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Patient Testimonial: A Day In the Life of an Idiopathic Hypersomnia Patient

Announcer:

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Dr. Schneider:

Hello, I'm Dr. Logan Schneider. I'm a Sleep and Cognitive Neurologist. And I'm here today with Diana Kimmel, a patient with idiopathic hypersomnia, so that we can learn a little bit more about this condition and how it affects people's lives. So, Diana, just to start us off, could you tell us a little bit about your condition and how you got to the point of being diagnosed?

Ms. Kimmel:

Sure. My name is Diana Kimmel, I live in Atlanta, Georgia. I was diagnosed with idiopathic hypersomnia in 2011, after a very long struggle with the diagnosis. Like many, you'll hear the same story over and over again, you go to the doctor, you complain about your symptoms, you explain them, and what you get is a lot of suggestions, lose weight, get to bed earlier, don't watch TV in bed, things like that. And nothing seems to help, exercise all those things; nothing helps. You go to the doctor over and over again. And what I was dealing with was just an extreme need to sleep during the day, after sleeping well all night. I could feel like problems with my executive function. I had sleep inertia when I woke up for hours. And then later in the day, something called, well, like brain fog, where you just feel like you're almost functioning underwater. You can't move, you can't see right, you're not even hearing things correctly. You just feel deprived of sleep, even though you slept all night.

Dr. Schneider:

Yeah, that can be quite a challenge. In fact, I think many people both in the general community, as well as even in the medical community typically underestimate the impact of the symptoms, thinking like well just sleep it off. So based on that, you described some of the core symptoms, like sleep inertia and brain fog. How was that impacting you from a personal and professional standpoint?

Ms. Kimmel:

Yeah, it was impacting everything. It was impacting how much I could do at work, paying attention, keeping on track, meeting deadlines, all of those things are affected. At home, every aspect of home life, time with your kids, trying to get house chores done, you know, keeping your, you know, your bills, your tasks, everything done at a timely manner. It affects everything you do. Especially, you know, like I said, work, your kids, social life, you do the bare minimum, anything that's going to take energy out of your day, when you need it for other things, you try to avoid it.

Dr. Schneider:

Wow. So, despite the long road to a diagnosis, once you achieved an understanding of what it was that was impacting you and how to label for it, I'm assuming that you started on some sort of treatment or treatment plan. What was your response to that? How did that impact your symptoms as well as your quality of life?

Ms. Kimmel:

Sure. Yeah, it took about probably 10 years to get finally diagnosed. And when I did, there's nothing really, at my time of diagnosis,

there was nothing FDA approved for idiopathic hypersomnia. So, there was nothing to prescribe, other than stimulants and anything that was used off label. For me, it was actually an antibiotic that helped me out originally. And I took that for several years. And that helped the slightest bit, it gave me a little bit more function, it gave me a little bit less brain fog. But that's about it. Through the years, since 2011, I've tried just about everything there. I am now on the, you know, one FDA approved drug, and that is giving me, you know, the most amount of relief I've been able to have since my diagnosis.

Dr. Schneider:

That's great. That's great. So, it sounds like the journey is long in every regard. So, one, it's getting recognition of the symptoms, sometimes even personally, but certainly having the people around you and your physicians understand that. And that can take a long time, because you have to have the appropriate workup, but then even arriving there, the journey to find the right medication often can be difficult. And the goal obviously as you highlighted is improving your symptoms and your daily function. So ultimately, do you feel like you're where you want to be? Or is there still progress that you feel could be made?

Ms. Kimmel:

I think there's still definitely progress that could be made. Some days are better than others. And, you know, it's not as predictable as I'd like it to be. So, I look forward to more options down the line or something else that I can add to really bring myself to a place where I feel like I'm functioning much more better.

Dr. Schneider:

What's great, yeah. I think science will forge ahead and hopefully we'll continue to make improvements as we already have today. Thank you.

Ms. Kimmel:

Thank you.

Announcer:

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