

# Illuminate Hypersomnia

*Shining light on the lived experience of IH*



## Voice of the Patient

Report on the Externally-Led Patient-Focused Drug  
Development Initiative for Idiopathic Hypersomnia (IH)  
and Meeting Held on April 11, 2024

Organized & Hosted By:  Sleep Consortium

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**The Illuminate Hypersomnia “Voice of the Patient” Report**

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## INTRODUCTION TO THE ILLUMINATE HYPERSOMNIA INITIATIVE FROM SLEEP CONSORTIUM

*On April 11, 2024, a diverse group of patients, caregivers, advocates, healthcare professionals, researchers, biopharmaceutical leaders, and federal agency staff gathered in a powerful forum for the Illuminate Hypersomnia externally-led patient-focused drug development (EL-PFDD) meeting. This event was the culmination of months of planning, collaboration, and information-gathering through an accompanying survey, interviews, webinars, written comments, and other forums. It marked a significant milestone in amplifying the voices of those living with idiopathic hypersomnia (IH).*

*Throughout this series of activities, including the meeting itself, we heard firsthand accounts from individuals affected by IH. Their stories were compelling, their challenges profound, and their resilience inspiring. This report summarizes the heartfelt testimonies and invaluable insights that highlight the daily struggles, unmet needs, and hopes for the future of those battling this frequently misunderstood condition.*

*Sleep Consortium was founded in 2021 to accelerate next-generation research, disease understanding, and therapy development for those living with Central Disorders of Hypersomnolence (CDoH) and related diseases, of which IH is one. As a consortium, we pursue this mission by bringing together diverse stakeholders in the firm belief that we are stronger when united in purpose.*

*We brought the Illuminate Hypersomnia initiative to life with that same foundational belief, engaging multiple patient advocacy leaders, life science companies, advisors, and partners to strengthen our foundational understanding of the lived experience of IH and to expand outreach to the global IH community. We worked closely with representatives from the U.S. Food and Drug Administration (FDA) to leverage their expertise garnered from hosting and guiding more than 115 FDA-led and externally-led PFDD meetings.*

*We sincerely thank everyone who joined this effort and contributed to its success, including the individuals acknowledged on pages 75-77. Our deepest gratitude goes out to thousands of members of the IH community whose voices were heard and whose hopes were felt by us all. We especially commend the bravery and openness of panelists who shared very personal journeys, highlighting the essential and urgent work ahead.*

*Our goal in creating this initiative and documenting what we have learned in this report is to ensure that the perspectives of the patient and caregiver remain at the forefront of drug development and regulatory decisions. We encourage you to help us distribute this resource far and wide to foster broader awareness and deeper understanding of IH, drive patient-centered research priorities, and ultimately improve the quality of life for all those affected by IH.*

*Together, we will light the way and continue to make a difference in the lives of those affected by idiopathic hypersomnia.*

*Sincerely,*

*Lindsay Jesteadt, PhD  
Co-Founder and Chief Executive Officer  
Sleep Consortium*

*Claire Wylds-Wright, MFA  
Co-Founder and Chief Experience Officer  
Sleep Consortium*

## EXECUTIVE SUMMARY

Hundreds of members of the idiopathic hypersomnia (IH) community from around the world took part in the Illuminate Hypersomnia initiative, including a four-hour virtual externally-led patient-focused drug development (EL-PFDD) meeting held on April 11, 2024, and a web-based survey for people living with IH and their care partners and caregivers. This initiative was a first for the IH community, as was the opportunity for a broad array of IH community members to directly share lived experiences with staff from the U.S. Food and Drug Administration, life science companies, academic researchers, healthcare professionals, and other people affected by IH.

### ILLUMINATE HYPERSOMNIA BY THE NUMBERS



10

partner organizations



338

unique stream viewers during the live webcast of the April 11, 2024 meeting

1,031

total views of the meeting recording as of Sept. 12, 2024



7

life science company sponsors



289

written comments received from community members before, during, and after the meeting (prior to May 11, 2024)



18

community-member presenters and discussion starters



170,298

total words written in response to open-text survey questions



811

total responses to the Illuminate Hypersomnia survey

*The meeting and survey addressed the burdens of symptoms and impacts of IH and ways that individuals manage the condition with medical and complementary treatments, lifestyle modifications, and other approaches.*

the learnings from testimony provided at the meeting, interviews conducted during the planning phase of the initiative, hundreds of written comments submitted before, during, and after the meeting, and complete and partial responses to the survey. Throughout the report, direct quotations support these learnings to preserve the authenticity of the community's experience. Key findings that emerged from all the community input about the lived experience of IH include:

**Lengthy Diagnostic Odysseys Are the Norm:** Many people recall mild to moderate symptoms of IH beginning in childhood or teen years that were more likely to draw comments about them being a "good sleeper" than provoke concern about a potential medical condition. Participants reflected that with age and increasing demands of life, symptoms intensified, became more prominent, or interfered with life in more significant ways by the early to middle adult years. It can be hard for people to explain their experience to healthcare professionals in a manner that communicates the true impact of symptoms on their lives and functioning, so complaints about excessive sleepiness, fatigue, and cognitive impairment can be attributed by doctors to lifestyle issues, stress, or depression. Numerous people mentioned that a dramatic or dangerous event ramped up the search for appropriate medical attention and a diagnosis. As many people looked back, they identified missed opportunities for earlier detection and intervention. In all, the delay in obtaining a proper diagnosis can extend for years and stretch into decades.

The meeting and survey addressed the burdens of symptoms and impacts of IH and ways that individuals manage the condition with medical and complementary treatments, lifestyle modifications, and other approaches. Meeting participants and survey respondents were also asked about the path to diagnosis, downsides of and barriers to treatment, aspirations for new treatment benefits, and clinical trial experience.

This report summarizes

**An Array of Symptoms Impair Daily Functioning:** In addition to the IH hallmark of “irrepressible” daytime sleepiness, participants described in vivid detail the severely compromised quality of life people with IH experience due to impaired quality of wakefulness, mental foginess or “brain fog” that persists well past the transition from being asleep to being awake, memory and concentration problems, overwhelming fatigue, weakness, and severe sleep inertia. Many people reported having just a few hours of modestly good functioning each day, and many require long hours of nighttime sleep, even if it doesn’t typically lead to feeling refreshed upon awakening. IH symptoms were reported by many participants to get worse over time and in response to stress, overexertion, and sensory overload.

**IH Symptoms Take a Toll on Every Aspect of Life:** Across all the testimonies, community members provided compelling accounts of the pervasive effects of IH on school and work performance, family functioning, social and intimate relationships, self-esteem and identity, and aspirations for personal, educational, and career-related attainment. Personal safety and the safety of others is a major concern. Several people spoke about the uncertainty of future hopes to continue or complete their education, enter into or stay in committed relationships, start or expand their families, work in a chosen field, or sustain a current level of employment, family, or social engagement. The impact of IH on other family members can be quite profound, and there were reports of family clusters of IH among blood relatives, adding another dimension to family impacts.

**Treating and Managing IH is Demanding:** A dynamic combination of medications, lifestyle adjustments, accommodations, and supportive strategies were used to mitigate the effects of IH, generally without complete or lasting relief. Nearly all participants had experience with medications, with past or current stimulant use being near-universal. Participants described using different classes and types of medications over time and at the same time to obtain modest improvement, often with unpleasant side effects and/or mounting concerns about long-term risks. Many reported frequent, ongoing recalibration of dosages, timing, and formulations to combat the loss of effectiveness or find an acceptable balance of benefits and harms. Being able to consider or try appropriate medications or combinations of medications was frequently limited by physicians’ lack of familiarity with IH and/or willingness to treat, insurance coverage, costs, drug shortages, and approval by various countries’ health authorities and market factors.

**Significant Unmet Needs Remain for Treatment:** Finding and accessing knowledgeable healthcare professionals was a major challenge that affected diagnosis and treatment options. Even with the help of a caring, informed professional to use available therapies, participants expressed unmet treatment needs. There are substantial gaps in achieving the outcomes that individuals with IH prioritize: feeling more refreshed by sleep and alert with adequate energy and liveliness to go about the day and be involved in meaningful relationships, work, and leisure activities; to stay awake without meds or the “fake awake” feeling of stimulants; to be free of side effects like cardiovascular strain, appetite loss, zombie-like existence, suicidality, and GI distress; and to have fewer restrictions related to medication schedules and travel, due to the nature of some treatments and the controlled nature of others.

**Stigma and Disbelief in the Reality of IH Add to Burdens:** A general lack of awareness of IH and familiarity with its severity and impact weakened self-esteem and hope. Many participants expressed an urgent desire to be believed, to be taken seriously, and to be treated with greater respect and empathy by family members, employers and coworkers, medical professionals, and friends. The community expressed optimism that the Illuminate Hypersomnia initiative and the tighter connections it forged across the global IH community could fuel positive momentum to improve awareness and understanding.

**Across all the testimonies, community members provided compelling accounts of the pervasive effects of IH on school and work performance, family functioning, social and intimate relationships, self-esteem and identity, and aspirations for personal, educational, and career-related attainment.**

*The meeting recording is available for on-demand viewing at <https://bit.ly/watch-IH-EL-PFDD>*

# Illuminate Hypersomnia

Shining light on the lived experience of IH

## SECTION 1:

# Setting the Stage



Lindsay Jesteadt, PhD  
Co-founder and CEO,  
Sleep Consortium

***“This collaborative effort is crucial for paving the way toward groundbreaking discoveries and enhancing the quality of life for those living with IH”***  
– Lindsay Jesteadt

“Today’s Illuminate Hypersomnia meeting is a unique opportunity to bring the global idiopathic hypersomnia (IH) community together before the U.S. Food and Drug Administration (FDA), life science companies, researchers, clinicians, and other advocates. This collaborative effort is crucial for paving the way toward groundbreaking discoveries and enhancing the quality of life for those living with IH, as well as other sleep disorders,” stated **Lindsay Jesteadt, PhD**, in welcoming comments that began the four-hour externally-led patient-focused drug development (EL-PFDD) meeting on April 11, 2024.

**Tiffany Farchione, MD, FAPA**, spoke on behalf of FDA staff from across the agency in attendance, emphasizing their dedication to patient-focused drug development. “We all share the patient community’s commitment to facilitate the development of safe and effective medical products for the treatment of IH. We’ve learned from PFDD meetings that patients are the experts in the lived experience of their disease or disorder. Patients are uniquely positioned to inform regulatory agencies and to provide an understanding of the burden of disease and currently available treatments. We’re here today to learn from the experts on the lived experience of IH.” She continued, “Hearing what patients and caregivers care most about can help us lead the way in figuring out how to best facilitate medical product development and to understand how patients view the benefits and risks of therapies and devices for IH. We learn so much from these meetings and look forward to incorporating what we learn today into the agency’s thinking and understanding. I want to personally thank everyone here for their participation. We’re grateful to each of you for sharing your stories, experiences, and perspectives. So, thank you.”

“What is idiopathic hypersomnia? It is a disorder of pathologic excessive daytime sleepiness, not explained by other conditions, despite what should be ‘good enough’ sleep at night.” **Lynn Marie Trotti, MD**, asked and answered as she began a clinical overview of IH to support patients’ and caregivers’ descriptions, which would be the focus of most of the meeting. She reviewed common symptoms of IH (see page 10), the current diagnostic criteria, and tests used to aid in diagnosing IH and distinguishing it from other sleep disorders. “Where we struggle in the diagnosis of IH is differentiating it from narcolepsy type 2 (NT2, or narcolepsy without cataplexy) and differentiating it from hypersomnia that might co-exist with a mood disorder like depression,” she noted. “In both these cases, symptoms can look the same as IH. While there may be some differences in the objective testing, there can be overlap in the results, and it can be difficult to be sure we have diagnosed someone correctly.”

Dr. Trotti also described the current treatment approach that includes the only medication that FDA has approved for the treatment of adults with IH, Xywav (calcium-magnesium-potassium-sodium oxybates), medications approved for the treatment of narcolepsy, and other off-label medications. She addressed limitations of the current clinical guideline for treating IH, published in 2021. “It was based on the available evidence at that time, which was before publications on the use of Xywav in IH, so those are not mentioned. Equally important, medications commonly used for IH don’t appear in the guideline if there wasn’t a publication in the literature supporting their use. So, what we do in clinical practice is to take medications that FDA has approved for narcolepsy, and we use them ‘off-label’ to treat people with IH. It’s reasonable to believe that a medication that works for NT2 will likely work for IH because the sleepiness is very similar between those disorders.” She addressed lifestyle modifications, indicating that naps often leave people with IH feeling worse when they awake than before the nap. She acknowledged there is little data available to understand what sleep schedules, exercise regimens, diets, or behavioral strategies might be beneficial to recommend.

“Other supports are critically important for people with IH, like accommodations for school or work, including late start times because of the sleep inertia (see description, page 20), days where people will miss school or work unexpectedly because they were too sleepy to get there safely, and cognitive accommodations like extra time on tests because of the attentional issues people with IH often have.” Before closing, Dr. Trotti encouraged patients and families to get involved in support groups. “This is a disease that profoundly affects patients and their families. I think patients and their family members benefit from talking to and knowing other people who are going through what they are going through. I look forward to hearing from patients and their families over the rest of this meeting,” she said in closing.

Moderator **Kim McCleary** then outlined the meeting format, split into two sessions, each of which started with pre-recorded statements provided by IH community members about their experiences, followed by a panel discussion with additional community members joining live by videoconference, telephone, and through written comments submitted live and in advance of the meeting. The first session was dedicated to symptoms and daily impacts of IH, and the second session focused on approaches to managing IH. Select interim data from the Illuminate Hypersomnia patient and caregiver survey was also shared, providing another dimension of experience from the first 446 respondents who submitted partial or complete answers to the survey by March 26, 2024. (Note: See Section 4, beginning on page 55, for final results from 811 survey responses received as of the closing date for the survey, May 11, 2024.)



## Diagnostic Criteria for IH

As Dr. Trotti reviewed during the clinical overview, according to the International Classification of Sleep Disorders, 3rd edition, text revision (ICSD-3-TR, 2023), the diagnosis of IH requires:

- Self-reported daily sleepiness (“irrepressible need to sleep or daytime lapses into drowsiness or sleep”) for three months or more
- At least one objective test showing sleepiness or long sleep duration:
  - In-lab sleep study polysomnography (PSG) and multiple sleep latency test (MSLT) with mean sleep latency (time it takes to fall asleep) less than or equal to 8 minutes
  - At least 11 hours of sleep occurring in up to 24 hours of PSG monitoring
  - At least 11 hours per 24-hour period of sleep in at least one week of actigraphy monitoring
- Exclusion of:
  - Insufficient sleep
  - Narcolepsy (absence of cataplexy, sleep lab testing doesn’t show narcolepsy)
  - Anything else that better explains the symptoms

## Patient-Focused Drug Development & the Illuminate Hypersomnia Initiative

In 2013, the U.S. Food and Drug Administration (FDA) began holding meetings to hear directly from patients, caregivers, advocates, and other key community stakeholders about living with various medical conditions and how well available treatments meet patients' needs. This meeting series called the "[Patient-Focused Drug Development](#)" initiative, or PFDD, was immensely beneficial to the FDA teams and the agency. The meeting series was expanded to enable patient organizations to host externally-led PFDD meetings (EL-PFDD meetings), with the input of FDA staff, and use the process established by FDA-led PFDD meetings as a model. To date, there have been more than [115 PFDD and EL-PFDD meetings](#) combined; the first PFDD meeting on a rare disease focused on [narcolepsy](#).

The Sleep Consortium conducted the Illuminate Hypersomnia initiative in collaboration with patient advocacy organizations that serve the IH community, acknowledged on page 76. It was a parallel effort to the FDA's PFDD initiative to more systematically gather patients' perspectives on their conditions and available therapies to treat them. The initiative included a survey to ensure that it included the experiences of as many people with IH as possible. This "voice of the patient" report summarizes the Illuminate Hypersomnia meeting and survey as an enduring resource for researchers, drug development sponsors, regulators, healthcare professionals, and others. The Illuminate Hypersomnia initiative also provided an important way for members of the IH community to learn from and support one another.

### Three key parts of the **Illuminate Hypersomnia** initiative:



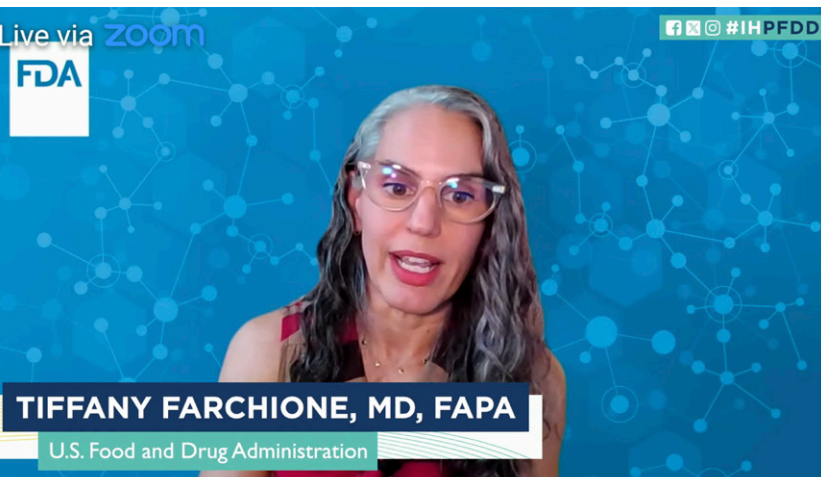
Virtual  
PFDD Meeting



Online  
Survey



Voice of the  
Patient Report



"We've learned from PFDD meetings that patients are the experts in the lived experience of their disease or disorder."  
– Dr. Tiffany Farchione, FDA



# Illuminate Hypersomnia

Shining light on the lived experience of IH

## SECTION 2:

# Symptoms and Daily Impacts

## SYMPTOM ONSET AND PROGRESSION

Many IH community members recall a life-long experience of long sleep duration and were often praised during childhood as being “good sleepers.” They relate memories of excessive daytime sleepiness and falling asleep easily in class, at the library, on family car trips, and even while engaged in activities. “My earliest memories of extreme sleepiness are from when I was about 12 or 13 years old, driving a tractor through the corn fields on my father’s farm,” recounted meeting speaker **Raymond Meester**, now age 71.

Others remember the difficulty of waking in the morning or from naps stemming back to childhood. **Beth Boyce**, age 62, reflected, “Even as a child, I understood the word ‘groggy’ because that’s how I felt, and not just when I woke up, but because it hung on all day.” These difficulties often affected school attendance and school performance. “All my life, I’ve been known to sleep a lot and to fall asleep very easily. I struggled with memory and didn’t do well in school like the other kids,” said 46-year-old **Jenny Greathouse**. **Michelle Chadwick’s** difficulties began during her first year of high school. “I slept through alarms and was always late to school. I slept through class and sometimes skipped school altogether. I would sleep at the local library.”

*“My mum always praised me for sleeping through noise as a baby. When in school, I struggled to stay awake. I was seen as lazy and tardy.” – Written comment submitted by L.J.Y., Scotland*

*“I seem to have had a long relationship with difficulties with sleep/wakefulness before being officially diagnosed in my late 40s. I distinctly recall my mum saying*

*“I am 47 years old and have dealt with this since age 5. I was held back in kindergarten because I would be exhausted after a half day of school. No one has ever understood, and I’ve always been called lazy.”  
– Written comment submitted by R.B., North Dakota*

## SYMPTOMS OF IH

### Mandatory symptoms

- Excessive daytime sleepiness
- Normal or long sleep durations

### Classic features (not mandatory)

- Severe, prolonged sleep inertia
- Long, unrefreshing naps

### Common symptoms (not mandatory)

- Fatigue
- Autonomic dysfunction (e.g., blood pressure and/or heart rate changes with changes in position)
- Cognitive dysfunction (e.g., attention)

From Dr. Trotti's clinical overview

Excerpts from interviews and written comments are attributed by the individual's initials and state or country to protect their privacy; some commenters expressed a desire to remain fully anonymous. All responses to the survey are anonymous and comments in that section of the report are unattributed.

