Mr. Thomas Feyer
The New York Times
letters@nytimes.com

August 16, 2021

To the Editor:

Re “F.D.A. Approves GHB, a ‘Date Rape’ Drug, for Rare Sleeping Disorder” (nytimes.com, Aug. 12):

I am the Chair of the Hypersomnia Foundation, a patient advocacy group for people who suffer from a chronic neurological sleep disorder called idiopathic hypersomnia (IH). This sleep disorder, which is debilitating for many people since it causes their lives to be consumed by sleep, had no FDA-approved medications until last week. Then, on August 12, the FDA approved the first medication for IH, which hopefully will be the first of many medications ultimately approved for this sleep disorder.

However, rather than celebrating this milestone, the Times chose to publish an article which was misleading and sensationalistic. In particular, the Times’ headline, which described the newly approved medication as a “date rape” drug, was simply “click-bait”--and beneath the journalistic standards long represented by the Times. The article itself failed to adequately discuss IH, its symptoms, or how it adversely affects the people who suffer from it. This article inappropriately stigmatizes the only approved medication for IH, and may discourage patients from trying a treatment and their doctors from prescribing it.

Since the Times’ reporter sought out (and received) an opportunity to speak to two of our Board members, we do not understand why the reporter did not think it important to present a more accurate, and balanced, picture of IH and this new FDA-approved medication.

Sincerely,

Diane Powell
Chair/CEO, Hypersomnia Foundation

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To the Editor:

Re "F.D.A. Approves GHB, a 'Date Rape' Drug, for Rare Sleeping Disorder" (nytimes.com, Aug. 12):

I have suffered with idiopathic hypersomnia (IH) for nearly 20 years. This chronic neurological sleep disorder is debilitating for many. We are not just sleepy; our lives are consumed by sleep. Until last week, the only available treatments were prescribed "off-label," which made them challenging to fill. People with IH looked forward to this milestone of the first FDA-approved medication for our condition.

The Times' misleading headline, describing the newly approved medication as a "date rape" drug, and its article lacking significant attention on IH itself and the patients whose lives may be dramatically improved by treatment, does a serious disservice to me and all others with IH. Additionally, this article inappropriately stigmatizes both the only approved medicine for IH and the patients themselves. This may discourage both patients and doctors from trying a desperately needed viable treatment.

I invite any Times reporter to spend time with members of our community to understand the immense challenges of living with idiopathic hypersomnia, especially without adequate treatment.

Sincerely,

David Burley
Board Member, Hypersomnia Foundation