none of them include why Idiopathic Hypersomnia (IH) is so debilitating that patients are willing to take a risky drug.

And of the 3 people quoted about experience with xyrem? One was a lawyer with narcolepsy, one the mother of a dead woman, and only one single person had hypersomnia. Where does that lead readers? I'm worried people will think we are increasing the danger of date rape, and won't be able to see past it and realize that some of us feel completely helpless every day.

I am frequently late to a job I love. I nod off on the couch, or the toilet. I have anxiety about public transportation, because what if I fall asleep and miss my stop? I have slept through classes, through lunches, through cheerleading practice. I've had sunburns from falling asleep outside in the blazing sun, and caught a cold taking a nap in the middle of winter because I didn't have the strength to get out from under part of a hay bale that had fallen on me. I've slept at family functions and holidays. I've canceled plans I was so excited for. If I had to drive longer than 30 minutes it was a constant battle of "do I keep splashing water on my face and blasting cold air to push through till I'm home, or pull over and take a nap for 45 minutes to 2 hours?" When I was 5, I was flower girl for my aunt and uncle's wedding. Halfway up the aisle, I laid down and slept till the reception.

All of that, and the painful knowledge that I'm higher functioning than a lot of people, but Jazz Pharmaceuticals brought in more than \$1.7 billion last year selling Sodium Oxybate to narcolepsy patients, and now it's going to make more.

It is one thing not to spread awareness about IH, that's the norm, but it's an entirely different thing to mention it only in a negative light on a wave of controversy.

•Kyra•

These are Kyra'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.

#LivingwithIH

Idiopathic Hypersomnia Awareness Week 2021