*that during primary school, the teachers would report that I would sometimes go missing, only to find me a bit later, asleep on the toilet. This was about age 6. At about age 15, I was so tired in school that I'd miss recess break to climb under my desk and nap on the floor." – Written comment submitted by W.B., Australia*

For some, symptoms intensify during adolescence and disrupt education and family life. **Suzanne Lecours** shared how her son Scott's symptoms progressed during his eighth-grade year at age 14. "Scott was sleeping a lot. He was having trouble getting up for school and was feeling sick to his stomach in the mornings. He could only finish his ninth-grade year with many accommodations, and he's at home for grade 10, trying to complete a couple of course credits through an online school."



*"She was our first child and was such a good sleeper. She took naps, fell asleep easily at bedtime, and usually fell asleep in the car, even on short trips. She was often hard to wake up, but it wasn't until high school, with its earlier start of the school day and more activities and demands on her energy, that we became concerned. She wasn't able to keep up with her schooling, so we sought medical attention." – Statement by M.S., United States, during a telephone interview conducted in preparation for the meeting*

For others, like **Jelissa Suarez**, symptoms may not be severe enough to substantially interfere with functioning until early adulthood. "Although I had always been one to sleep eight to 11 hours a night as a child and through college, 10 years ago, at age 26, I was studying for the medical school entrance exam when I was abruptly hit by the sudden and overwhelming urge to sleep. I could barely keep my eyes open. I felt my brain shutting down. There was no amount of coffee I could drink or cold water I could splash on my face to become more alert. I quickly gathered my books and went to my car to sleep. This began my odyssey as I became more reliant on naps to subdue the overwhelming excessive sleepiness that became more problematic for my daily functioning. I was also having trouble getting out of bed in the morning, and it was taking me longer to transition from being asleep to feeling fully awake, sometimes hours. My brain didn't function as it used to. I felt foggy and groggy, even when I was fully awake," she stated.

**Michelle Chadwick** shared an observation from her work with Hypersomnolence Australia that symptoms of IH become more severe and/or more challenging to explain away or compensate for as the demands of adulthood intensify. "Speaking to people with IH all over the world, I've found that the more they take on, the more work, family, or life pressures, the harder their symptoms are to manage." **Sam Bell's** experience fit this pattern, as he described at the meeting. "I had symptoms in high school. Back then, falling asleep was funny. But as I got older and started working full-time, it became more of an issue I couldn't ignore."

## Shortcomings of language to fully describe IH symptoms

A common theme throughout discussions in preparation for and at the meeting is the inadequacy of clear, well-understood terminology to describe the symptoms and experience of IH. Participants stated that terms like “fatigue,” “sleepiness,” and “feeling tired” are so pervasive in today’s culture that they feel meaningless, if not derisive, to people with IH. They reported that terms used in clinical descriptions of IH, including “sleep inertia” and “sleep drunkenness,” are not broadly known or used and may not come into the awareness of individuals with IH until after they are diagnosed and better informed about the condition.

The intensity and persistence of how these aspects of IH manifest in the life of the person experiencing it make it difficult for them to describe and for others to comprehend, including family members, friends, colleagues, and healthcare professionals. Many participants noted that the disconnect can strain relationships and may contribute to the lengthy path to diagnosis and treatment that so many IH community members reported.

*“How do you explain IH to someone? Your eyes are open, but you are not really awake. Your mental acuity is non-existent. When you are awake, you find yourself staring aimlessly at nothing, like sleeping with your eyes open.*

*“Someone speaks to you, and although you hear them, your brain does not really process what was said, and your most common response is ‘huh?’*

*“You must constantly keep moving, or you will nod off, and you have done so in inconvenient locations such as at the movies, the doctor’s waiting room, during your business meeting, or in traffic while waiting for the red light to change...and this is on a good day when you are actually able to leave the house.*

*“It’s like swimming underwater, and everything is muted. You head toward the surface, but you just can’t seem to break through, ever.” – Written comment submitted by Kelly McClelland, New Jersey*

## THE PATH TO DIAGNOSIS

Among the individuals with IH who engaged with this initiative, there were very few reports of an abrupt onset or worsening of symptoms that led to a relatively quick diagnosis of IH. **Michael Sparace** described his wife’s straightforward path to diagnosis this way, “We had only been dating for a few months when I began to notice that she didn’t have a ton of energy and needed more and more sleep. I knew this was different from the pattern that enabled her to be a straight-A student with a rich social life and heavy involvement with lots of extracurricular activities. She was fortunate to have been referred to the sleep clinic at Emory University, where her doctor ordered an overnight sleep study. She was diagnosed with IH fairly quickly.”

*“My situation is a rare example of a ‘best-case scenario.’ I was going through a lot personally and began feeling extreme sleepiness, fatigue, and brain fog. To manage it, I was seeing a therapist, trying to exercise regularly, doing yoga, eating a healthy diet, using acupuncture and chiropractic treatments, you name it. Nothing seemed to help, and my work performance was suffering. My therapist connected me to a neurologist who happened to be involved with clinical trials for IH and ordered sleep tests right away. I was diagnosed with IH and prescribed medications that helped with the fatigue and sleepiness. Getting good care makes all the difference when you have IH. I was never **not** taken seriously by the professionals I saw. I had excellent healthcare insurance, and fortunately, I was able to see a specialist within a few miles of my home who understood sleep disorders and IH.” – Statement by anonymous, United States, during a telephone interview conducted in preparation for the meeting*



Michael Sparace noticed a different pattern in his wife’s energy and need to sleep

**Many people reported that they languished for years, even decades, before declining further or when an upsetting, sometimes dangerous event pushed them to advocate more forcefully for testing and follow-up referrals.**

Far more common were reports that worsening symptoms led individuals to pursue medical attention, but the care they received left them feeling dismissed, downplayed, or diverted from obtaining meaningful answers. “I feel like I’ve been tired forever,” lamented **Shelly Gonzalez**. “During college, and then when I entered the grown-up workforce, I thought it was normal. I made excuses because I thought to myself, isn’t everyone tired? When I would bring it up to doctors, the only feedback I ever received was to work on sleep hygiene, which was absolutely infuriating and, to this day, will send me into a rage. In 2017, it was my dentist, of all people, who asked if I was tired during the day. He suggested that I might have sleep apnea. I was referred to have a sleep study, and that is how I was diagnosed with IH.”

Many people reported that they languished for years, even decades, before declining further or when an upsetting, sometimes dangerous event pushed them to advocate more forcefully for testing and follow-up referrals. **Diana Kimmel** shared her experience at the meeting. “After years of searching for answers, I crashed my car while driving my son to practice. Yet that very morning, I had been at the doctor’s office, hearing him tell me once again that I was fine. He told me that I was probably depressed and needed to lose weight and exercise more, things so many of us hear. Clearly, I was not fine. After years and years of searching, frustration, embarrassment, and trying to hide my difficulties from everyone around me, I found the specialists at Emory who got me to the correct testing, and I was finally diagnosed with IH.”

Self-doubt about the reality and extent of the symptoms, as well as the individual’s ability to cope effectively with what others deem “normal” tiredness, can also inhibit action. **Jenny Greathouse** struggled with symptoms from childhood. “I had two children and threw myself into parenting and all their activities while also working full-time. It seemed normal to always feel exhausted and to fall asleep in any downtime during those years.”

*“I have had numerous chronic conditions, and doctors treated my symptoms for years. Cognitive and memory issues made me think I had early Alzheimer’s. I changed insurance and got a new neurologist who couldn’t believe I had never had a sleep study. A few months ago, after a 20-hour sleep study, I was diagnosed with IH and began reading everything I could about it. I’ve had symptoms since my late teens, and now I’m in my 50s. I spent most of my life misdiagnosed and feeling frustrated being told I was ‘just depressed.’” – Written comment submitted by A.L., United States*

*“I was told so often that everyone is tired that I started to doubt myself. Now that I have effective treatment, I can say with confidence that it is not normal to feel so sleepy.” – Written comment submitted by T.R., The Netherlands*



*“I find that when physicians see a normal test result for something they think might be the reason you are so tired, they fail to test further to find an abnormal test. I can’t count how many times I’ve been tested for mononucleosis, Epstein-Barr virus, Lyme disease, and thyroid issues.” – Written comment submitted by K.L., New Jersey*

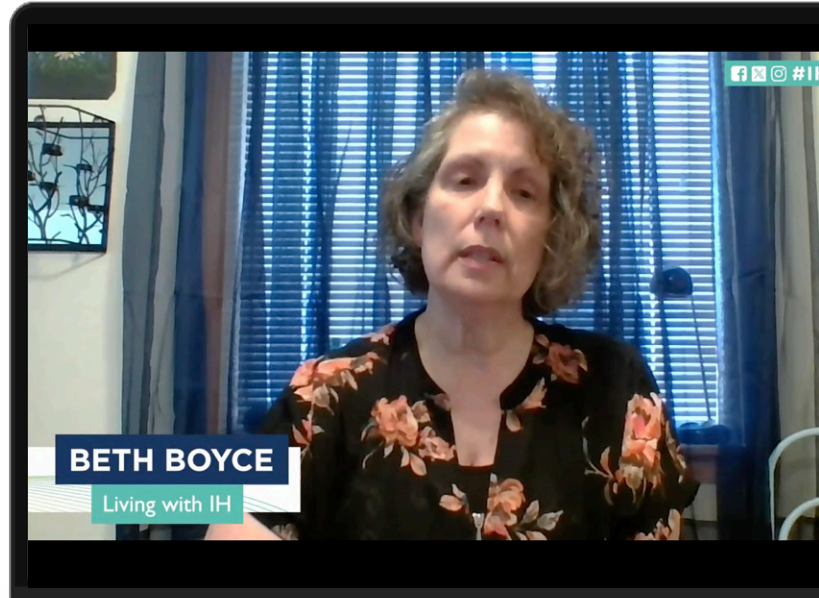
Some obtained related diagnoses and treatment on the way to a diagnosis of IH, either to address potentially treatable symptoms or as part of the process of ruling out possible explanations. **Beth Boyce** relayed the long odyssey she traveled, an event that pushed her to step up the search for answers, and a progression of diagnostic labels. “At different times in my 20s and 30s, I would tell doctors about difficulties I was having thinking and functioning and the feeling of being perpetually sedated. They reached many conclusions about things that were not the cause but never had an explanation for what might have been the underlying reason. By my late 30s, I was so discouraged that I stopped going to doctors,” she said.

Beth continued, “My late 40s ushered in worsening symptoms, and I started having trouble driving. One morning, after a good night’s sleep, I was stopped at a traffic light. Moments later, I woke up in the middle of the intersection with cars coming at me from both directions. Fortunately, no one was hurt, but it was the wake-up call I needed to, again, try to figure out what was causing my problems. The traffic scare led me to a new doctor, who ordered sleep and nap studies and finally arrived at a diagnosis of hypersomnia. I was referred to an ear, nose, and throat specialist for surgical consultation for airway improvements. The surgery was deemed successful, but to my dismay, hypersomnia symptoms and struggles continued. Additional sleep studies added a name-mate, ‘idiopathic,’ to my diagnosis. I was officially diagnosed with idiopathic hypersomnia.”

**Raymond Meester**, a retired pastor, went most of his 71 years without an explanation for symptoms that began early in life and became progressively worse. “In 2011, I discussed my sleepiness with my doctor, and she referred me to a pulmonologist who had me take a sleep test. I was diagnosed with sleep apnea and prescribed a CPAP machine. It didn’t provide much relief for my symptoms, so in 2017, my pulmonologist prescribed armodafinil, and then in 2020, I was prescribed modafinil. However, the sleepiness was getting worse. I was taking four naps a day, experiencing brain fog with cognitive difficulties and forgetfulness. By about 2021, my sleepiness got to be rather unbearable. My pulmonologist ordered an MSLT, and I was diagnosed with IH,” Raymond stated.

Co-morbidities can add to the complexity of making a diagnosis. “I struggled most with waking up, brain fog, automatic behaviors, poor memory, and declining cognition. In 2016, at age 35, I started having medical investigations. My childhood history of photosensitive epilepsy led doctors to think that it might be happening again. Epilepsy was ruled out, and my neurologist sent me to a sleep clinic where I had a home investigation for sleep apnea, then an overnight study at the hospital, then the MSLT, and that was when I was diagnosed with IH,” **Gemma Jones** relayed at the meeting.

**Robin Leader** described her experience with her 17-year-old son, Zachary. “He is the oldest of our three kids, and he’s had a challenging journey with several conditions, including celiac disease. It’s been a multi-year diagnostic journey. His celiac is severe, and it took us a long



*“By my late 30s, I was so discouraged that I stopped going to doctors.”*  
– Beth Boyce, meeting presenter

**A recurring theme at the meeting was the challenge of accessing knowledgeable care, including getting referred to appropriate specialists and diagnostic testing.**

time to reduce the damage caused by consuming gluten prior to being diagnosed. We did not have sleep disorders on our radar and thought his symptoms were either psychological or due to the celiac disease. At one point, we took Zack to a pulmonologist for what we thought was going to be hypnotic therapy to help him mentally deal with having a chronic illness. But when we arrived, the doctor wanted to do a sleep study based on his medical history. The pulmonologist ordered both daytime and nighttime tests and determined he had severe obstructive sleep apnea and restless leg syndrome. He was later diagnosed with Klein-Levin syndrome, narcolepsy, and IH.”

The evolving criteria for various sleep disorders, including IH, and variability with the methods for conducting and evaluating results from different types of sleep tests can complicate the process of establishing a diagnosis and assessing its accuracy over time, as Dr. Trotti described in the clinical overview and several community members attested to, based on personal experiences. This also contributes to challenges with treating IH and accessing prescribed medications – a topic explored more deeply later in this report.

*“The sleep study I completed back in 2019 resulted in a diagnosis of IH. My neurologist later said that I have symptoms of mild cataplexy. It is possible I have [type 1] narcolepsy with cataplexy with overlapping symptoms of IH.” – Written comment submitted by K.G., Virginia*



*“I wish there was a clear and reliable diagnostic test for IH. I have been diagnosed with having both narcolepsy type 2 (NT2) and IH based on results of MSLT testing. I recently had an intake appointment with a sleep specialist in the United States. They sent my records to the Mayo Clinic and a new sleep study was their recommendation. The MSLT test is not reliable at separating NT2 and IH.” – Written comment submitted by A.H., Ireland*

*“My journey into my sleep disorder started in February 2022, when I completed my second sleep study (the first was 10 years prior) and was diagnosed with type 2 narcolepsy. Finally, after 12 years of being diagnosed with ‘medication-resistant’ major depressive disorder (when numerous attempts to treat me with antidepressants were unsuccessful), I felt more validated and on the right track of diagnosis than I ever had before. I began seeing a second sleep specialist who got me off meds and did a second sleep study. He changed my diagnosis to IH and am still struggling daily to function with this condition and find appropriate treatment.” – Written comment submitted by N.G., Illinois*

A recurring theme at the meeting was the challenge of accessing knowledgeable care, including getting referred to appropriate specialists and diagnostic testing. Even people with health insurance can struggle to get coverage for the costly sleep studies required to substantiate a diagnosis of IH.

*"I have worked for more than 12 years for a contract research organization in drug development and was recently diagnosed with IH after years of struggling with the disorder. I went through multiple sleep doctors to find appropriate care and have had to constantly battle my medical insurance providers to cover testing and treatment." – Written comment submitted by R.R., Ohio*

Receiving or arriving at a diagnosis can elicit a range of emotions. "In late 2013, on a second date with my now fiancé, he recognized signs in me that were similar to his diagnosis of sleep apnea and suggested that I may have a sleep disorder. I dismissed it thinking, 'That's not true,' until I took an online sleep apnea quiz. Every answer I typed suggested I should see a doctor. So, I called and scheduled a sleep study and almost canceled on my way to the clinic, thinking, 'This is absurd,' and that's when I got the diagnosis of IH, a condition I'd never heard of and really could not believe was true. Eventually, denial gave way to curiosity, and I started to research IH on my own. The symptoms completely fit my reality. It was a blessing to me to have a name for the cause of things I struggled with my whole life, but it was also a curse. Doctors didn't seem to know much about it, there was no clear treatment plan, and there was a very minimal list of medication options. Nothing was clear cut," **Jenny Greathouse** recalled.



Jenny Greathouse

*"When our daughter was diagnosed with IH at age 16, very little changed for her, but it was a big help to our family. It helped us know that she wasn't depressed, she wasn't lazy. It gave us something to help manage and organize life around." – Statement by M.S., United States, during a telephone interview conducted in preparation for the meeting*

*"I'm 64 years old and was diagnosed a year ago. Before that, I thought I was a failure at life. Knowing it wasn't my fault was huge. I am so grateful to find out that there is a reason that I can't accomplish what everyone else does." – Written comment submitted by T.S., Oregon*

*"I was diagnosed in 2010, and it saved my life. I finally got the answer that I would never feel better, that I could never sleep this feeling away. I mourn the YEARS I lost to sleep before my diagnosis. Since the diagnosis, I treat my sleep like how I imagine you'd treat an amputated leg – you adjust. I figured out how to accept and compensate. I am proud to be an associate director in one of the world's top universities, and I've been able to be in a committed relationship for years. I am so grateful that I got a diagnosis." – Written comment submitted by A.S., Washington*

**Beth Boyce** described her feelings upon being diagnosed with IH, "After four decades of struggling with such an elusive set of symptoms, there was tremendous validation in finally getting a diagnosis, even if the name of my neurological condition contained the term 'idiopathic,' a most unfortunate word that highlights the lack of understanding of its underlying cause, and in society's measure, downplays the seriousness of the disease, even among physicians." The impact of the name of the condition on how individuals viewed their circumstances post-diagnosis was mentioned by other community members too.

*"If anyone has even heard of IH at all, the minute they hear the term 'idiopathic,' they minimize it and think it's not legitimate or legitimately difficult. They may know of narcolepsy (and this is quite similar), but when they hear 'idiopathic,' they think it's a symptom of being sleepy and that they know how we feel. Even Klein Levin Syndrome, an even rarer illness, has a name that doesn't include 'idiopathic,' even though they don't entirely know what it is. Changing the name would help others take us and what we deal with more seriously." – Written comment submitted by B.M., United States*

**"It was a blessing to me to have a name for the cause of things I struggled with my whole life, but it was also a curse. Doctors didn't seem to know much about it, there was no clear treatment plan, and there was a very minimal list of medication options." – Jenny Greathouse, meeting presenter**

## Family Clusters of IH

During the meeting, a few people commented on having more than one person with IH (or suspected of having IH) in a family. **Diana Kimmel's** daughter's diagnosis with IH was a turning point for her. "I knew something needed to change. It really fueled my want to bring change, see advocacy, and expand education. I wanted to create that space that I needed in our community."

**Jenny Greathouse** expressed concern about her oldest son's health and shared his resistance to the idea of pursuing a diagnosis. "Like me, he's always been a good sleeper. He falls asleep very easily and has a very rough time getting up. A few months ago, he called me after having a car accident. His words confirmed my fears, 'I didn't even know I fell asleep.' Those were the exact same words I had spoken for years before my diagnosis. I recognize many similar symptoms in him, classic with IH, and he has been to countless doctors, all telling him he's perfectly healthy despite the symptoms he's experiencing. I have asked him to consider a sleep study, and his words to me are, 'Why? So, I can struggle as much as you have and eventually get a medication that they'll just take away, and I, too, will lose my job one day?'"

“*My daughter's diagnosis with IH was a turning point for me. It fueled my want to bring change, see advocacy, and expand education.*”

*"I do not want anyone else to suffer like me. I have recently noticed my grandson may be suffering from IH, too. He sleeps way more than the average child."*

*- Written comment submitted by R.B., North Dakota*

*"My son and I both have IH. Looking back, I believe I may have been misdiagnosed with depression as a teenager, and it wasn't until 30 years later that I was able to get a diagnosis of IH. When I noticed similar signs and symptoms in my teenage son, I followed through with the referral and he too was diagnosed."* - Written comment submitted by R.B., Australia

*"My daughter, age 14, and I both have IH."* - Written comment submitted by J.W., Tennessee



Diana Kimmel



## MOST BURDENSOME SYMPTOMS

Like other disorders that disrupt normal sleep patterns, IH presents with various burdensome symptoms that impair functioning, well-being, and safety. Participants used a collection of terms to describe the symptoms they experience, with some potential overlap among them. To be faithful to their statements, this report catalogs these dimensions of the IH experience without attempting to distinguish between them.

