

Remarks to the House Judiciary Committee

Monday, March 8, 1999

I am William E. Speakman, Jr. I reside and work in Washington County, Pennsylvania. I am the father of Matthew Speakman who is afflicted with narcolepsy.

I very much appreciate the opportunity to share with you my views on the medication -- GHB -- which Matthew is taking as a result of his condition.

Early in Matthew's high school career, we learned that he had narcolepsy. We -- and he -- learned that what we all considered simple every day tasks were becoming difficult, even dangerous.

For example, he was very active in the Boy Scouts and a group from his Troop, including his brother, went to Philmont Scout Ranch in New Mexico. It's every Scout's dream. His bags were packed, his money was paid and he was ready to go, only to be told that he couldn't because of the narcolepsy. Hiking and climbing at high altitude in remote places was too hazardous.

He was a successful member of the high school swimming team. Because he could not get adequate rest and sleep, he found it very difficult, if not impossible, to get to the practices before school which hampered his development.

He had trouble staying awake in class. Obviously, this did not contribute to his academic standing.

There was the embarrassment of cataplexy and slurred speech in front of friends and in the check out line at the K Mart. There was the danger of operating a motor vehicle. There was stigma. There was the need to tell every prospective employer about it.

To quote from Narcolepsy Primer, a monograph by a nationally-known physician who works with narcoleptics:

The long-term effects of narcolepsy can be devastating, with drastic emotional, psychological, social and financial consequences. Narcoleptic persons endure educational, occupational and marital problems.

Certainly, Matthew was starting down the road described by the doctor. That monograph apparently was written before GHB was considered for treating the condition because it is not mentioned as a possibility. Ritalin is mentioned as a means of "first line therapy" because it "causes less decrease in appetite or increase in blood pressure than amphetamines."

Matthew participated in a study at the University of Pittsburgh. He was given Ritalin and Vivactil, an anti-depressant. They were of some help, but they did not eliminate the problems and they had unpleasant side effects. Ritalin has a short duration of action. More importantly, the body develops a tolerance to Ritalin which meant that Matt's dosage had to be kept low and he was not to take it on weekends and other days when he did not have to go to school. Obviously, this created problems with his social life and with working. In no way, shape or form was the Ritalin therapy effective or satisfactory.

Since Matt started on the GHB therapy three years ago, he has been able to manage his condition much more successfully. Neither narcolepsy nor the medication interferes with his life in a significant way. He was able to take a job as a camp counsellor last summer. He can manage a demanding academic load as a junior computer graphics major. He is no longer tied to a sleep schedule as he was in the pre-GHB days.

Significant, from my perspective, is Matt's much-improved outlook on life. He no longer seems to feel imprisoned by narcolepsy and tormented by the side effects of Ritalin. The difference between Ritalin and GHB is like the difference between night and day.

Other drugs which are capable of abuse and misuse such as narcotics are controlled, but not banned because they have legitimate medical purposes as well. I cite an example which seems to be exactly on point. Choral hydrate, commonly known as knock out drops, can be misused in a date rape situation, but it is a controlled substance, not an illegal one. Marijuana can be used for medicinal purposes in some states. Ritalin, the drug he took and which did so little for him, is capable of misuse and is regulated.

Legal stuff

Enabling people to overcome disabilities is consistent with the trend of American law and with historic American principles. I call your attention to the American With Disabilities Act and with the right to pursue happiness. GHB permits Matthew to overcome his disability and to pursue his dream.

I would urge you to permit narcoleptics in Pennsylvania to continue taking GHB. Control it, yes. Regulate it, yes. Please don't ban it. GHB gives my son the opportunity to overcome his disability and lead a normal, productive life. Does he not have that right? Don't penalize Matthew and others afflicted with narcolepsy because of the misdeeds of the criminal element.

Thank you.