

LIVING WITH IDIOPATHIC HYPERSOMNIA

I am Aisa Magsombol, a single mother to a 15-year-old, working tirelessly to provide for my family while battling idiopathic hypersomnia, a rare neurological sleep disorder. Each day, I wake up feeling like I haven't slept, facing challenges like excessive daytime sleepiness, brain fog, and sleep drunkenness.

I sought help from a new doctor in 2018 for answers and treatment. However, I was surprised when my driver's license was revoked due to safety concerns, adding another layer of difficulty in my life as I had to rely on public transportation or the kindness of others. I was forced to pull my daughter out of school and homeschool her throughout middle school—a blessing in disguise pre-covid.

As a recovering addict for ten years, I faced another obstacle when the only available medications for my condition were stimulants (Adderall, Vyvanse, Provigil, and Ritalin) that had caused my past struggles. This led me into a cycle of withdrawal and side effects, making it harder to grieve my old self, accept the treatment I needed, and be the best mother I could be. Today, I am no longer on prescription drugs, and I manage my condition holistically.

Working as a Talent Acquisition Manager in 2019, I struggled to disclose my condition to my employer and protect myself. Unfortunately, my fears became a reality when I was unjustly fired just a week after requesting reasonable accommodation to make my doctor's appointments, highlighting the discrimination many face in the workplace. I worked remotely three days a week, so my request was more than reasonable.

Throughout these hardships, I remained firm, discovering my resilience and determination. I believe that my journey with idiopathic hypersomnia happened for a reason - to help others going through similar struggles. I started raising awareness about the complexities of this condition, becoming an advocate and source of inspiration for those facing invisible illnesses.

I became a Rare Disease Legislative Advocate with RARE on the Road, a rare disease leadership series hosted by [Global Genes](#) and the EveryLife Foundation for Rare Diseases, providing critical education and insight into the rare disease community. During this time, I wrote and presented to Vice President Kamala Harris' office about Community Home Health & Telehealth Policies.

In 2021, I was accepted to participate in two cohorts with The RARE Compassion Program, which provides an opportunity for medical students to learn about the unique needs and challenges individuals and their families face living with an undiagnosed or rare disease. It was beyond impactful to have the opportunity to share my experience regarding all areas of my life due to my rare condition with the medical students I was partnered with.

In my darkest moments, faith provided solace. I believed that God chose me to endure these hardships so I could provide hope and support to others. Sharing resources and techniques, I empowered others to manage their condition and fight against discrimination.

My story touched hearts, initiating conversations about empathy and understanding. Despite adversity, I proved that one could rise above and create a positive impact. My journey with idiopathic hypersomnia became a beacon of light for those feeling lost, reminding them to embrace their struggles, turn them into strengths, and never lose hope.

Aisa – 2023



IDIOPATHIC HYPERSOMNIA
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