### Irrepressible Excessive Daytime Sleepiness

As the central and sole symptom of IH required under the current diagnostic criteria (see page 7), excessive daytime sleepiness (EDS) was frequently among the first symptoms mentioned by community members. It is a force that many fight every day, during every waking hour, no matter where they are or what they are doing. The term itself was contested as inadequate to describe the magnitude of the experience. **Rebecca Bonnar** stated, "My primary symptom is termed 'excessive daytime sleepiness.' That in itself leads to a vast misconception that I'm tired. I am not tired. Living with IH is constant work. It feels like wading through mud every day. It's physical and mental exhaustion. It's an active fight minute by minute, hour by hour, to push past your brain shutting down. It's triggered by any heightened emotion. So, anger, joy, stress, excitement, feeling anything are met with sleepiness. It's amplified by any illness, a cold, a migraine. Sometimes, if the weather changes too abruptly, that causes an immense amount of worry about how I'm going to feel in a day."

**Michael Sparace** described his wife's struggle to stay awake, which reflects the "irrepressible" aspect of EDS. "I help her get to and from doctor's appointments and may follow her back to the exam room to help her stay awake since she falls asleep easily without constant stimulation. She has a narrow slice of time when she's typically as fully awake as she can be, generally from about 5:00 p.m. until 9:00 p.m. After that, I often have to help her shower because she may otherwise fall asleep while doing it on her own." **Diana Kimmel** added this dilemma, "I'd sleep all night, yet I would struggle to get the kids to school. By 10:00 a.m., I was already needing a nap. It hurt to be awake, but naps were unrefreshing. Oftentimes, I wake up from a nap feeling worse, but you just have to sleep, even though it makes you feel worse."

In the fight to stay awake, EDS can prompt compensatory behaviors that may be experienced as symptoms. "The more sleepy I am, the more uncoordinated I am, so I can be very clumsy. It's like when toddlers are super tired, and they wobble a little bit. I can be like that, which again is very embarrassing for me. When I'm trying hard not to fall asleep, I can become very talkative. I need to move a lot, and I'm very fidgety. All those things alter people's perception of me, and I'm quite aware of that," reported **Gemma Jones**. This description resonated with **Rebecca Bonnar**, who added, "The toddler analogy that Gemma used is something that gets raised frequently for me. People comment when I wake up from a nap, I have that face of a toddler when you've woken a toddler up from a nap. Now that's cute, but I'm 32 years old."

*"I help her get to and from doctor's appointments and may follow her back to the exam room to help her stay awake since she falls asleep easily without constant stimulation."*  
– **Michael Sparace**, meeting presenter



I don't really want to look like a toddler waking up from a nap." **Raymond Meester** agreed with another aspect of Gemma's description, saying, "Gemma mentioned that she can be chatty. I talk way too much. I try not to do it, but I keep doing it. It can be very embarrassing. I understand it is a way to keep me awake."

*"Soporific sluggish drowsiness just is overwhelming at times and causes all kinds of issues." – Written comment submitted by R.S., U.S. Minor Outlying Islands*

*"I have fallen asleep at a college football game with 60,000 screaming fans." – Written comment submitted by T.S., Oregon*

*"My life revolves around naps. I wake up thinking about when my nap will take place. I plan naps days in advance. I can fight the urge to sleep but will feel seriously ill if I don't sleep within a period of time after it hits." – Written comment submitted by K.L., New Jersey*

*"It's debilitating to have a disease where so much of your limited energy is designated to pretending to be more awake/alert than you really are." – Written comment submitted by C.L., California*

*"If we are to get the public to understand, we need to speak clearly. People who are 'tired' are (mainly) exhausted from their activities. 'Sleepiness' is the want to sleep. While IH is exhausting, we are sleepy." – Written comment submitted by A.H., Ireland*

**"Trying to focus at work is just awful. I write everything down, and even then, I will forget my notes."**  
– **Amanda, a caller during the meeting**

## Brain Fog and Lack of Mental Clarity

The symptom most often mentioned as being the most difficult to live with was described by various terms, including "brain fog," "lack of mental clarity," and feeling "groggy" and "foggy." People with IH report this feeling of brain fog and impaired cognition persisting long past the transition from sleep to being awake, as "sleep inertia" is defined.\* Indeed, for some, they describe it as constant.

People's descriptions of this "oppressive" symptom were generally brief, although the impacts on people's lives were pervasive, as described in the next section. **Beth Boyce** noted, "I had trouble thinking and functioning, even when I was fully awake." She described it as "feeling perpetually sedated." Caller **Tamara** used a similar term, "I tell people I feel sedated, and that's because I have a lot of brain fog when I'm experiencing the effects of IH."

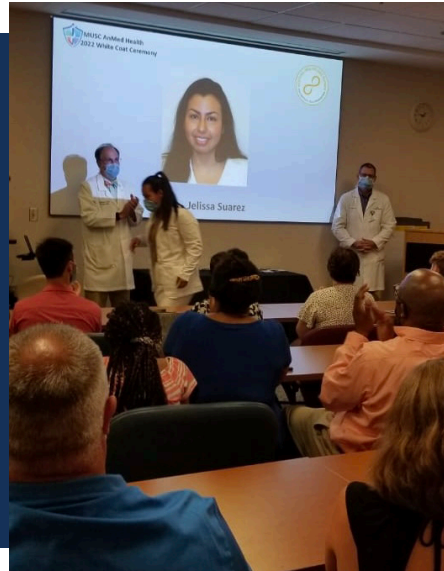
"My declining executive functioning was negatively affecting every part of my day," said **Diana Kimmel**, speaking about prominent symptoms that compounded a long journey prior to diagnosis. **Gemma Jones** said the impact of brain fog "is evident when I write, with missed words and things like that. Conversations can be very hard to keep up with. I can be a bit blank. My cognition has been declining for some time." "I forget simple things, and when it really gets to its worst, I struggle to put the names to the faces of people that I love," added **Rebecca Bonnar**.

Caller **Amanda** stated, "With brain fog, I struggle to remember short-term things, like promises I might make or work-related things. Trying to focus at work is just awful. I write everything down, and even then, I will forget my notes." "I might be able to stay busy or awake all afternoon [with the treatments I take], but brain fog makes thinking tasks more difficult," reported **Becky Tallman**. Similarly, **Shelly Gonzalez** said, "Brain fog really impacts

\*Sleep inertia is defined as "the temporary time of sleepiness, disorientation, and impaired cognitive performance experienced upon awakening."



Jelissa Suarez



*“The effects of IH on my cognition were compounded by the rigor of academia. I found it difficult at times to think critically on the spot.”*  
– Jelissa Suarez, meeting presenter

my ability to function.” **Sam Bell** described how brain fog and exhaustion compound “to make simple little things more difficult. When I get brain fog, even pouring a glass of juice or water is hard. I might miss the glass.”

**Jelissa Suarez** provided a detailed description of how she experienced medical school after the onset and diagnosis of IH. “The long hours, the compact curriculum with little respite time, and the continuous cognitive demands were not compatible with IH. Moreover, the effects of IH on my cognition were compounded by the rigor of academia. I found it difficult at times to think critically on the spot and to integrate information in a way that I once was able to do. It was as if my brain was in a nebulous state, with scattered knowledge that was inaccessible or difficult to find when I needed it. And when accessed, the executive function of working memory and cognitive flexibility was faulty and lacked cohesion.”

*“The worst symptom for me has been brain fog. It can be so bad it nearly incapacitates me. I can’t recall how to use basic things.”* – Written comment submitted by C.C., Indiana

*“It’s not just the feeling of my brain being broken; it’s the feeling that I’m also broken.”* – Written comment submitted by P.B., New York

*“In meetings and conversations, I struggle to find the right words, and my mind feels scrambled like I’m searching for something I can’t quite grasp.”* – Written comment submitted by J.F., New York

*“It’s like I am sleepwalking during the day – my eyes are open, and I appear alert, but my brain isn’t processing correctly. I’ve put my toothbrush in random places, forget to put laundry detergent in the washing machine, and over- or under-pay bills. Once, I took my dog out and forgot what I was doing, so I came back in. An hour or so passed, and I looked around for my dog. When I realized I left her outside, I went out, but she was nowhere to be found. I walked up and down the road calling for her and feeling so bad. When I came back in, I saw that she was lying in her dog bed. It’s like my brain isn’t turned on.”* – Written comment submitted by K.W., Alabama

*“When I get brain fog, even pouring a glass of juice or water is hard. I might miss the glass.”* – Sam Bell, meeting discussion starter

*María Vargas lives alone, and she shared a tour of her apartment and a carefully constructed system of alarms to help her deal with severe sleep inertia so she can get to work in the morning.*

## Sleep Inertia and Sleep Drunkenness

Another sentinel symptom of IH is sleep inertia, an extended, difficult transition between sleep and wakefulness. Severe sleep inertia is sometimes referred to as sleep drunkenness. Numerous participants spoke about the daily challenge of making this shift and the grogginess, confusion, impaired functioning, and strong pull to return to sleep that extends much longer than is normal. In this state, some people also reported automatic behaviors – doing things without full awareness or control.

**Beth Boyce** recalls this being difficult for her even as a child. “My mom and my sister could testify that it always took me a long time to wake up, especially in the morning.” When her sister was diagnosed with type 2 narcolepsy during their teen years, no one thought Beth might also have a sleep disorder. Beth noted, “My sister’s problems occurred when she was asleep or was having trouble staying asleep, so a sleep disorder made sense. My problems were more connected to establishing wakefulness and breaking the bonds of sleep. This was long before I’d heard terms like ‘sleep inertia,’ ‘sleep drunkenness,’ or ‘sleep paralysis’ to describe what I was experiencing. I also hadn’t yet heard of terms like ‘brain fog’ or ‘cognitive impairment.’”

“The hardest thing I do every day is wake up,” stated speaker **Michelle Chadwick** in a written comment she submitted during the discussion about symptoms. “Sleep inertia and sleep drunkenness can be so severe that some days I just don’t feel like my brain wakes up at all. No amount of sleep helps. A good day is when my sleep drunkenness isn’t as severe, and I manage to get 3-4 hours of wakefulness before my brain starts to shut down again.”

**Michael Sparace** plans his morning work-from-home schedule around his wife’s experience of sleep drunkenness. “I take my first work break around 10:30 a.m. to help her start to wake up and take her first round of medication. Thirty minutes later, I take a five- to 10-minute break, bring her coffee, help her take her second medication, and make sure the lights are on and that she is sitting up and doesn’t fall back asleep. Despite this help, it may take another three hours for her to be awake enough to get downstairs. From there, it takes another one to two hours for her to be fully awake.”

**María Vargas** lives alone, and she shared a tour of her apartment and a carefully constructed system of alarms to help her deal with severe sleep inertia so she can get to work in the morning.

Near her bed is a light that comes on 45 minutes before she wants to wake up. “It turns on slowly, simulating the sunrise, which allows me to start being aroused without being angered by a noisy alarm. Thirty minutes before I want to wake up, an alarm on my phone goes off. It’s a very calm alarm, and that one reminds me to take my pills. Usually, I’ll take them and go back to sleep. Twenty minutes before I want to wake up, a playlist starts playing from the speaker in the hallway outside my room. The music has to be a good combination of metal music that is intense enough not to lull me back to sleep but doesn’t make me angry enough to get up, turn



it off, and go back to sleep. Then, at the time I want to wake up, a regular alarm clock with a terrible sound goes off in the bathroom. I must get up to turn it off. I turn on the bathroom light and put some water on my face. If I do go back to my bed and fall back asleep, which happens often, the light's already on, there's music playing, and an alarm will go off on my phone five minutes after that terrible alarm in the bathroom went off. After all that, if none of it worked, there is a different alarm on my phone set for 15 minutes before I have to get to work, and the stress of not getting to work would wake me up."

Caller **Amanda** echoed this battle and the process she goes through. "It's a struggle to wake up. With sleep inertia, I'm not sure how I'm going to wake up. It feels like you're drunk or passing out. It takes an hour minimum for me to get out of bed and five or more alarms to actually wake up. I've turned my alarm off in my sleep."

*"Before the IH diagnosis, the symptoms were terrifying. I didn't know what was happening, especially with the sleep inertia when I tried to wake up. I called 911 many times because I couldn't even walk for hours after waking up. By the time the doctor could see me, I would appear fine. Sleep inertia lasts most of the day. I only have 2-4 hours a day where I feel somewhat functional. I almost never feel awake. I feel like I'm faking being awake when interacting with people. I barely feel alive."*  
– Written comment submitted by K.K., North Carolina

*"It's a struggle to wake up. With sleep inertia, I'm not sure how I'm going to wake up. It feels like you're drunk or passing out." – Amanda, a caller during the meeting*



*"The symptom that most affects me is sleep inertia. It is impossible for me to wake up with regular alarms. I purchased the Sonic Alert Sonic Bomb that is 113 decibels, has flashing LED lights, and a vibrating pad, and even after a time I could sleep through it and most of the time not even remember it going off. I now have a Pavlok 2 shock-bracelet alarm that works."*  
– Written comment submitted by E.P., Oklahoma

## Fatigue, Sleep Attacks, and Long Sleep Duration

Many participants spoke about feeling perpetually exhausted and/or being prone to "sleep attacks," a sudden uncontrollable urge to fall asleep. Others reported being unable to function at all without 12 or more hours of sleep.

**Diana Kimmel's** journey started with a deep level of fatigue in her late teens and early 20s. "In the beginning, I was just exhausted. I didn't feel good. It almost felt like I was underwater with goggles on my head or like I was walking through concrete," she said in an interview in preparation for the meeting. "Every time I talked to a doctor about being tired, they talked about depression and me losing weight."

Caller **Kelly** described fatigue and other symptoms. "I've had a lifelong journey with IH. My first sleep study was in 1995, and at the time, I had a lot of physical symptoms, not just brain fog. I was gaining weight. I was tired and lethargic, and I had stomach issues. And, of course, when you're tired, and you have to go to work, you do crazy things to stay awake; you drink pots of coffee."

*“For our teen daughter, the long hours of sleep she requires is the most limiting aspect of IH. Once she’s awake she can mostly get through the school day. But sleep occupies so many hours that there isn’t enough time for school, homework, social activities, and family. She’s had to pull back from a lot of things she might otherwise want to do.” – Statement by M.S., United States, during a telephone interview conducted in preparation for the meeting*

“My poor son, I can barely keep up with him,” caller **Amanda** said. “He is 11 and wants to do activities with me, and by the time I’m home, I’m so fried. I’m just lying there trying not to pass out to interact with him. On top of that, I have what I refer to as sleep attacks while driving, more than I care to admit. It’s very hard. I can’t focus on a TV show. I pass out. In fact, this last weekend, my boyfriend made a retort because I passed out three times during a TV show, ‘Hey, there you are. Welcome back,’ he said to me.”

*“The fatigue caused by IH is so overwhelming that sometimes I have to take a nap on the couch before I can even make the short journey to my bed.” – Written comment submitted by J.F., New York*

*“I’ve learned to put down glassware, dishes, or eyeglasses when I need sudden naps because I don’t have the energy to clean broken glass or the funds to replace broken items.” – Written comment submitted by R.S., Maryland*

*“I had a microsleep while driving and hit someone. No major damage to either myself or the other driver, thank goodness, but that was the catalyst for the GP referring me to a specialist.” – Written comment submitted by W.B., Australia*

## Mood

**Tamara** called in during the meeting from Oregon to share how IH affects her mood at times. “I call it ‘slangry,’ like people who are hungry and angry say ‘hangry.’ It’s not necessarily when I wake up in the morning, but when my kids were little, if they needed to wake me up at night for something, I just was a bear, even though I didn’t want to be. I would apologize the next day, but I just would be so angry, because I was so tired. I just wanted to sleep. That’s ‘slangry.’” **Gemma Jones** described her experience of irritability. “I can be very moody, particularly when I’m being woken up. I’m not always aware of what I’ve said, and thankfully my husband has a good sense of humor about it, but I am quite embarrassed by it.”

*“Getting too tired becomes painful. I can get really irritable and angry at everyone around me when I get so tired that it hurts to be awake. It’s like every part of my body is screaming for sleep and it’s all I can hear and feel. Nothing else matters but sleep. I am glad that my husband is supportive, and he reminds me that it’s okay to check out and get some sleep, that I shouldn’t fight too hard and cause myself pain.” – Written comment submitted by C.M., Ohio*

There were many comments about the topic of depression in connection with IH, both at the meeting and in written comments. Many related to people’s experience with doctors who believed they were depressed when examinations and standard laboratory tests showed results in the normal range. “Along with normal test results and insignificant findings, it may have been my comments that, ‘My brain hurts,’ or, ‘The problem is in my head, and I can feel my brain,’ that earned me various psych evaluations along the way. I suppose I was fortunate they ruled out those brain things, too, because I know some people are misdiagnosed for years before receiving a proper diagnosis,” **Beth Boyce** reflected.

Others spoke about feeling depressed because of the many limitations they experience due to IH. Caller **Katie** stated it plainly. “My quality of life is terrible, and one thing that I’d really like people to understand, especially providers, is that I’m not sleepy because I’m depressed; I’m depressed because my quality of life is so bad.”

*"With all the medical professionals that I had been to [before my dentist suggested I get a sleep study], it's infuriating that my symptoms were dismissed as depression, obesity, or dietary issues. All these issues are all directly related to my inability to fully care for myself due to my IH." – Written comment submitted by C.B., Texas*

*"We are not lazy, and we are not necessarily depressed, although sometimes the effects of IH can make us more prone to suffer from depression." – Written comment submitted by T.B., Iowa*

*"I am currently struggling with depression accompanied by IH. I feel so lazy, and nobody around me gets it. I'm a student in STEM, and I just want to find something that works." – Written comment submitted by M.W., West Virginia*

## Exercise Intolerance and Sensory Processing Issues

Several people remarked that with IH, they can't do even moderate physical activity without severe repercussions of worsened symptoms. Others commented on being very sensitive to environments with a high degree of sensory stimuli like sound or lights or that demand interacting with people. In fact, these factors were among the most common responses to the open-ended survey question, "What have you found makes IH and its symptoms worse?" (See page 63.)

One of the red flags that **Suzanne Lecours** noticed when her son, Scott, first started experiencing symptoms of IH at age 14 was exercise intolerance. "He had to stop playing sports due to extreme fatigue and weakness," she recalled. Doctors couldn't find anything to explain his extreme fatigue. "He wanted to go to school and play sports, but his body wouldn't allow him to." Referring to guidance that people with IH typically hear about the benefits of healthy habits, **Becky Tallman** said, "Regular exercise unfortunately makes me more tired, and good sleep hygiene and a healthy lifestyle don't make a whole lot of difference."

Describing factors that contribute to son Zack's need for alternative one-to-one high school educational services, **Robin Leader** indicated, "Sometimes he thinks about going back to his traditional high school, but just the thought of walking down the hall through a sea of other people is too exhausting." She also noted the importance of Zack having a quiet place away from the family to rest and how his brother and sister share a room without him while on vacation instead of joining his siblings.

