Hypersomnia Foundation's Response to the New York Times article of 8/12/2021 concerning the FDA's approval of Xywav for idiopathic hypersomnia in adults:

Like many of you, we at the Hypersomnia Foundation were very disappointed in the New York Times article of August 12 concerning the FDA approval of Xywav for idiopathic hypersomnia. Rather than celebrating that there is finally a medication approved for IH, we instead all have to deal together with the fallout from this article. We believe that the article, and especially its "click-bait" headline, fails to adequately discuss the scientific testing and FDA review that went into the approval. In addition, the article fails to discuss what it's really like to live with IH, and why getting the first FDA approval for a medication is so critical for people who suffer from this debilitating condition.

Obviously, we do not control the NY Times reporter, what the reporter chooses to write, or what the Times chooses to publish. Although we support open discourse and the First Amendment, we disagree with much of the article and wish it would have better portrayed the realities of living with IH. We also invite the reporter (or any Times reporter) to spend a day or two with a person suffering from IH, to learn how this disorder so adversely affects a person's life.

All of us on the HF Board are volunteers, and all of us have a special connection to IH. Some of us have IH, some of us have loved ones or friends with IH. While other people may try to speak for us, they are not authorized to do so.

Please be assured that we're not ignoring this article. Rather, we are taking the time to carefully consider the best way to respond with factual and accurate information in support of, and on behalf of, the IH community for whom we so proudly advocate.

The Hypersomnia Foundation Board of Directors
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