*"Becoming exercise intolerant is one of the most significant impacts of IH on my life. It has taken an incredible toll in so many ways and it has grown to a point that I can oftentimes struggle to exert myself at all." – Written comment submitted by J.C., Georgia*

*"I exercise but then find myself trading off functioning the balance of the day." – Written comment submitted by R.S., Maryland*

*"The dizziness and vertigo associated with exercise happens on occasion as well as headaches and nausea, and that's really associated with not getting that nighttime sleep." – Written comment submitted by anonymous*

*"IH is made worse when my daughter has to be in crowds or with a lot of stimulation." – Written comment submitted by anonymous*

*"I'm only depressed because I am missing life, and everything is slipping away from me. I can't even think about going to work, and I have been homebound for the last three years. I'm watching my 10-year-old son grow up, and I can't participate in his life as much as I want to." – Written comment submitted by C.M., Ohio*

*“It’s hard for me to get people to understand that this is a sleep disorder that affects every single thing I do. There’s nothing that isn’t in some way affected by it.” – Diana Kimmel, meeting discussion starter*

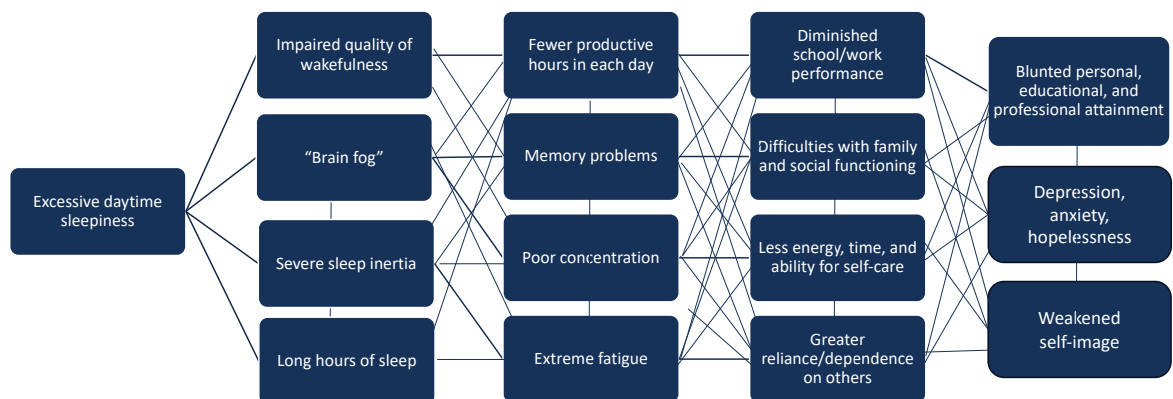
## IMPACTS OF SYMPTOMS

Throughout the meeting, people spoke and wrote in compelling terms about the all-encompassing physical, emotional, psychological, social, interpersonal, and financial impacts of IH on daily life, well-being, and aspirations. Caregivers relayed the impacts on their loved ones as well as their own lives. Some of the impacts are referenced in comments about the symptoms themselves, illustrating the inextricable nature of these aspects of IH on the lives of people with it, as illustrated in Figure 1. As **Diana Kimmel** stated, “It’s hard for me to get people to understand that this is a sleep disorder that affects every single thing I do from the minute I wake up in the morning. There’s nothing that isn’t in some way affected by it.” “My life is like a little snow globe,” said **María Vargas**. “Everything has to be very small and very controlled so that I can keep my relationships, keep my job, and keep being a functioning member of society.”

FIGURE 1

### Symptoms and Life Impacts

(for illustrative purposes only)



### Self-Care and Activities of Daily Living

A central theme of the meeting was the many tradeoffs people with IH must make because of their symptoms and the reduced number of hours of alert functioning they have each day. **Gemma Jones** described the contrast now compared to before IH when she was working full-time and had an active social life. “I was very independent before and I’m now quite reliant on other people, particularly for waking up or helping me to keep up with house chores, cleaning, cooking, things like that. My husband is great. In the past, I lived with my adult daughter, and she was also very helpful. But there are things that I don’t want to have people do for me; I often feel like I’m a burden.”

Several people described the constant prioritization of roles and tasks and the payback of symptom exacerbation that’s felt after overextending even by a modest amount, including **Diana Kimmel**. “If you do something like participating in this meeting today, I can guarantee all of us will crash tomorrow, and that goes for everything in your life. If you do two loads of laundry when you know you can only handle one, but you had to get it done, that’s going to affect everything the next day. It’s that big of a snowball effect.” **Jenny Greathouse** echoed that pattern. “[Not having access to treatment now] I just wait for a good day when I have a



bit more energy than I normally do, but that's always followed up by several payback days after I use all the good time to catch up on the things I've let slide."

**Bridget** called in to share her experience as the parent of a 20-year-old who has IH and autism. "He will typically sleep until 2:00 p.m. or later, so we have a window from about 4:00 p.m. until about 10:00 p.m. where we have to get everything done. He still goes to special needs schooling to learn life skills and sample jobs. Just showering and doing hygiene is very difficult. We have so little time in our day to accomplish anything that we have to pick and choose. My entire life as his caregiver revolves around getting him out of bed and basically pushing him, gently supporting him through every part of the day. I have no other life."

**Michael Sparace** starts his day around 5:00 a.m. to get household chores like laundry and dishes done before starting his workday and assisting his wife in waking, taking her medications, eating, and slowly progressing toward being more fully awake, as described on page 20. He does the cooking, driving, shopping, and errands and coordinates her medical care. "I take care of follow-ups with doctors, medication, insurance, appeals, all those kinds of things," due to the limited hours of alert and focused time she has each day due to the effects of IH.



Scott and Suzanne Lecours

*"I'm a working single mom. Before IH, my son Scott was really helpful at home doing yard work, making his own meals, doing his laundry, and cleaning, but now I have to do everything myself. Some days he isn't even able to warm up his own food or take a shower." – Suzanne Lecours, meeting discussion starter*

*"I don't have the energy for the necessities of adult life. Several times I have not had enough energy to do laundry until several days after I ran out of clean underwear. It's not just gross but embarrassing, even if no one else knows." – Written comment submitted by A.W., Washington, D.C.*

*"IH affects all aspects of my life, making it challenging to perform basic daily tasks like cleaning, laundry, and self-care. I rely on delivery for groceries and meals, but there are times when I'm just too fatigued to even be able to wait for those delivery drivers, so I go without. Completing chores like laundry leaves me exhausted for the rest of the day, and I often have to take time off of work if I've done too much on the weekend. This condition has caused me to limit my life and my world to what feels like only a fraction of my true self." – Written comment submitted by J.F., New York*

*"I struggle to fit life into the 4-8 hours of alertness that I may have for 3-5 days a week." – Written comment submitted by R.S., Maryland*

*"A bad day for me is sleeping all day and barely eating or drinking. The thought of getting up and going to the kitchen is too much. A decent day for me is one where I can get up and shower and spend a little time with my loved ones and have actual conversations. On a 'good' day I can drive and get some chores done. A great day is when I can help with chores and clean the house and cook meals. However, those days rotate into bad days, and I have to spend days sleeping and recovering after." – Written comment submitted by C.M., Ohio*

*"I have never thought of it as 'borrowing sleep from another day,' but that makes so much sense because if I happen to be super active one day, or I do what others consider a normal amount of activity for multiple days, I will sleep 2-3 full days afterward." – Written comment submitted by B.T., Alabama*



Rebecca Bonnar, waking from a nap in the middle of a skiing run

*"When I go on dates or to a party, I'll sneak away and take a nap just to keep myself going." – Rebecca Bonnar, meeting discussion starter*

## Initiating and Maintaining Relationships

Participants provided details about how the effects of IH and misunderstandings about it frayed and fractured family, intimate, personal, social, and work-related relationships. Those who were able to keep up appearances of relative normalcy did so at a cost to their ability to engage as fully as parents, partners, siblings, and friends.

In interviews with several speakers conducted in advance of the meeting, several disclosed the strain of IH on marriages and long-term committed relationships, as well as the challenge of engaging and maintaining mutually affirming intimate relationships. "As my symptoms got worse, my ex perceived I was just being lazy. IH played a big part in our separation and divorce," said one. Another had a similar realization upon being diagnosed, "It was a blessing to have a name for the cause of things I'd struggled with my whole life, including things that came between me and my husband that contributed to our divorce."

**Rebecca Bonnar** added her experience, "From the perspective of someone who's trying to date. I don't know if you've tried to go on first dates or second dates and explain to someone that you've never met before that you're not yawning because they're boring. You are yawning because you are knackered. When I go on dates or to a party, I'll sneak away and take a nap just to keep myself going. To achieve the life things I want to achieve, I will push myself so that one day, I, too, can say, 'I have a really supportive partner who helps.' Trying to get to that stage takes you to breaking point."

Several people shared the impact of IH on their ability to actively parent as they wished.

**Beth Boyce** phrased it this way, "Most of my 'feel better' time, as I call it, was used to keep my paying job. So, the harshest reality I faced was with my favorite job, parenting, which suffered. Friends, other family members, or hobbies got even less of me." **Jenny Greathouse** shared an encounter that illustrated her son's lack of understanding about IH. "Over Thanksgiving, my youngest told me that I needed to give up this disability thing, 'Do better, be better,' he told me. That crushed me."

*"IH is affecting my marriage, as my husband accuses me of faking it." – Written comment submitted by R.B., Nebraska*

*"I can't tell you how many times I've wanted to give up because I am tired of being tired and living my life this way, or better yet, not living my life. It is a helpless feeling. I am tired of feeling like a bad parent because I feel like I can never do*



Zack Leader with his sister



*"He finds it hard to maintain his relationships with friends and cousins. He doesn't play any team sports or do any group activities currently." – Robin Leader, meeting presenter*

*enough for my child or be enough or do better or be better not just for my child but my husband and family." – Written comment submitted by J.B., Oregon*

*"How can we be of any good to ourselves, our families, and society if we can't be awake and our brains don't function even with meds? Personally, this keeps me from being a fully present parent and spouse." – Written comment submitted by B.O., Nebraska*

*"I am 32 and was diagnosed with IH when I was 27, but I believe it started when I was around 12 years old. Now I have a 10-month-old baby. Although he is my pride and joy, I have barely been able to function since he was born. He sleeps great, but my biggest problem is dealing with sleep drunkenness in the morning despite getting good sleep at night. I'm just a walking zombie, and I can't really provide for him much past basic care needs, and I feel like a horrible mom. I'm exhausted all through the day, too." – Written comment submitted by D.L., Texas*

*"My husband and I usually spend weekends together doing things we enjoy. Almost every time we are out enjoying our time together, we have to head home early because my sleepiness starts to take over. I know it's very disappointing to him; he just doesn't say so. I wish I could spend an entire day doing what I love to do, but that just isn't my reality with IH." – Written comment submitted by P.L., Texas*

The effects of IH make it difficult to form and sustain social relationships. Many participants expressed these being the most expendable in a practical sense, but how losing friendships and connections diminished quality of life. "I would love to have the energy to do the things 30-year-olds do. I would love to go out with friends, meet new people, have hobbies on top of my job, and travel. All of those things are very hard for me because they can impede my being functional," **María Vargas** stated. **Michael Sparace** said that among the things his wife wishes she had more energy for, the ability to do even low-key activities with friends and family is at the top of the list.

**Robin Leader** spoke about the impact on her son's social life and relationship with his sister. "Zack has a very solitary experience. He doesn't know anyone else dealing with severe hypersomnia. He finds it hard to maintain his relationships with friends and cousins. He doesn't play any team sports or do any group activities currently. He doesn't know what each day will be like for him, so he can't make plans. My daughter, our youngest child, started exhibiting signs of anxiety due to her worry over Zack's health. As she was so young, it was hard to explain why Zack wouldn't spend time with her playing games or going to family events like he used to."

*"I would love to go out with friends, meet new people, have hobbies on top of my job, and travel. All of those things are very hard for me because they can impede my being functional." – María Vargas, meeting presenter*

*“Finding a doctor familiar with IH can be difficult, finding a treatment that works can be a long and frustrating process, but trying to get people in your life to understand the struggles we face every single day is the biggest challenge, in my opinion.” – Written comment submitted by T.B., Iowa*

*“Having a healthy social life is extremely difficult because of constantly canceling plans, and more often than not, being physically present, but with overwhelming brain fog.” – Written comment submitted by S.K., Virginia*

*“I live alone, and I don’t have any family and have lost most friends due to IH. I don’t have a social life because I can’t keep plans. I cannot wake myself up, and I don’t have anyone to help wake me up or help around the house. I’ve become extremely isolated.” – Written comment submitted by K.K., North Carolina*



*“My social life is almost nonexistent. Friends get annoyed if I have to cancel plans even though they know about my IH. They just don’t understand how IH affects me. Forget any romance; I have no energy for meeting a partner. I am sick of unsupportive siblings commenting about always being late to family do’s. (I’m in my 50s, by the way.)” – Written comment submitted by W.B., Australia*

*“I moved shortly after my IH symptoms began, so I have not had the energy to make new friends here, even though it has now been three years. My only friend is someone I knew before IH. Between her busy work schedule and my inability to get myself outside the house most days, we only see each other about four times a year. When we do meet up, we’re limited to walking activities because perpetual motion is the only way for me to stay awake. I was late once recently because I fell asleep on the bus going to meet her and completely missed my stop. All of this makes me feel like a bad friend or a burdensome friend, even though I only have one friendship to maintain.” – Written comment submitted by A.W., Virginia*

## Performing Consistently and to Full Ability in Educational and Job-Related Settings

Participants shared many impacts of IH on schooling and work. First, the time-bound structure, schedules, and setting required by most educational and workplace environments posed problems for many participants due to the nature of IH symptoms. Just getting to school or work was challenging, including the drain on precious alert time that alone consumed. A lack of understanding or misunderstanding of what IH is and, in some cases, a lack of empathy and compassion compounded these difficulties.

**Suzanne Lecours** described how IH has affected her son Scott’s schooling. “In grade nine, I paid for cab rides to get him to and from school when he was able to go. He’s at home for his grade 10 year and trying to complete a couple of course credits with an online school. Some days, he does not do any work at all, and other days, he can complete only a few minutes of his coursework due to extreme fatigue, brain fog, and his inability to concentrate and process information.”

Zack Leader also required substantial accommodation to continue high school education, as his mom **Robin Leader**, described. “Zack is a very self-aware and independent kid. He is bright, funny, smart, and used to be energetic, but now he struggles with EDS every day.

He's enrolled in Fusion Academy, which provides one-to-one direct instruction with a shorter day schedule that doesn't start early in the morning. With that accommodation, he's able to take the full complement of junior-year honor classes. It enables him to perform at his academic potential. Before we found this learning environment, he had been missing more school than he was attending and cycling through falling behind, catching up, working hard, and feeling lousy about it."

Graphic designer **María Vargas** described trying several work environments before finding one that accommodates the impacts of her IH symptoms. "Working for a design firm in front of a screen for eight hours a day was unbearable. I would have to take naps in the bathroom, which wasn't ideal. Two friends and I opened a studio, which was amazing because we could choose our work times and projects, but the stress of having a start-up ended up having a bad impact on my mental health and increased my IH symptoms." Now she works for an agro-ecological project in Mexico City, taking clients to sunrise culinary experiences and talking with them about food sustainability. "Because I have to be engaged with people and moving around, it's great for me. There is no chance for me to just fall asleep. But that's also why I rely so much on my sleeping routine and my whole system and having a very set lifestyle, because I can't get late to work. The sun won't wait for me to come out."

**Sam Bell** was working as a caregiver when he was diagnosed with IH. "As I got older and the symptoms grew worse, I moved to a night shift because it's a lot less pressure and there's a lot less risk, so I have a much more laid-back job, but less fulfilling. It's a rough trade-off." **Steve Koch** said that having the opportunity to work from home made it possible for him to continue working as an IT architect, especially after treatments that had once provided symptom relief became less effective. He also noted that his career had plateaued due to IH-related limitations. Working from home was also essential to **Michael Sparace** being able to support his wife's needs.

*"It feels impossible to have a 'normal' job, I'm grateful my husband can provide for both of us and that my job is flexible enough for what I need. I really relate to the idea of prioritizing the most important things to get done, and then everything else falls by the wayside." – Written comment submitted by I.H.A., Minnesota*

*"Extreme sleep drunkenness upon waking and brain fog that can last for several hours in the morning have impacted my job as a nursing education manager. I try to schedule meetings after 10 a.m., and light brain work for the morning when I can, but it's not always possible. I have fallen asleep in meetings; if someone notices, I offer the excuse that I'm not feeling well. I have struggled at times to stay awake in the midst of interviewing, performance managing staff, etc. I can start wide-eyed and awake but quickly just deteriorate."— Written comment submitted by W.B., Australia*

*"I wish my work colleagues would watch this meeting so that they could better understand IH. They always make little comments about my boss having to call*



Zack Leader

*"Before we found the Fusion Academy learning environment, he had been missing more school than he was attending and cycling through falling behind, catching up, working hard, and feeling lousy about it." – Robin Leader, meeting presenter*



Raymond and Ramona Meester

*“Living in rural areas, I had to sometimes drive rather long distances to make hospital calls or to go to meetings. Those drives would be quite a challenge for me sometimes because I would get very sleepy.” – Raymond Meester, meeting presenter*

*me every day to make sure I’m awake and on my feet. I’m usually still late because the brain fog makes it a longer process to get ready. Whether it’s meant as a joke or not, it’s embarrassing and has taken a toll on my self-esteem.” – Written comment submitted by B.M., Alabama*

Others found it difficult to consistently meet performance expectations due to IH symptoms. **Becky Tallman** is a physical therapist and excessive sleepiness interfered with her schooling and patient care. “In my early 20s, I began falling asleep in my physical therapy classes during college, but I went undiagnosed until the age of 48 when I went back to work full time. I was exhausted, and I found

myself falling asleep in patients’ rooms and at least once in the middle of doing exercises with a client; fortunately, we were both sitting down. I sought concrete answers and was diagnosed with IH in 2013. Working full-time as a physical therapist became more and more difficult because of the compounding effects of the symptoms. Patient care didn’t suffer, but documentation sure did.”

EDS interfered with **Raymond Meester’s** performance as a pastor early in his calling. “After being shamed for taking a nap at my first church, from then on I always found a place in a church where I could stretch out and take a nap without anybody knowing it. I would never nap for more than 20 minutes; I usually set an alarm. Sometimes I would nod off while I was visiting parishioners, which wasn’t exactly the best for me or for them. Living in rural areas, I had to sometimes drive rather long distances to make hospital calls or to go to meetings. Those drives would be quite a challenge for me sometimes because I would get very sleepy. I would pull over at a rest stop or at some safe place, but there were occasions when I fell asleep at the wheel.” Years later, he benefited from treatment after being diagnosed with IH but has lingering symptoms. “I still have to take a nap or two many days and experience some brain fog. Because of that brain fog, I am no longer preaching.”

**Jenny Greathouse** described the difficult decision she faced to seek Social Security disability benefits after she lost access to a medication she needed for IH because the insurer wouldn’t cover it. “That’s when the biggest spiral began. Without any treatment, my symptoms returned with a vengeance. I was having trouble keeping up at work, and I was making many more errors. I often arrived late to the office and my boss wouldn’t let me work a different schedule. I went on temporary medical leave only to lose my job. I lost my job, my health insurance, and my purpose. I was physically and emotionally wrecked. I did apply for Social Security disability and after three long years of fighting and two denials, I finally got a hearing in front of an administrative law judge. She granted benefits because of the effects of IH and said my case was one of the most interesting she had encountered.”

*“I am not able to work. I have too many bad days. I was hopeful my recent start of medication would save the day, and it saves many of them. But adjusting to it, the side effects, and maybe having to shift into trying another medication, etc. there are still so many days I just can’t get to work as reliably as businesses need.” – Written comment submitted by J.C., Georgia*

*“I can’t keep a job, even part-time, when my symptoms get bad. This is such a hard thing to live with for myself and for my family to be forced to support me. It is also*

*not recognised [by the government] in any serious way to receive financial help with my limited ability to work. I hope this will change in the future, so I no longer feel like I am sleeping my life away.” – Written comment submitted by L.J.Y., Scotland*

**Suzanne Lecours** noted to better meet her son’s needs, “I have considered taking a leave of absence from my teaching career, but this would be very difficult financially. I have applied for the disability tax credit [for family caregivers in Canada], but I was denied.”

Others who have left or lost a job but hope to return to the workforce noted the challenge of a job search with IH and finding a position with appropriate accommodations. **Gemma Jones**, a U.K. citizen who had recently relocated to Denmark, spoke about this in an interview prior to the meeting. “While I’m waiting to establish a relationship with a medical provider, I don’t have access to treatment, so it’s even more difficult for me to function well, and my concentration is poor. I find it very hard to talk to people, especially with the language barrier. I can’t participate in long classes, and I just don’t know if I will be able to find any kind of job as a foreigner with these limitations.”

*“In trying to get back to a professional career, I recognize that I would not have accommodated an employee in competitive industry roles that demand critical thinking and heightened response to time or client pressures. My esteem suffers when I consider lesser work and compensation that does not sustain my goals for life and a family. I fail most daily evaluations of completing to-dos the job hunt itself requires, including personal hygiene, getting food, staying current on the industry, completing work samples, advancing skills, networking, etc.” – Written comment submitted by R.S., Maryland*

*“How do I find time to dedicate to my job search? Now more than ever, the feelings that have always been there are heightened, such as the shame of not being able to perform like a ‘normal’ person. My boyfriend believes I am still unemployed because I share awareness and educational posts about IH on social media. He doesn’t understand that in a year’s time, I’ve probably submitted less than 50 job applications. That’s pathetic by my standards, but my need for sleep takes over. I am fighting off depression every day.” – Written comment submitted by anonymous, United States*

**Jolie** called in to express the circumstances some people with IH find themselves in as a result of illness and its impact on earning a living. “Depending on the severity, how long it takes to get a diagnosis, and whether you have financial support, life can get scary really quickly. Instability and the inability to afford to live is a real possibility. Today, I was really hoping to use my voice to stress the possible reality those with IH face: the inability to afford life itself. While IH is not life-threatening, it can get you there.”

*“Living with IH has a significant impact on my capacity to work and jeopardizes my ability to keep a roof over our head, let alone bring in an income to save for emergencies or a median standard of living. I live with this constant stress every day. What will I do if/when I get worse??” – Written comment submitted by T.A., Australia*

*“Without a decent job, I’m a month or two from complete financial instability and needing to spend 90% of Social Security Income for housing. Sometimes, I can offer grace to myself or others with challenges, but it leaves a sense of impending consequences. Living alone, I don’t have support most days, but also recognize*

**“Although I was sleeping a lot and was still tired during the day, my first major cause of concern was with driving... Now that I live in a city with decent public transportation, I do not drive at all, which has limited my current job search to this and other major metropolitan areas.” – Written comment submitted by A.W., Virginia**

*that I don't have the wherewithal to mutually support others well." – Written comment submitted by R.S., Maryland*

*"I started feeling symptoms of IH as a teen and was diagnosed with it at age 26. It has turned my life upside down. As of right now, I am unable to hold a job, and I am surprised that the Social Security Administration rejected my claim for disability." – Written comment submitted by T.M., Pennsylvania*



Jelissa Suarez

*"I'm very hopeful that there are other paths ahead for me that will enable me to put my talents, skills, and perhaps what I've learned through my experience with IH to help others." – Jelissa Suarez, meeting presenter*

*"I also came to accept that even if I could get through school, life as a practicing physician would not permit a healthy and sustainable work-life balance for me." – Jelissa Suarez, meeting presenter*

### Fulfilling Aspirations for Family and Career

In addition to impacts on day-to-day life, IH takes a toll on longer-range hopes and ambitions. **Jelissa Suarez** recounted how she took time off during her third year of medical school to focus on finding a better IH treatment regimen. "However, even with an improved therapeutic regimen that helped address EDS and sleep inertia, I recognized that the physical and especially the continuous mental demands of medical school were not built with someone with my limitations in mind. I also came to accept that even if I could get through school, life as a practicing physician would not permit a healthy and sustainable work-life balance for me. I left medical school at the end of my third year; a painful loss but a necessary one. I did earn my master's degree in medical science, an achievement I am proud of. I'm very hopeful that there are other paths ahead for me that will enable me to put my talents, skills, and perhaps what I've learned through my experience with IH to help others," she said with determination.

**Beth Boyce** reflected on how IH affected her career aspirations even before she was diagnosed. "To cope with symptoms, I used different compensatory strategies, taking jobs with less and less responsibility and accountability that required less of me; consequently, frequently with less and less compensation, all at a time when my same-age peers were progressing in their careers, not regressing."

**Michelle Chadwick** offered this reflection in a written comment. "I used to fear that I would literally lose a large part of my life to sleeping excessively and wading through life, never feeling fully awake. That fear has unfortunately been realised. I HAVE lost my life to IH. I



couldn't fulfill the career aspirations I had or do any of the other things I hoped to achieve. My fear now is that without more research into the cause(s) of IH and without targeted treatments, more people will continue to lose their lives to IH."

"When I look to the future and moving into life stages that I should be really excited about, like finding a partner and becoming a parent, instead of excitement, I am caught up in the anxiety of what adding that load could do to my overall health," admitted 32-year-old **Rebecca Bonnar**. "I live alone. I take several naps. I mentally burn out. I forget simple things. I'm extremely ambitious, and I am a senior vice president in my company, but the toll of the approach being taken to treat IH [described on page 47] worries me that this is all I'm going to be able to achieve. I ask myself, 'Am I not going to be able to progress further in any aspect of my life?' I think I can speak for all the panelists today in saying that we're not tired. We're sick. When asked what I worry about, I'm just worried full stop that all of this is really not good enough. I'm worried that having IH is just going to stop me from living my life."

Worry about a limited life was echoed by **Suzanne Lecours**, speaking of her son's future. "I worry about Scott's mental health, physical well-being, and his happiness. I wonder when he will be able to hang out with friends again. Will he be able to finish high school, and if so, how long will it take? Will he be able to pursue his goals? Two years ago, I had a healthy, happy, independent, social teenager with so much drive and ambition. The next thing I knew, I had a teen who was feeling hopeless, frustrated, and stuck at home. The life he wants is on hold, and we are at the mercy of the medical community to help us figure this out. I only hope that we are able to find a solution very soon that will allow my son to get back to living his life again."

**Robin Leader** expressed similar concerns about her son. "As we look ahead to college, we recognize Zack can't manage his medical needs independently. We don't know if he'll be able to attend college, when that might be, and what support he'll need to live on his own. We have several concerns. For example, he might not be able to wake up in the middle of the night if there's an emergency in his dorm. We're not sure whether there will be issues with him accessing his medication on campus and how he will manage to get his food supplies and classwork if he's too tired to leave his room. We are working with somebody who has expertise in navigating colleges for kids with disabilities. Yet, a normal college disabilities office would be challenged by the complexity of Zack's conditions. For other conditions, there is a playbook. For IH, there isn't," she said emphatically.

Caller **Aika** shared that the most burdensome aspect of IH for her is trying to be a wife, a parent, and an employee all at once. "It's so debilitating that I feel I need to eliminate something to be able to have some semblance of a normal life. That is very sad, and I constantly think about it. Sometimes, I wonder if I lived alone, whether I might have more energy and more time if my son was with me part-time. Being a wife and taking care of a partner feels like another burden, which is very sad."

*"I never felt like I would be able to have the energy required to be able to have children. So, my decision not to have children has been heavy on my heart. It is probably the worst part for me about IH." – Written comment submitted by L.J.Y., Scotland*

*"I've had to come off my medication to try and conceive a baby with my partner because there are no 'safe' options whilst still working a job where stress is unavoidable. I am in my 30s, and I desperately want a family, but the impact of not taking my medication to try and go into this next life stage is anxiety-provoking*

*"When I look to the future and moving into life stages that I should be really excited about, like finding a partner and becoming a parent, instead of excitement, I am caught up in the anxiety of what adding that load could do to my overall health."*  
– **Rebecca Bonnar**, meeting discussion starter



Sam Bell

*"I used to ride a moped, one day I felt like something was wrong when I realized I was on the wrong side of the road. I had such bad brain fog that I was just going through the motions." – Sam Bell, meeting discussion starter*

*and has a wide-reaching impact – all of which I imagine is not going to improve my chances of conception. It's desperately sad, and I feel in a constant battle with myself about every major life decision I try to make." – Written comment submitted by K.M., United Kingdom*

*"Imagine losing precious time. Time that could be spent with friends or family. Time that could be spent outside. Time that could be spent working. Time that could be spent on the upkeep of your home. Time that could be spent with your kids or your significant other. Instead, it's time spent in bed, alone, physically unable to get up while the world and everything important to you in it continues to live on. And you're reminded of that every time you wake up. Those are the worst days." – Written comment submitted by A.M., Minnesota*

*"I live 20 minutes from work, and sometimes, after just 10 minutes in a car, I'm struggling to stay awake." – Written comment submitted by W.B., Australia*

## Protecting the Safety of Themselves and Others

Personal safety was an issue that arose frequently, especially in connection with driving. Others worried about falling asleep in public and being vulnerable because of this tendency or due to brain fog or other symptoms. **María Vargas** put it first on her list of treatment aspirations, "I would like to not pose a danger to myself or others."

**Sam Bell** said he used to ride a moped. "One day I felt like something was wrong when I realized I was on the wrong side of the road. I had such bad brain fog that I was just going through the motions. Luckily, nothing happened, but after that, I really cut down on my driving. Luckily, I live in Chicago where the train is an option." Even with treatment, **Raymond Meester** said he is still concerned about his ability to drive. "I hardly ever drive out of town unless my wife is with me, and on our long drives, she does most of the driving. I'm grateful for the driver assist on the newer cars that help me stay in my lane should I get a little bit sleepy while driving near my house."

*"Sleep attacks on public transport made me vulnerable to being attacked while I was asleep, and I was often mocked by people pointing out my inability to stay awake. When in Uni, I once slept through a fire alarm and firemen chapping on my door. Luckily, the fire was stopped two doors down from where I slept." – Written comment submitted by L.J.Y., Scotland*

*"I fell asleep sitting on the floor with my six-month-old grandson, and he fell backward, hitting his head on the floor." – Written comment submitted by T.S., Oregon*

## Validation Conveyed Through the Illuminate Hypersomnia Meeting

In contrast to the heart-aching statements about the impact of IH on identity, self-esteem, and personal worth, several participants expressed feeling a boost through this opportunity to be heard, learn from others affected by IH, and connect shared experiences around the globe. **Sam Bell** was among the first to raise this point. "This conversation means a lot to me, just getting some validation because it can be really difficult not to get that in your head a little bit. I hate that these things are happening to people, but it's helpful to hear that it's not just me. It can be really difficult, but I'm happy to be here and be discussing it."

**Diana Kimmel** built on Sam's comment. It's hard to hear person after person talking about lack of self-esteem and being embarrassed that sleep is debilitating your life. It's a very lonely life with IH. But as Sam says, it's good to hear, and this is where talking to somebody else with IH and getting support is so important because it really does affect you, just deep in who you are, when you can't do the normal things in a day that you're expected to do. It's good to hear, and it's hard to hear."

For **Becky Tallman**, participating in the meeting provided a huge, unexpected benefit. "Thank you for having me and for the coordination and all the behind-the-scenes work to pull this meeting together. Having not yet met a fellow IH-struggler in real life, only over phones and screens, the validation of the shared symptoms, struggles, losses, and coping strategies has me pretty much gob smacked."

**Beth Boyce** concluded her statement by expressing this hope for the meeting. "In all my decades of IH experience combined, I have found there are no more powerful words than these three: I believe you. My hope is that all who hear the experiences of members of the IH community today will believe us, believe the complex and complicated reality of IH and the unacceptable quality of life, the urgent need for more awareness and understanding, broader access to care and other services, and more and better treatment options. Even if you can't see our invisible disorder, believe us."

*"Having not yet met a fellow IH-struggler in real life, the validation of the shared symptoms, struggles, losses, and coping strategies has me pretty much gobsmacked."  
– Becky Tallman, meeting discussion starter: (bottom left)*



## SECTION 3:

# Perspectives on Current and Future Approaches to Treating IH

*The purpose of the discussion was to understand better how well available therapies meet patients' needs and what unmet needs remain.*

Meeting participants described an array of strategies and combinations of approaches they use in an attempt to relieve IH symptoms, extend the functional hours they have each day, and achieve a modest quality of life in the face of IH. Some shared experiences with treatments that are working well for them; others addressed the downsides of treatments and challenges they encountered. Experiences with clinical trials for potential IH therapies and treatment aspirations were also covered.

Participants were reminded that the purpose of the discussion was not to spotlight any particular medication or treatment approach in either a positive or negative way but to understand better how well available therapies meet patients' needs and what unmet needs remain.

As summarized in Figure 2, **Dr. Lynn Marie Trotti** reviewed the treatment landscape for IH, including the one FDA-approved medication, the treatments recommended in clinical guidelines, and those commonly used by physicians familiar with IH and other sleep disorders and non-pharmacological approaches.

## THERAPIES USED BY PEOPLE WITH IH

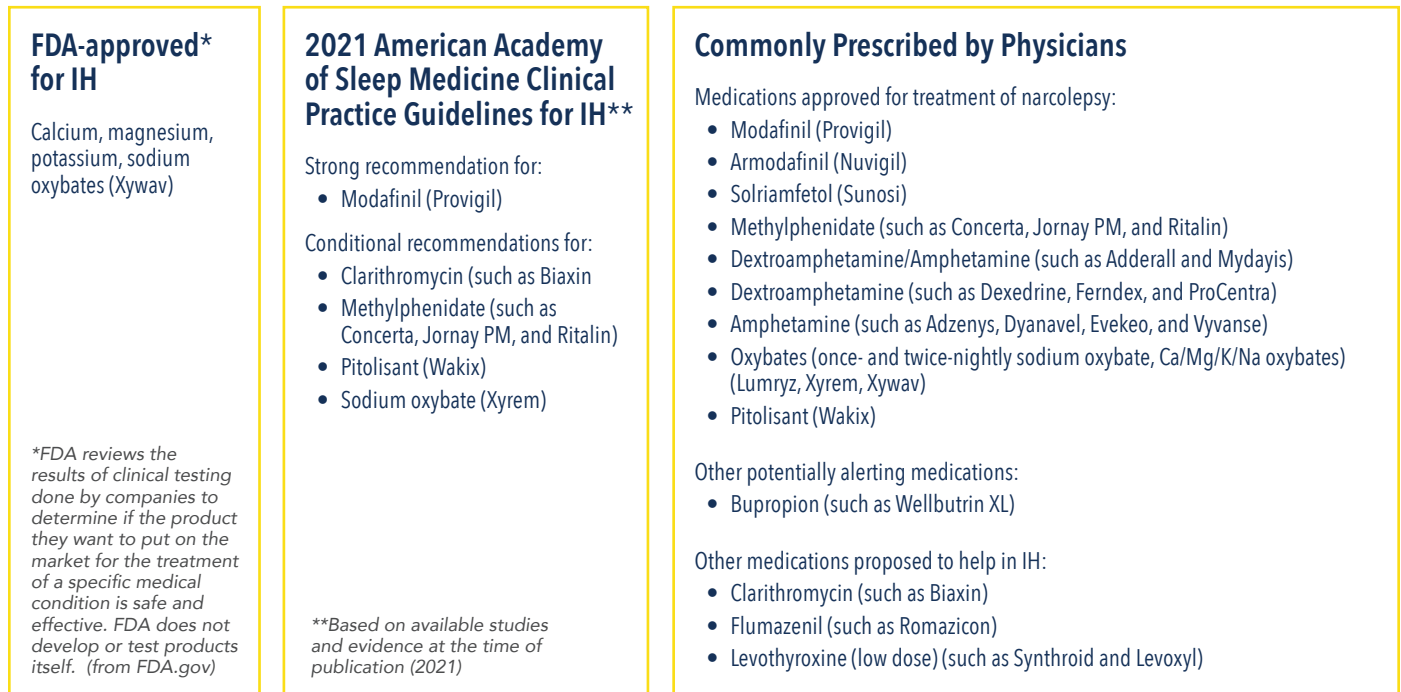
### Prescription Medications

Throughout the meeting, participants spoke about medicines of various types prescribed for them, both over time and often in combination. **Raymond Meester** had been taking a stimulant, armodafinil, to treat daytime sleepiness ascribed to sleep apnea, along with using

FIGURE 2

## Treatment Landscape for IH

Adapted from Dr. Trotti's clinical overview presented at the meeting



a CPAP machine. His pulmonologist ordered the MSLT after Raymond's symptoms got worse, and that led to the diagnosis of IH. "He prescribed Ritalin on top of armodafinil, and he also prescribed Xywav. It took me a little over a month to titrate to the right dose for me. I did start noticing a difference. It helped me in terms of being able to stay awake during the day."

**Becky Tallman** also uses a combination of medications spaced out over the course of each day. "Before I'm even fully awake, I take 150 milligrams (mg.) of armodafinil and 75 mg. of bupropion. A few hours later, I take 200 mg. of caffeine and 10 mg. of Ritalin, and then I might be awake for an hour before the need to nap becomes unavoidable. Sleep inertia is real, and transitions are hard. At lunchtime, I'll take another 200 mg. of caffeine, another 75 mg. of bupropion, and another 10 mg. of Ritalin. At dinner, I take a regular vitamin and 10 more mg. of Ritalin. At bedtime, I take 4.0 milliliters of Xywav. I gave a double nightly dose a long and dedicated trial, which seemed to help minimally with sleep inertia, but the side effects were not worth the benefit for me. But taking the single dose at night does seem to help cancel out the effects of the stimulants so I can get to sleep."

*"I am treating IH with Xywav and sleep hygiene. Moderately effective."  
– Written comment submitted by B.T., Colorado*

The need to adjust medications (used alone and in various combinations), doses, and timing frequently came up in the discussion and written comments. **Kathleen Collins** described the different regimens she's been on since being diagnosed with IH during her first semester of medical school. "I was initially prescribed Adderall, which was completely ineffective.

**The need to adjust medications (alone and in various combinations), doses, and timing frequently came up in the discussion and written comments.**

*“While using higher doses of stimulants enabled me to take care of the basic things I needed to do in life, that also came with increased side effects, like increased anxiety, irritability, blood pressure, and heart rate.” – Steve Koch, meeting discussion starter*



Steve Koch

I felt nothing. I was then first prescribed modafinil, and I felt awake for the first time in a long time.” As time went by, that was no longer adequate for her needs. “We worked on changing the dose, but then I was prescribed armodafinil in the morning and modafinil later in the day. Later, that was changed to armodafinil twice daily. In 2021, my sleep doctor added Sunosi to my treatment plan. In January of 2022, I started on Xywav. I was initially skeptical that Xywav would be useful for me because I feel like I sleep great at night. I’m really glad that I trusted the expertise of my sleep physician because Xywav has given me hours of my life back. I used to sleep 12 hours a night on weekends to catch up from the week, but now, with Xywav, I have more control over the hours I sleep, and I’m better able to wake up in the morning. It’s not the be-all, end-all; I do still need to take my daytime wake-promoting medicines in addition to Xywav, and I do still use caffeine as needed.”

*“For 17 years, I’ve been using stimulants and have been on the highest approved dosage. On certain days, I take extra pills based on my activities and the level of alertness I require. Consequently, I have to skip my medication on other days to compensate for the additional doses. I’m hesitant to switch to new medications due to concerns about availability and the potential trial-and-error phase, which might render me inactive for a period of time. Additionally, my doctor recently recommended trying Xywav, which is the first time he’s suggested an alternative medication.” – Written comment submitted by J.S., Wisconsin*

For some people, adjustments to treatment are required when medications lose their effectiveness or do not provide the same level of benefit over time. **Steve Koch** detailed how his treatment has changed over the years. “I was diagnosed with IH about 19 years ago. At first, they tried all the stimulants available at the time. None of them worked until we got to Adderall and Vyvanse. Until about a year ago, I was on Vyvanse with Adderall boosters in the early and late afternoons, along with lots of caffeine throughout the day. For a long time, these were enough for me to lead a somewhat normal life. But after many years, they started to lose their effectiveness and higher doses were needed. That didn’t really bring the same quality of life I previously had. While using higher doses of stimulants enabled me to take care of the basic things I needed to do in life, that also came with increased side effects, like increased anxiety, irritability, blood pressure, and heart rate.”

Steve continued, “During the pandemic, I started working from home, and usually, I was able to get by taking Vyvanse only in the morning to reduce those side effects. However, I found that my decreased performance led to a plateau in my career, and I also often had to forego activities in my personal life. Soon after, it became difficult to get Vyvanse and Adderall due to the pharmacy shortages. The uncertainty of whether I’d even have medication to be able to continue working added a new level of anxiety and I also became concerned about my ever-increasing blood pressure and heart rate. So, I asked my doctor to prescribe Xywav. That has helped me stay awake, and my blood pressure and heart rate have returned to normal healthy levels, but unfortunately, it does very little for fatigue. So, I’m awake, but it’s not what I would call a useful state of awake. After many years of successful treatment, the best I can get now without potentially serious side effects is to not fall asleep. And I feel like I’m eternally under just a weighted blanket. What I really want is to feel good enough to live my life again and not just well enough to watch it fly by. So, now I’m trying additional medications in addition to Xywav. While things are better than they were a few months ago, I’m still really far from feeling normal.”

**Shelly Gonzales** described building up a tolerance to a medication that was, at first, life-changing. “After getting diagnosed, my doctor started me on Adderall. It was fantastic. I had so many more usable hours in my day. I had more energy, and I could actually get things accomplished, which was great. The downside is I built up a tolerance to it fairly quickly. After trying several different medications (and two new sleep doctors, because that was also an issue), I am now on a combination of Xywav and Adderall. Even with that combination I struggle with fatigue and brain fog.”

*“The only thing that helped was Adderall, and now it works very little. Xyrem has way too many side effects. I would rather live just a few years than live another 40 the way I live now.” – Written comment submitted by J.W., Arkansas*

*“Nuvigil and Provigil both stopped having an effect within a few weeks of starting the medication, even on the highest dose.” – Written comment submitted by J.F., New York*



*“Unfortunately, my IH now seems to be getting worse, even with meds. I’m on Modafinil and Xywav, but I’m having problems with sleep inertia again. I have no idea what I’m going to do now. I hope and pray that new meds are on the horizon.” – Written comment submitted by L.M., Alabama*

**Michael Sparace’s** description of his wife’s continuing search for an effective treatment regimen echoes many others who expressed difficulty finding a modest level of sustained benefit from available medications. “Even with the help of expert physicians, finding the right medication has been a lengthy process.” Michael shared in a preparatory call before the meeting that his wife relies on a combination of stimulants, Sunosi, and a specially compounded cream preparation of flumazenil. Caller **Shannon** indicated that she tried clarithromycin but had an allergic reaction to it. She also tried flumazenil. “I was so excited because I thought I might have the awakening that a patient at Emory reported, but it didn’t happen. It’s been like a roller coaster with IH, getting excited about possible treatments and then being let down if it didn’t work at all or if it didn’t work as well as I had expected it to.”

When **Steve Koch** mentioned an unexpected effect after having minor surgery a few months earlier, his observation elicited several written comments about GABA-A receptor agonists. Steve recalled, “The only time I have felt ‘normal’ was a few hours after surgery when the anesthesia wore off. Without having taken any IH meds or caffeine, I felt fully awake, alert, and full of energy for about five hours despite just having had surgery. I experienced no anxiety, irritability, or high heart rate. I know sometimes you’re given flumazenil or something like that [to recover from sedation]. I don’t know if that’s what I was given, but it still baffles me to have felt the best I can remember feeling after surgery when I was also given other medications that make you drowsy. That day sticks with me because it’s the only time I’ve had energy and felt so much motivation just to do the things I love to do without any side effects. That’s how successful treatment should be measured, not just if I can stay awake, but if I’m also feeling good enough to live my life.”

*“I was diagnosed five years ago. I discovered clarithromycin helps my symptoms.” – Written comment submitted by B.D., Georgia*

*“It’s been like a roller coaster with IH, getting excited about possible treatments and then being let down if a particular one didn’t work at all or if it didn’t work as well as I had expected it to.” – Shannon, a caller during the meeting*



Tammy Anderson

***“Our situation is all the more aggravating because we don’t have access to medication already in use around the world, nor do we participate in new research. The few medications we do have access to are in short supply on the market.”***

***– Written comment submitted by A.B., Brazil***

*“In response to Steve’s comment about the impact of coming out of surgery and feeling better, it was probably flumazenil that was applied to reverse the sedatives. Because of flumazenil’s very short half-life, to be effective for IH, the drug needs to be delivered transdermally.” – Written comment submitted by A.H., Ireland*

*“In Australia, they were experimenting with the drugs they use to wake people up after surgery. Unfortunately, it has a very short half-life, so they needed an infusion pump.” – Written comment submitted by B.M., Connecticut*

*“I can relate to the experience of the young man. I recall feeling fully awake after anesthetic and surgeries; I assume it’s due to meds used to reverse anesthesia. Also, I was on prednisolone for a year and was much more alert.” – Written comment submitted by V.M., United Kingdom*

Several participants living outside the United States commented on having fewer options available to them. **Michelle Chadwick** has had IH most of her life and was diagnosed more than 20 years ago at age 36. “Life didn’t improve much, despite diagnosis and stimulant medication,” she said. She noted that in Australia, the first line of treatment is dexamphetamine, and modafinil and armodafinil are only available to people who are intolerant to dexamphetamine. “One of the biggest changes in my approach to treatment has been that I actually take less medication now than I once did. I’ve found that no amount of stimulant medication replaces my need for excessive sleep. I may be able to get by on eight or nine hours of sleep a night for a few days with stimulants, but I will eventually crash. So, it’s not unusual for me to have medication-free days where I let myself sleep a lot more. Unfortunately, on these days, I’m not productive at all. Those days are completely lost.”

**María Vargas** also commented on the relatively few options she has in Mexico. “I’ve been interested in sodium oxybate and have read a bit about that, but sadly, it isn’t available in Mexico. So, methylphenidate and modafinil are all we have so far.” **Gemma Jones** recently moved from England to Denmark and found big differences between the two countries. “There are not as many specialists in Denmark, and the treatment plans are different. My medication was changed, and my quality of life just plummeted.”

*“I have tried modafinil and armodafinil, and neither works. It frustrates me that the only alternative is dexamphetamine. I do not want to have to resort to a drug of addiction to function like a normal human being.” – Written comment submitted by J.B., Australia*

*“Current treatment in Scotland is very restricted – mostly melatonin.” – Written comment submitted by L.J.Y., Scotland*

## Non-Prescription Products

Caffeine use was among the most common management strategies named by meeting participants. **Rebecca Bonnar**, **Becky Tallman**, **Kathleen Collins**, and **Steve Koch** each indicated a need to supplement their prescription medications with caffeine when they described their individual regimens. There were several references to coffee and energy drinks. Steve said, “5-Hour Energy is one of my favorites. It’s portable and effective-ish, with a heavy emphasis on the ‘ish.’” Becky referenced using caffeine tablets.

Becky said she also takes vitamin supplements, as did other community members. There were a few comments submitted about the use of cannabis-based products as well.



*"The best days for me aren't much better than the worst. You're still reminded that you're different. For me the best days are the days I can get through without a nap. But those days, too, come at a cost: stimulants, energy drinks, coffee, caffeine pills, and more stimulants. And if you miss one, you're done. What kind of a best day is that? What kind of a life is that?" – Written comment submitted by A.M., Minnesota*

*"I've found that B-12 injections have major positive impacts on symptoms, and this connection should be explored." – Written comment submitted by A.L., Illinois*

*"I was diagnosed with IH in 2017 and have been successfully managing my IH since December 2021 by consuming cannabis, specifically an RSO-infused creamer with 12 oz. of coffee daily. Since then, I only take naps 2-3 days a month, and I no longer take Adderall, Vyvanse, and modafinil. I'm the most energized and focused I have been in my entire life." – Written comment submitted by A.M., California*

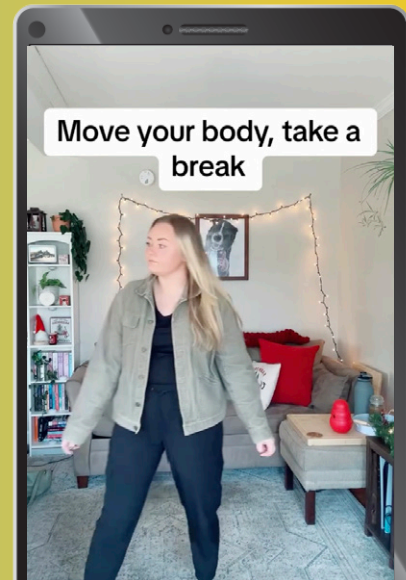
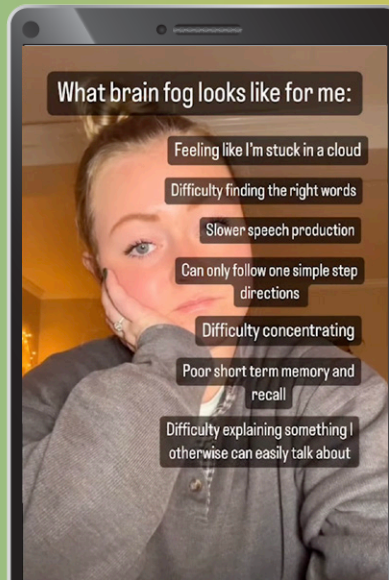
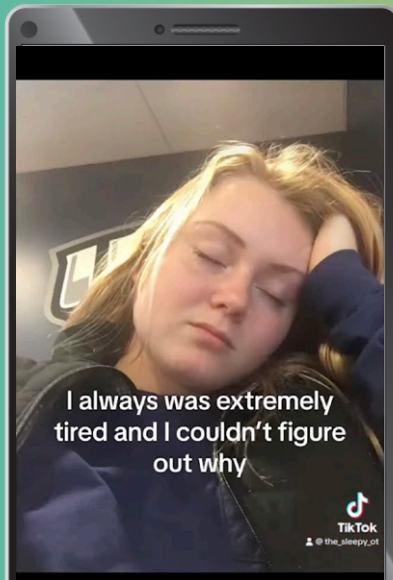
*"While it is great that [cannabis] helps me after work and on the weekends with feeling physically better, I wish I could find something that helped with focus and concentration." – Written comment submitted by D.A., California*

*"My current medication doesn't really work for me, so I've had to add coffee, Red Bull, and vitamins that give me energy. I worry about my heart and wonder how long I can keep this up." – Written comment submitted by P.B., New York*

## Lifestyle Adjustments

In the report section dedicated to the impact of IH symptoms beginning on page 24, participants describe a broad array of life changes necessitated by IH. Participants indicated that some of these changes are in response to symptoms, and others are made in an effort to curb symptoms and work around them as best as possible. Prioritizing key responsibilities, shifting starting times to later in the day, pruning family, social, civic, and leisure activities, practicing good sleep hygiene, napping (as planned or out of necessity), and avoiding both overly sedentary and high-stimuli environments were common strategies described by meeting participants. Others mentioned having family members available to take on added responsibilities or outsource routine tasks as a means of conserving available energy and focus.

**Haley Wall**, an occupational therapist with IH, posts short videos on social media with tips on living with IH. A few were shared during the meeting between prerecorded presentations by other community members, including one recommending taking frequent breaks for physical movement throughout the day. Several participants raised this need in preparation for being on-camera during the meeting, indicating that they use movement to compensate for or



Haley Wall



*The search for a beneficial diet was another topic that arose before and during the meeting. Suzanne Lecours shared that they had changed her son Scott's diet to a high-protein, high-fat diet in hopes of seeing some improvement.*

ward off sleepiness. They expressed concern about their ability to stay seated and fully awake for an hour-long discussion without time to move around. Some people, including **Gemma Jones**, described being “fidgety” as an extension of this tendency to use movement as an adaptive technique.

Another common adaptation was to have a series of alarms and other stimuli to deal with the impacts of sleep inertia, as described by **María Vargas** and others beginning on page 20. María shared other techniques she uses to improve sleep quality. “I have blackout curtains to keep my bedroom as dark as possible at night and during the day when I want to take naps. I live in

Mexico City, which is super noisy all day and night, so to help fall asleep I use a sleep mask and have custom-made earplugs to fit my tiny ear canals,” she said during a video tour of her living space shared at the meeting.

The search for a beneficial diet was another topic that arose before and during the meeting. **Suzanne Lecours** shared that they had changed her son Scott's diet to a high-protein, high-fat diet in hopes of seeing some improvement. **María** said that while she tries to eat a balanced diet and exercise three to five times a week, IH can get in the way. “Sometimes that's not possible because sometimes I'm so sleepy. I'm barely going to work, so when I get back home, I eat a piece of cheese and just go back to sleep. It's really about trying to keep a balance but also not being too hard on myself when I lose it, and I'm having a harder time with it.”

Diet and acceptance were two strategies **Michelle Chadwick** found important along her journey. “Living with IH led to inactivity and poor diet. Over time, I not only ended up overweight, but I was really unhealthy. Poor health was impacting the severity of my IH symptoms and my ability to manage them. Since adopting a keto lifestyle with intermittent fasting, I've lost about 45 pounds or 20 kilos. I still have IH; not a lot has changed there, but my lifestyle changes mean that my overall health and well-being have improved. So, I'm in a better position health-wise to manage my IH symptoms. The combination of intermittent fasting, a diet with fewer carbs, and keeping hydrated seems also to help dexamphetamine to be more effective. Another thing that I've learned over time is the importance of stress management. I've seen how mounting pressures and the responsibilities of adult life can make IH symptoms worse. I had to learn to reduce stress as much as possible and be kinder to myself. Learning not to take on too much and to resist trying to meet other people's expectations are absolutely necessary. Surrounding yourself with a supportive network and taking care of your mental health are really important aspects of managing IH.”

**Diana Kimmel** spoke about making similar adjustments to expectations of herself being a key accommodation. “Not working and not having kids at home, you feel like everything should get a little bit better, but I do feel like I have declined over the years. I can get a medicine that helps me with the daytime sleepiness, but I still have brain fog and diminished executive function. I could just try to rest a little bit more, do a little less, and change my routine again. But that doesn't always give you the results you want or really need. There's always that trade-off, 'If I do this, then I can't do that. If I do this, I can't do that.' I haven't found anything that really gives me that total package of getting back to what I think 'normal' once was.”

*“Unlike many people with IH, I have actually ceased medication as it stopped being effective. Instead, I have learned to pace myself and focus on lifestyle changes such as mindful movement, mental health therapies, and healthier choices. I have had to reach a place of acceptance for what I am able to do in the present rather than focusing on what I can’t do.” – Written comment submitted by A.V., Australia*

*“I am using a blue light, bilateral stimulation music, and movement.” – Written comment submitted by B.R., Texas*

*“To help with treatment, I would love to have access to someone, part-time at least, to help me with basic needs. I need help setting appointments, calling new doctors, and picking up groceries when I can’t drive. So many basic chores fall behind because I just get too tired, and it’s just too much. Basic life chores make it even harder to enjoy life and use the little awake time I do get to do things that make me happy. I would love to have help with simple tasks.” – Written comment submitted by C.M., Ohio*

*“If our mental health can be strengthened, that might then mean that some of the IH symptoms are easier to manage. We would put less pressure on ourselves to conform to standards. We might increasingly allow ourselves to utilise supports or strategies that we need (e.g., resting more, taking naps when needed, having accommodations in place at work, job sharing, etc.). This would enable IHers to live more meaningful and fulfilling lives generally while we wait to find out more about its underlying cause and treatment options.” – Written comment submitted by J.L., Australia*

***“I have meditated daily for over 20 years, and sometimes meditation helps during the day, but not always.”***  
– Written comment submitted by D.A., California

“

*“Your entire day and life you are almost running out a playbook and living life on a schedule, one hour at a time: When to eat, sleep, stand, sit, take breaks. Maintaining your IH is a full-time job.”*

– Written comment submitted by M.W., Florida



Scott Cameron



Stevie Jo Foreman



Payton La Frenz



*“Once I had a name for my symptoms, I felt a great sense of relief. Surely, I thought, treatment would take care of making these symptoms obsolete. I was wrong.”*  
 – Jelissa Suarez, meeting presenter

## DOWNSIDERS OF AND BARRIERS TO IH TREATMENT

*The necessity of using multiple treatments at once and over time was described as a “moving target,” with less than satisfactory results for most participants.*

### Inadequate Relief

A resounding expression from across the IH community about the current state of IH treatment is the challenge of finding a single therapy or combination regimen that delivers sustained relief with an acceptable tradeoff for side effects and long-term risks. The necessity of using multiple treatments at once and over time was described as a “moving target,” with less than satisfactory results for most participants.

“Once I had a name for my symptoms, I felt a great sense of relief,” **Jelissa Suarez** said about her diagnosis with IH. “Surely, I thought, treatment would take care of making these symptoms obsolete. I was wrong. I worked with a healthcare provider who prescribed what was, at the time, a first-line treatment for IH. Treatment was suboptimal and not as efficacious, but the time had come to resume medical school. I wasn’t prepared for how challenging the combination of IH, learning how to manage it, and medical school would prove to be. Early on in my internal medicine rotation, I hit a physical and mental wall that I could not surpass. I took time off from school to focus on getting better treatment. I had started taking an oxybate, which helped, but it really took some fine-tuning of that regimen and adding a stimulant to get me back to a better level of functioning.” Within months of this new stage of treatment, Jelissa had to withdraw from medical school because of the limitations imposed by IH and the lack of truly effective treatment, as she describes on page 32.

**Robin Leader** conveyed appreciation for the improvements her son has experienced with treatment, as well as gaps that remain. “Zack has improved his quality of life over the last year thanks to Xywav, [specialized educational services at] Fusion Academy, and the great fortune we have spent in time and dollars to provide everything we can for him. Despite the improvements, there’s still a huge gap to get Zack back to feeling great so Zack can pursue whatever he wants for the future. We are still searching for every improvement we can find, and we are hopeful medicine and science can provide answers and improvements.”

*"I have had IH for over 40 years. I struggle daily to function, even on three medications. I want to live and function better." – Written comment submitted by C.S., Florida*

*"Stimulants have not worked for me. They may keep me awake, but it's like comparing the zombies in the original movies with the zombies in more recent movies. Without medication, most of the time, I feel like a zombie in old movies, moving in slow motion, struggling to think and interact. With stimulants, I'm hyperactive but still struggling to think and interact. The lights are on, but no one is home." – Written comment submitted by B.M., Connecticut*

*"I have taken Adderall in the past, but it both became less effective, and I was told by my new doctor (when my former doctor retired) that I could not take it with my pain meds. I tried bupropion which my doctor said was ok with pain meds, but I didn't notice any difference. It is frustrating to not have treatment." – Written comment submitted by M.H., Ohio*

## Lack of Physicians Knowledgeable About IH

**Kathleen Collins** began her comments by expressing gratitude for the sleep physicians she has seen over the years. "I really credit my prompt diagnosis of IH and a constantly evolving treatment plan for allowing me to complete my medical training and continue to practice medicine today," she said. **Michael Sparace** also commended his wife's physicians for immediately recognizing the need for testing, readily making the diagnosis of IH, and working with them to try various treatments. Many others were not as fortunate, and the difficulty of finding a physician knowledgeable about IH was a top barrier to getting even modestly effective treatment for IH.

**Suzanne Lecours** described the early treatment her teenage son received after being diagnosed. "Through virtual appointments, this doctor started prescribing off-label treatments. Scott began taking stimulants in varying amounts and combinations. These medications, which were not always in stock at our pharmacy, had many side effects. Scott was losing a great deal of weight and had no appetite. These meds were not helping him much at all. It was like he was a zombie, and it was hard to have a conversation with him. I requested a second opinion. At one point, I was feeling so desperate that I was going to take him to the emergency room at Sick Kids Hospital and refuse to leave until someone helped us. It's hard to find healthcare professionals who understand IH, diagnose it correctly, and know how to treat it and its symptoms. Last fall, we were put on waiting lists to see specialists at Sick Kids Hospital. Scott was referred to the EDS clinic, infectious disease department, rheumatology, and neurology, all in hopes of finding out what was wrong. These doctors all cleared him, which was a relief, but also frustrating. That left us with more questions. Now Scott has been to the sleep clinic at Sick Kids for two appointments, and that doctor has prescribed 54 mg of Concerta each morning. He has another sleep study and MSLT coming up. He's not looking forward to that; he felt like a 'lab rat in an experiment' the last time. I've spent many hours researching and teaching myself as much as I can about IH to be well-informed and know how best to advocate for the care of my son. Right now, we still have a lot of questions and uncertainty in our lives."

*"When I finally was diagnosed and got access to modafinil, my primary care physician decided that I was a drug seeker. He then spent the next three appointments telling me that whatever was wrong with me was because of the modafinil. That included*

*"I have struggled with IH since my 20s but was only diagnosed in my 50s. Medication is not truly effective. Works sometimes. Other times, it doesn't." – Written comment submitted by P.O., Virginia*

**“Most doctors don’t understand IH and are shocked at my medication regimens for IH; even pharmacists ask me questions about why I am taking so much stimulant medication and insinuate that I am abusing the medication.” – Written comment submitted by I.H.A., Minnesota**



Becky Tallman's medications

*ignoring an asthma attack I had in front of him, saying it was just a modafinil side effect. I broke down crying, telling him that it was the only med that had ever helped me feel like a normal human. He still dismissed me and told me I had to stop taking it. I stopped seeing him instead.” – Written comment submitted by M.R., Washington, D.C.*

## Side Effects

Meeting participants described a wide range of side effects of varying magnitude and tolerability in the search for effective treatment. Some side effects led to changes in doses, timing, or formulations, while other participants described the need to switch medications or stop taking a particular class of medicines altogether. **Jenny Greathouse** shared her experience with various side effects. “Initially, Adderall worked for me. It helped me to be able to get out of bed and to stay on track through the day, something I had never experienced before. I had more energy, I was more productive at home and at work, but it came with a loss of appetite, and I began to lose a lot of weight. In my neck of the woods, West Virginia, if you start to lose weight, you’re immediately associated with abusing drugs. At that point, I reached out to my doctor about other treatment options. Everything we tried had severe side effects. With more than one medication, I became suicidal, something I had never considered in the past.”

**María Vargas** encountered other side effects from two medications she now takes in combination after some trial-and-error to find an acceptable benefit-risk tradeoff. “I started out with modafinil, which does nothing for me on its own. I can take up to 400 mg, feel nothing, and go back to sleep for several hours. I’ve tried extended-release modafinil, which also does nothing except give me nausea. I’ve tried extended-release methylphenidate with modafinil, which had very modest results. Even though it’s the treatment that works best for me, it also has some undesirable side effects, such as tachycardia and heart palpitations.” These two side effects were cited frequently by meeting participants, including as a long-term health concern (see page 47).

Other specific side effects were noted, too. In the description of her regimen, **Becky Tallman** stated, “I could take as much as 600 mg of caffeine daily and 200 mg of armodafinil, but I’ve found that the increased stimulant causes me to chew on the inside of my lip or the tip of my tongue and to clench my teeth, and that causes other difficulties for me. I will take the extra 100 or 200 mg of caffeine if there’s something I really need to be alert for, but my lips and my tongue will pay the price.” **Sam Bell** was still searching for something other than stimulants, which gave him really bad headaches. “I’m still trying to find the right fit,” he said.

Caller **Shannon** experienced side effects while taking Xyrem. “I know there is now Xywav that doesn’t have as much sodium, but when I was taking Xyrem, it was like drinking concentrated seawater. I would get extremely hungry after taking it, after having no appetite at all during the day. I literally had to choke down food. I never told my providers this because there was nothing else for me to take, and I didn’t want this treatment taken away from me. I was still working, and I didn’t know how I would live without treatment. After taking it at night, I would get up to eat, and I stumbled around like I was drunk. I fell numerous times. Once, I stumbled backward, and I couldn’t react fast enough to break my fall. I landed on the back of my head, got up, went back to sleep, and hoped for the best. I could have had a brain bleed.”

*“Regarding treatment with medication, the issue for me was the side effects. I suffered greatly from hallucinations, headaches, and lethargy that was worse than the*

*sleepiness itself. This made me less productive. We tried medications like Stavigile, venlafaxine, and others, but ultimately, I preferred to switch to alternative therapies without medication. It has been four years since I made that change, and I am doing well, all things considered. I still deal with constant sleepiness; however, I remain productive within my limitations.” – Written comment submitted by J.S., Brazil*

*“I was first prescribed stimulants for IH. But, obviously, they only work (if they work at all) if I take them. Unfortunately, just waking up to take these medications was nearly impossible. Therefore, Xywav was added, and I was finally able to wake up in the late morning to take my other medications. However, I can only take the lowest dose, and even with that, the side effects are strong. Shortly after taking Xywav, I experience dizziness, nausea, and high anxiety. If I can’t get to sleep immediately after taking Xywav, the side effects increase until they actually prevent me from going to sleep. Additionally, I often sleep through the second dose per night, despite having five different alarms that stimulate three different senses.”*

*– Written comment submitted by A.W., Virginia*

*“Xywav was NOT effective for me. It raised my blood pressure, caused severe migraines, and gave me severe anxiety that I had never had prior. It was not worth continuing the medication as the side effects were too overwhelming.”*

*– Written comment submitted by O.W., Tennessee*



*“I currently take Vyvanse, which has worked the longest; however, its side effects of hyper-focusing, elevated heart rate, and increased anxiety are uncomfortable. Vyvanse, like the other stimulants I have tried, masks the symptoms, and I am still extremely fatigued. Yet, this medication allows me to literally get out of bed.”*

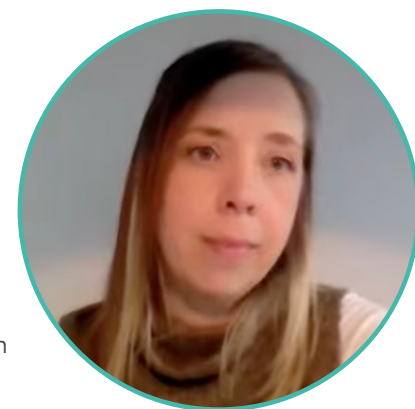
*– Written comment submitted by J.F., New York*

*“We take very strong medications and it’s something I really worry about, too.” – Gemma Jones, meeting discussion starter*

## Long-Term Health Risks

In discussing health concerns for the future, meeting participants zeroed in on the risks of long-term use of stimulants, especially in terms of cardiovascular health. **Rebecca Bonnar’s** comments opened a flood of other comments, from other panelists and submitted in writing. She explained, “At the moment, I’m on a really high dose of stimulants, which just gets me through an eight-hour workday. To have a life outside of that workday, I have to make constant sacrifices. If I want to see a friend after work, I have to build in naps. To get through my workday on that occasion, I drink approximately 14 shots of espresso. I delay my medications so I can stay awake for a little bit longer in the evening. Because of all of that, a massive worry for me is my cardiovascular health. The stimulants I take on top of all the caffeine I drink have my heart working overtime. Right now, I can feel my heart racing through my chest, and yet, all I want to do is lie down and take a nap. Long-term that feels incredibly unsustainable, and is not a lifestyle that I wish to sign up for.”

**Gemma Jones** seconded the concern. “Rebecca mentioned worrying about cardiovascular health. We take very strong medications and it’s something I really worry about, too. I tend to try and stay on a lesser dose, which is not great. Developing treatment alternatives is



Gemma Jones

really, really important for me as well. That would relieve the added worry about other health issues caused by the medications you take.” **Shelly Gonzalez** added, “I’m also concerned about the long-term use of stimulants and having to continue to increase the dose to get an effect. I feel like even pharmacists and some doctors look at the amount of stimulants that we are taking and the length of time that we’re taking them and have their own feelings and judgments about it. That adds another layer of anxiety.”

*“What Rebecca said about cardiovascular health is a real concern. It takes an ungodly amount of stimulants and caffeine to do the bare minimum. Unfortunately, these side effects are still worth it. Anything is better than how untreated IH feels. But looking into the future, heart problems and high blood pressure are scary.” – Written comment submitted by anonymous*

*“My IH was at my worst between 2018 and 2020 when I was treating it with 30mg Adderall twice daily, 200mg modafinil, 200mg Vyvanse, and Wellbutrin. My resting heart rate was as high as 153 bpm. I struggled with functioning and focusing, and I suffered from skin picking and suicidal ideation. At that point, I was done with medications and their side effects.” – Written comment submitted by A.M., California*

## Kathleen Collins' Regimen



Travel pillbox to stay on track with midday medicine



My current go-to source of caffeine



What's on my bedside table?

*“It took a lot of back and forth with my physician to find that right dosing for me.” – Kathleen Collins, meeting discussion starter*

## Challenging Regimens

As **Becky Tallman** (see page 37) and **Michael Sparace** (see page 20) described, some individuals live by a carefully regimented schedule of medications in an attempt to maximize hours of wakefulness and not degrade nighttime sleep. **Raymond Meester** spoke about his schedule and the way it impacts his life. “The alarm on my smartphone seems to be going off constantly. My current regimen requires me to take medication seven times a day, and five of those are related to my IH medications, including one at 1:30 a.m. My wife and I would occasionally like to go to some evening events with friends or to plays and concerts, but it’s difficult because of my medication regimen. I need to be home by about 9:30 so that I can get ready for bed and take my first dose of Xywav by about 10:30. Often we are not able to attend the events because of the timing or the length of the events. We enjoyed European river cruises very early in my retirement. My daughter got married right after I was diagnosed with IH, and we hoped to return to Europe with her and my son-in-law. I’m not sure I can do that anymore. I’m very reluctant because the time zone changes make taking the medications quite a struggle. I’m also concerned about what could happen were I to have a sleep attack and about traveling with my medications, given the controlled nature of them.”



**Kathleen Collins** and others indicated that adjusting medications to find an optimal dose can require a lot of interaction with your treating physician. “My current treatment plan involves taking 150 mg of Sunosi as soon as I wake up, so I keep it on my bedside table. I take armodafinil (200 mg) at lunch, and use caffeine as needed throughout the day. For Xywav, I take 3.75 grams at bedtime and then three grams in the middle of the night. It took a lot of back and forth with my physician to find that right dosing for me. When I was still feeling a little sleepy in the morning, he recommended decreasing the second dose. We worked together with me reporting symptoms to really fine tune it. It’s nice in a way that Xywav has that flexibility.”

## Shortages

Many people expressed difficulty obtaining medications they rely on due to widespread drug shortages, especially for medications also used to treat attention deficit hyperactivity disorder (ADHD). In some cases, shortages required people to try multiple pharmacies and coordinate getting new prescriptions from their physician’s office as availability moves from one pharmacy to another. **Michael Sparace** noted that this search could add additional tasks to his day, including needing to drive across Atlanta if he locates a distant pharmacy with medication in stock.

For others, shortages lead to changing medications or going without. All these scenarios introduced more burden and anxiety. **Shelly Gonzalez** described how panic about availability further colored others’ impressions of her. “When you throw in the anxiety of possibly not being able to get your medication and knowing what that means for your ability to function, I know for me, I respond with fear-based anger. I have been known to say something like, ‘But no, you have to give it to me!’ which, of course, if they already have their own judgments or thoughts about the use of stimulants, does not put me (or people like me with IH) in a good light. But it’s something that we literally have to have. So that’s just one more struggle of taking these meds.”

*“In recent months, there have been shortages of Vyvanse, including both the generic and name brand. As a result, I spend hours each month on hold with various pharmacies located around my neighborhood to find out if they have the medication in stock. Then, I have to communicate back and forth with my doctor to decide where to place the prescription. Every month has become a gamble because I am prescribed a controlled substance, and the prescription can only be filled on the 30th day following the last date the 30-day quantity was filled. This means that I run the risk of not having access to my medication each month, and without it, I am unable to stay awake.” – Written comment submitted by J.F., New York*

## Coverage by Payers

As Dr. Trotti described in the clinical overview at the beginning of the meeting, most medications prescribed for and taken by people with IH are used “off-label.” That means these medications have been approved by regulators (like the FDA) to treat conditions other than IH based on the evaluation of data from appropriately controlled clinical trials to establish safety and effectiveness. Using their best medical judgment, physicians (in the U.S.) can prescribe any approved medication for any condition. Although off-label prescribing is a common medical practice, patients may experience challenges if payers (including private insurance companies and government programs) deny coverage for uses other than those approved by regulators. Coverage denials may require the patient and physician to engage

**“Just this week, my doctor painted the picture that I will have good days, and he wants me to work those days. However, it will likely not only take a year to sort out what meds work, but many of these medications don’t come in on time, and I’d likely be out of work when the medication is out of stock. I don’t know any employers willing to take that burden on with me. If you do, please let me know!” – Written comment submitted by J.G., Georgia**

**“After multiple appeals, my only option was to change jobs to be able to access insurance that I knew would approve the medication.”**

**– Jenny Greathouse, meeting presenter**

in an appeals process, adding to the burden of obtaining medication, or may lead to periods when the individual goes without medication unless they can afford to pay for it without help from the insurer.

**Jenny Greathouse** recounted how a change to her employer’s insurance provider had disastrous consequences for her ability to function and her life. “My company was acquired by another company, and the new insurance plan did not recognize Adderall because it was not FDA-approved for IH. After multiple appeals, my only option was to change jobs to be able to access insurance that I knew would approve the medication. That’s when I learned how severe IH was. Two years into the job change, I was still trying to learn new things and was struggling. Thinking that the job just may not have been the right fit, I changed jobs again. I didn’t connect the struggles to IH. I had the same challenges there, and my doctor requested approval for an increased dosage of Adderall only to be told that they were denying the medication completely as it was not FDA-approved for IH. My doctor did offer to change my diagnosis to narcolepsy to help me get the medication, but I don’t want to risk needing something in the future that depends on having the true IH diagnosis in my record, so I lost my access to Adderall.” Jenny’s health crashed, and she lost that job, as described on page 30.

**Kelly** called into the meeting to share a similar experience. “After I was finally diagnosed, I was treated with medication, and within two days of starting treatment, I had a completely different life. I lost 60 pounds. I was able to exercise. It didn’t take away the daytime

sleepiness, but it alleviated a lot of the physical symptoms. After a period of time, my insurance no longer covered the medication, and I was no longer able to take it. Without medication, I was forced into retirement, and that’s where I am now. I have occasional good days, but I’d say five out of seven days are not good days, and I just can’t express to anybody the difference between treatment and not getting treatment. I’m still fighting because I had that glimpse of what it was like to be ‘normal.’”

While coverage issues were most frequently connected to off-label medications, some reported coverage issues with dosing changes related to the one medication approved specifically for IH. As **Robin Leader** described, “Zack has been using Xywav since December of 2023, and it is helping him. We recently increased his dose and are starting to see his personality again. While it has significantly improved his daily productive time, he still has a significant gap with normal.

Xywav can be hard to access, and we just went through our first gap, due to a delay in getting his new dose in the patient assistance plan approved. It took over two months. A five-day disruption in his access caused Zack to miss several days of school and to sleep significantly longer nightly.”



Zack Leader

**“A five-day disruption in his access to Xywav caused Zack to miss several days of school and to sleep significantly longer nightly.”**  
**– Robin Leader, meeting presenter**

**“The biggest (and I am talking HUGE!) hurdle came when I turned 65 and had to go on Medicare vs. my private insurance. It was like starting over. For two years, I have been without proper medicine (Adderall), and my life has spiraled downhill. The law reads that no medication has to be provided if it is not listed by the FDA as an approved medication for IH. My doctor at the Mayo Clinic has fought to no avail. I have been deteriorating and have become nearly reclusive, unable to function most hours. I am able to purchase a small portion through GoodRx.”** – Written comment submitted by T.G., United States

*“The armodafinil I’m prescribed here in Australia is not approved for IH, and so for me to get this drug, the doctors (including the Sleep Consultant Specialist and the GP) have to say that I have the diagnosis of ‘narcolepsy’ when they call the Government special authority drug line.” – Written comment submitted by W.B., Australia*

## Affordability

The final barrier to treatment identified by meeting participants, affordability, is linked to coverage and extends to out-of-pocket costs for medications that may be covered by insurance programs or other patient support programs. Drug pricing and access issues are typically beyond the scope of patient-focused drug development, so they were not part of the panel presentations or discussions. They do, however, affect which medications people with IH can consider and obtain in the search for effective treatment, as numerous people with IH expressed in interviews and written comments such as these:

*“I am currently trialing sodium oxybate through a public hospital. I expect to need approval for subsidization for ongoing treatment as I cannot afford this medication without it.” – Written comment submitted by J.S., Australia*

*“I have been trying to manage my symptoms of IH and had consults at the Mayo Clinic Sleep Center. During the consult, I was advised to try Wakix. My doctor back home sent the prescription to the manufacturer, but my insurance denied coverage since I don’t have a diagnosis of narcolepsy 1 or 2. Even though I have a diagnosis of IH, I don’t qualify for any financial support from the manufacturer. I am not in a position to pay for the medication out of pocket.” – Written comment submitted by J.F., New York*

## CLINICAL TRIAL EXPERIENCE

Several panelists described experience participating in a clinical trial or actively considering participation. **Diana Kimmell** has participated in several clinical trials, and she spoke about the challenges she encountered. “These are difficult because they require you to come off your medications and then do all the things that we’re not good at, like keeping logs and accurate sleep diaries and being on time for appointments. We have to endure excessive poking, prodding, and struggle, and it’s nearly impossible for us to do.”

**Shelly Gonzalez** shared a more positive experience. After learning about a new treatment being tested in IH at a support group meeting and then seeing a post from the Hypersomnia Foundation about a clinical trial, she looked into it. “There was a site near me, so I was able to enroll in that study. Luckily, I did not have to stop taking my medications. I understand the reason many studies require that, but I also think that would be a huge barrier. I would not have been able to function if I were required to stop my medications. I literally couldn’t do it because I would lose the small business I own. I’m just incredibly grateful that they were able to do their study without making any changes to my medications.”

When **Steve Koch’s** treatment regimen started to become less effective and was causing worrisome side effects, he investigated participating in a clinical trial. “The combination of Vyvanse and Adderall just wasn’t effective anymore, and I was already approaching maximum doses. My heart rate and blood pressure were getting up there, so I was interested in an

*“I’m struggling to pay for the meds that help keep me awake, even with patient assistance programs. I just want to know what’s wrong with my brain, and hope there is more funding for research over time.” – Written comment submitted by A.C., Michigan*



Michelle Chadwick

*“Unfortunately, the medications, no matter how great they are, are never approved in Australia because the drug companies don’t make applications to our government for regulatory approval here.” – Michelle Chadwick, meeting discussion starter*

*“I would love to see something that could help me do things I love without needing five days of 20-hour sleep days.” – Written comment submitted by M.H., Ohio*

alternative, and I looked into participating in a clinical trial. I live in Dallas, and the closest location was in Austin, about four hours from here (by car). I’d have to go there about a half-dozen times. From a work standpoint, I couldn’t afford to take time off to travel that far for it. If there had been something local that I was eligible for, I absolutely would have participated.”

**Jenny Greathouse** also expressed interest in participating in clinical trials, but her location in rural West Virginia made it hard to pursue that possibility. **Michelle Chadwick** observed that there have been clinical trials in narcolepsy and IH conducted in Australia. “This is fantastic. Unfortunately, the medications, no matter how great they are, are never approved in Australia because the drug companies don’t make applications to our government for regulatory approval here. So, we are the trial participants, but we don’t gain the benefits of the studies. That’s very frustrating and something that I’d like to see change.”

## TREATMENT ASPIRATIONS

Throughout the meeting, participants expressed a range of unmet medical needs and priorities for more and better treatment options. People with IH want to feel more alert, refreshed by sleep, with adequate energy and liveliness to go about the day and be involved in meaningful relationships, work, and leisure activities; to stay awake without medications or the “fake awake” feeling of stimulants; to be free of side effects like strain on the cardiovascular system, appetite loss, and suicidality; and to have fewer restrictions on medication schedules and travel, due to the nature of some treatments and the controlled nature of others. Many articulated a simple desire to feel and function like “normal.”

During the meeting, **Michelle Chadwick** said, “We need to be relieved of our need for sleep rather than just being kept awake, because that actually ends up leaving us feeling chronically sleep-deprived. That is very hard to explain to other people without them thinking that we don’t get enough sleep. We actually get more than enough sleep, but it’s just not enough for our brains. A common thread across the IH community is that we want more quality wakefulness during the day, and I’m convinced the answer to that is relieving our need for excessive sleep.” **Becky Tallman** expressed something very similar, “What I would love to have access to is something that actually helps me feel ‘alive’ when I’m awake. Right now, the meds keep me awake but don’t stop me from feeling sleepy or sedated all day.”

Caller **Shannon** made the following wish, “That there were medications that could block the GABA-A receptors from absorbing the sleepy substance in the first place, instead of just putting a Band-Aid on it and just trying to stimulate us. I’d like something to treat the problem itself versus having the problem exist, and then try to treat that sleepiness.”

**Steve Koch** followed her statement with, “The Band-Aid analogy really resonates with me. Medications do a good job of keeping you awake, but you don’t ever really feel normal.”

**María Vargas** also included feeling normal in her wishes for treatment. “Feeling alert would be a top priority. Second, waking up feeling refreshed. I would love waking up to not be the absolute worst part of my day, to wake up feeling like I want to make breakfast and do things; I haven’t felt like that in ages.” **Shelly Gonzalez** quantified her request. “I would honestly love to be able to count on six, or if it’s not too much to ask, eight hours in a day that I would be alert, thinking clearly, and able to actually get things done without needing to take a lot of breaks.” A selection of the many written statements expressing treatment aspirations follows:



*“I am looking for potential treatment options that are safe to take while trying to conceive and during pregnancy that allow me to maintain a quality of life that I find acceptable.”*

– Written comment submitted by K.A.M., United Kingdom

*“I hope for something that is not a stimulant, assists me in waking up in the mornings, and is expected to be safe long-term. When considering a new treatment, it is important for me to know the potential side effects and for them to not be too severe and/or dangerous. Ideally, they also would not result in me having a period of days/weeks of being sleepy before the medication begins to work.”* – Written comment submitted by O.W., Tennessee

*“I mostly wish that there were more behavioral modifications and lifestyle changes that had been studied and were shown to be helpful. I want to avoid medications when I can because of other health issues and the interactions of other medications. I want to know if pushing myself to exercise through my sleepiness would actually be a benefit, or if it is causing a crash the next day. Could changes in my diet actually be worth the effort?”* – Written comment submitted by M.R., Washington, D.C.

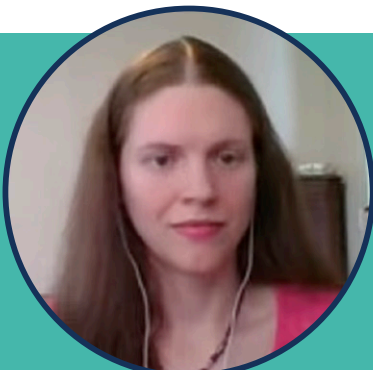
*“It would be nice to have a medication to take at night that would help with symptoms during the day instead of needing to take the medication during the daytime. Also, some people have sleep events like sleepwalking, etc., so if the medication can combat both nighttime events and daytime fatigue, that would be helpful.”* – Written comment submitted by S.G.

*“It seems psychedelics may have promise. A newer sense of the mechanism of action of ketamine may be increasing slow-wave sleep. This may benefit those of us with IH.”* – Written comment submitted by B.M., Colorado

*“I would like to see the development of non-drug devices that are covered by insurance that may help with IH. I understand transcranial magnetic stimulation and transcranial ultrasound are used for other neurological disorders. Like the promising results from using certain frequencies of light and sound to treat or slow the progression of Alzheimer’s, I feel like non-drug therapies are under-researched for IH (as well as other disorders).”* – Written comment submitted by S.S., Georgia

*“The thing I want most in my horrible existence is to be able to remain awake, but it’s so painful and a living hell. The thing I want most also is to not always be sleepy and have such irrepressible excessive daytime tiredness. But the only peace I find in life is when I’m sleeping!”* – Written comment submitted by B.B., New York

*“Short of a cure, I would love a treatment that would actually last all day and help me wake up in the morning.”* – Written comment submitted by E.P., Oklahoma



Shelly Gonzalez

*“One of my hopes for treatment is that drugs they’ve already discovered to work for narcolepsy might speed their way over to IH a wee bit faster than they do right now.”* – Shelly Gonzalez, meeting discussion starter

Note: For a brief description of the process sponsors follow to secure FDA approval for a new medicine and add new uses for an existing medicine, please visit <https://bit.ly/FDA-approval-info>.

Sleep Consortium and Illuminate Hypersomnia partners (see a listing on page 76) posted information and images like the ones below to alert people affected by IH to this initiative, the meeting, and the survey. This coordinated outreach helped to attract participants from at least 21 countries in numbers far exceeding any predictions.

**ANNOUNCING**

**Illuminate Hypersomnia**  
Shining light on the lived experience of IH

You are the expert on what it's like to live with idiopathic hypersomnia. Together we'll spark better understanding and a new dawn for treatment and care.

**SAVE THE DATE**

**Illuminate Hypersomnia**  
Shining light on the lived experience of IH

**April 11, 2024**

**Illuminate Hypersomnia**  
Shining light on the lived experience of IH

Join the interactive livestream at [bit.ly/illuminate-IH](https://bit.ly/illuminate-IH)

Twitter post: **Hypersomnia Australia** April 11  
Did you miss the live Illuminate Hypersomnia event? Watch the recording here: <https://sleepconsortium.org/illuminate-hypersomnia/>  
Have you completed the survey yet? It's not too late! Share your experiences with idiopathic hypersomnia (IH) by taking the Illuminate Hypersomnia survey: <https://bit.ly/ihs-survey>  
#IH #PFDD #illuminateIH #idiopathichypersomnia #livingwithIH #livingwithidiopathichypersomnia #idiopathichypersomniacare #PFDD #patientfocused #sleepconsortium #IHUSA

Twitter post: **Brazilian Association of Narcolepsy & Idiopathic Hypersomnia** February 23  
ONLY YOU KNOW WHAT IT'S LIKE TO LIVE WITH IDIOPATHIC HYPERSOMNIA. Join other people with IH around the world. Share your experiences, your UNDERSTANDING and new KNOWLEDGE for the treatment and care of IH. Be part of the GLOBAL ACTION "Illuminate hypersomnia" by taking the survey: <https://sleepconsortium.org/illuminate-hypersomnia/survey/>  
See Translation

Twitter post: **Hypersomnia Foundation** April 11  
Join us for the Illuminate Hypersomnia interactive LIVESTREAM at [bit.ly/illuminate-IH](https://bit.ly/illuminate-IH)! We'll be live from 12:00-4:00 PM ET on April 11. People living with IH and their care partners can shine a light on their experience by calling or writing in. Share your IH symptoms, how IH has impacted your daily life, and your perspectives on IH treatment needs and aspirations. ... See more

Facebook post: **Project Sleep** April 2  
Illuminate what it's like to live with IH!  
Project Sleep is partnering with Sleep Consortium and organizations around the world to Illuminate Hypersomnia. This landmark initiative will bring members of the global IH community together to shine a light on the lived experience of IH and what matters most to people living with IH for effective treatment. JOIN IN ON APRIL 11 FROM 12:00 NOON-4:00 PM EDT.  
On April 11, the Illuminate Hypersomnia virtual externally-led patient-focused ... See more

Facebook post: **Project Sleep** April 2  
THE BIG DAY IS ALMOST HERE!  
Actions you can **take now** to **Illuminate Hypersomnia**

- Virtual EL-PFDD Meeting April 11, 2024 12:00-4:00 EDT
- RSVP to participate
- Check out the meeting program, including the agenda, speakers, and discussion Q's
- Online Survey
- Begin or complete the survey
- View select survey responses from 446 fellow community members in the program

Facebook post: **Compartilhe sua experiência de viver com Hipersomnia Idiopática**  
Responda a pesquisa

Facebook post: **Share your experience living with IH**  
Take the survey

Facebook post: **Share your experience living with IH**  
Take the survey



**Illuminate Hypersomnia**  
Shining light on the lived experience of IH  
Lance luz sobre a experiência de viver com Hipersomnia Idiopática

**Share your experience living with IH**  
Take the survey

**Illuminate Hypersomnia**  
Shining light on the lived experience of IH

**Illuminate Hypersomnia**  
Shining light on the lived experience of IH

Together we'll spark better understanding and a new dawn for treatment and care

**Learn more and sign up for updates**

# Illuminate Hypersomnia

Shining light on the lived experience of IH

## SECTION 4:

# Illuminate Hypersomnia Patient & Care Partner Survey Results

## OVERVIEW AND METHODS

In preparation for the April 11, 2024, Illuminate Hypersomnia meeting, the Sleep Consortium launched a survey on February 6, 2024, to gather insights into the experiences of those affected by IH, including their diagnostic journeys, what it's like to live with IH, and views on current and future treatments. The survey was open to adults living with IH (age 18 and older) and adult caregivers or care partners of people of any age who live with IH. It was developed with help from people living with IH, caregivers, university researchers studying IH, and medical specialists who provide care to people with IH. The survey was available in English only. It was also only available to be completed online, although respondents could access it and respond using a computer, tablet, or mobile device.

The 67-item survey and all supporting materials were reviewed by the WCG Institutional Review Board (IRB). The IRB determined it to be low-risk research exempt from rules that guide human subjects research. Respondents provided consent to proceed with the survey on a voluntary basis before advancing to survey questions. Individuals who indicated they were under 18 years of age were excluded from the survey. Respondents are anonymous, and no personal identifying information was requested or collected.

Once consented, respondents were asked about their connection to IH as either being personally affected or caregivers/care partners to one or more individuals with IH. This question routed them to questions about their own experience (patients) or the experience of the person with IH on whose behalf they were responding (caregivers/care partners). All questions after this routing question were optional and voluntary. Respondents could complete the survey in as many sessions as personal needs required.

Sleep Consortium and collaborating organizations promoted the opportunity to participate in the survey via e-mail and social media. Well-coordinated messages and consistent visuals

View the survey instrument at <https://bit.ly/IH-survey-instrument> or scan QR code below:



*The 67-item survey launched on February 6, 2024, to gather insights into the experiences of those affected by IH.*

helped amplify outreach across the global IH community. Survey respondents did not receive compensation or any other form of remuneration for participating.

Survey data collected over the first several weeks informed the meeting's planning. Selected interim results from responses received as of March 26, 2024 (a total of 446) were included in the meeting program published just before and referenced during the meeting. The survey closed on May 11, 2024.

The summary below includes complete and partial survey responses to represent the broadest segment of the IH community possible. Additional analyses of the survey data are planned and may be developed into manuscripts and submitted to peer-reviewed journals.

**811 responses from across the global IH community makes it the most extensive patient-reported data set collected to date.**

## RESPONDENT DEMOGRAPHICS

The survey attracted 811 responses, including 394 fully completed surveys and 417 partial surveys. This response from across the global IH community makes it the most extensive patient-reported data set collected to date.

Ninety-three percent of responses were made by adults (age 18 and older) who reported having IH; care partners to adults diagnosed with IH made up 2.5 percent, and two percent were received from caregivers to children and teens diagnosed with IH. An additional 2.5 percent indicated their connection to IH as "other," most of which were individuals who had self-identified as IH or were being tested for suspected IH.

The individuals represented in the survey responses range in age from 16 to 83. The median age of all respondents is 39. Eighty-three percent of the patients in the survey identify as female, 14 percent as male, and three percent as non-binary. Of the care partners and caregivers who responded, 66 percent identify as female, and 34 percent identify as male. Most respondents (86%) are White; 12 percent identified as Hispanic or Latino.

FIGURE 3

### Survey Respondents: 811 total

#### Predominantly adults with IH

93% adults with IH  
2.5% care partners to adults with IH  
2% caregivers to children with IH

#### Gender of Patients Represented

83% female  
14% male  
3% non-binary

#### Age

16-83 years old range  
39 years old median

#### Race/ethnicity

86% White  
14% non-White  
12% Hispanic or Latino

#### Work/school status

44% working or attending school full-time  
16% Fully disabled or not working or attending school due to IH  
14% working or attending school part-time

Percentages in this and other figures may not total to 100%; other multiple-choice options available to respondents received small fractions of responses.





Responses were received from people living in 21 countries: the United States (62%), Australia (19%), Belgium, Brazil (8%), Canada, Chile, Czech Republic, Denmark, Egypt, France, Germany, Iceland, Ireland, Italy, the Netherlands, New Zealand, Norway, Portugal, Sweden, Switzerland, and the United Kingdom. In the United States, responses were received from all regions of the country. Fifty-two percent live in suburban communities, 31 percent live in urban areas, and 15 percent live in rural areas.

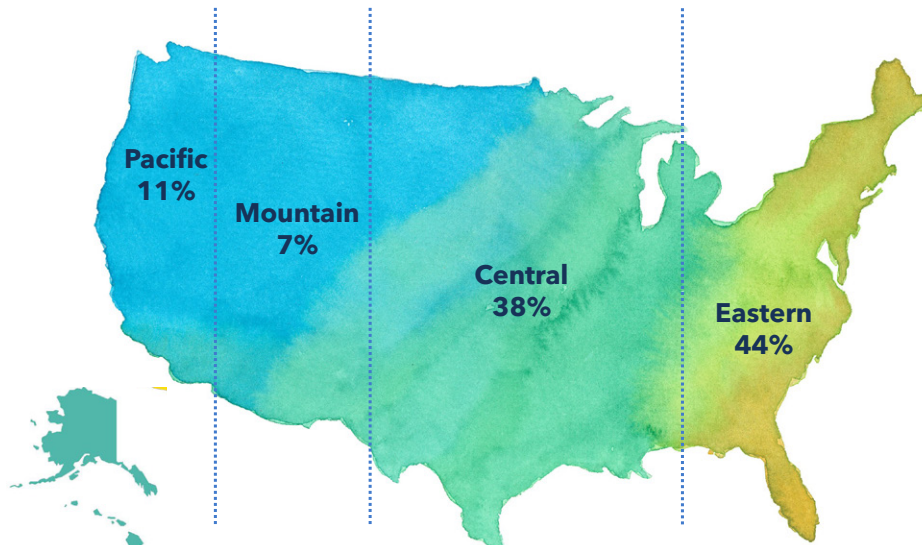
**Responses were received from people living in 21 countries.**

**FIGURE 4**  
**21 Countries Represented in Survey**

*Note: The survey was available in English only*



**FIGURE 5**  
**Distribution of U.S. Responses**



Forty-four percent of respondents are employed or attending school full-time; 14 percent are employed or attending school part-time; and 16 percent are currently not working or attending school due to IH or are entirely disabled by IH. Among those living in the United States, 65 percent reported having health insurance coverage through a plan provided through their own, a spouse's, or a parent's employer. Eighteen percent were covered by either Medicare (13%) or Medicaid (5%), and four percent were covered by another government program. Eight percent had coverage under a plan purchased through the Affordable Care Act Marketplace or a private insurance company. One percent reported having no health insurance coverage, and two percent were unsure or preferred not to answer.

**As reported by respondents, the average age at which symptoms began interfering with daily life is 28. Respondents report seeking medical attention within 4 years on average from when symptoms began interfering with daily life.**

## DIAGNOSIS, SYMPTOMS, AND IMPACT

### The Path to Diagnosis

As reported by respondents, the average age at which symptoms began interfering with daily life is 28. Respondents report seeking medical attention within 4 years on average from when symptoms began interfering with daily life. There was a wide range in the number of years between seeking medical attention and diagnosis of IH, from 0 to 60 years, with an average of 6.5 years. The number of years between symptom onset and diagnosis ranged from a low of 0 to a high of 67 years, with an average of 14 years. The average age at diagnosis is 35, with a range from 6 years old to 81 years old.

Respondents were asked to recall what symptoms first raised concerns. The irrepressible pull of sleep and difficulty transitioning from sleep to being awake and alert were typical among the open-text comments, such as these:

*"Low energy, sleeping a long time at night, naps that would go on for hours, and I wouldn't feel rested after waking up. I would also eat an incredible amount, like my body was telling my brain that I needed more food to get energy. To this day, if I'm off all my medications, I still get all these symptoms, including the need to eat 3000+ calories a day."*

*"My mother remembers that I would fall asleep into my dinner, playing in my bouncer, and generally being a sleepy child. I personally remember spending my teenage years being exhausted and going to the GP with my frustration with being so exhausted and sleepy regardless of how much sleep I had, crying with frustration and feeling like my mind and body wouldn't work properly. Needing excessive amounts of sleep."*

*"She was unable to wake in the morning without being physically woken repeatedly by a parent; sleeping on the floor inside the shower stall while taking a shower before school in high school; inattentiveness that was labeled as attention deficit disorder at the time."*

*"Falling asleep driving, being unable to remember conversations due to fatigue, struggling to stay awake for more than 4-6 hours at a time."*

*"This has not been a problem my whole life. I had no problems with sleep or alertness until I reached adulthood."*

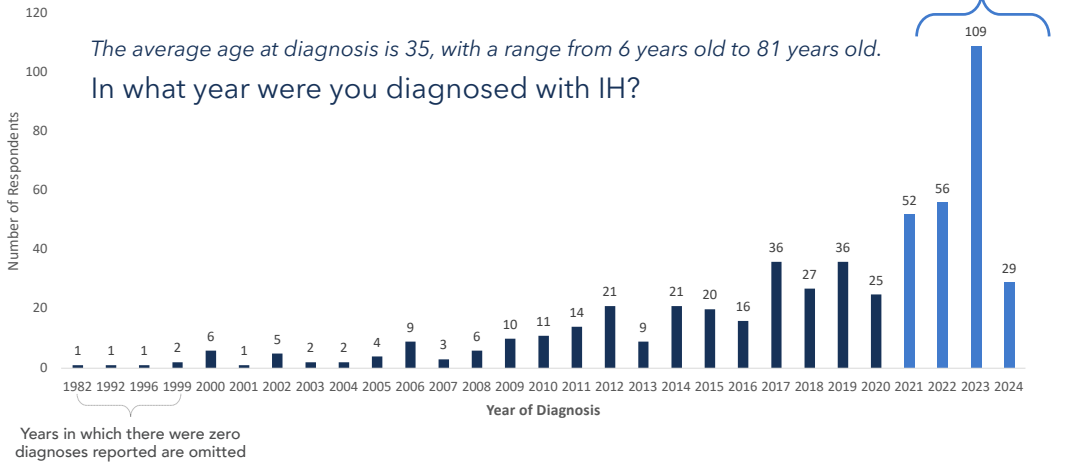
FIGURE 6

## Diagnosis

**91%** of survey respondents have been diagnosed by a healthcare professional

The average age at diagnosis is 35, with a range from 6 years old to 81 years old.

In what year were you diagnosed with IH?



Ninety-one percent of survey respondents report that a healthcare professional diagnosed IH. The peak year of diagnosis among all respondents is 2023, with 26 percent reporting diagnosis in 2023 or 2024. Respondents reporting an IH diagnosis in the years 2021-2024 represent 46 percent of total responses. An overnight sleep study (PSG) was used to diagnose 94 percent of those responding, a daytime nap study (MSLT) was used in 87 percent, a sleep diary was used in 34 percent, and actigraphy was used in 14 percent of reported diagnoses.

Respondents shared challenges with the diagnosis process that mirror what was heard at the meeting. A sample of survey comments follows:

*“We visited our general practitioner four times in 2021 to seek help for our daughter’s extreme tiredness and high volume of sleep. He said it was due to her being a teenager, then he said it was because she is tall, and then he said, ‘It’s just the way it is.’ That’s when we changed doctors. The new GP immediately said this was not normal and referred us to a pediatrician, who immediately referred us to a sleep physician. And then we got all the tests done and got the answer. It took almost two years, from beginning to end. Not great.”*

*“The biggest barrier was all the providers who suggested my wife’s symptoms were psychiatric in nature. Her primary care doctor refused to provide a referral to neurology. Eventually, we insisted we would not leave the hospital until we were helped, and we were seen by a neurologist who specialized in sleep. The results from MSLT were clear and definitive.”*

*“The sleep study was extremely difficult and, at times, traumatic. Going without coffee induced a severe migraine for 48 hours, and being in a stuffy hospital environment really increased anxiety. You are also communicated with through a tiny speaker, and that really spikes any anxiety when being woken up, etc., leaving you feeling really on edge. Also, hospital food – not great, so overall, it was a bad 24 hours.”*



Kathleen Collins, during a sleep study

**“Her primary care doctor refused to provide a referral to neurology. Eventually, we insisted we would not leave the hospital until we were helped.”**

## Comorbidities

Current comorbidities reported by at least 15 percent of those responding are anxiety (57%), depression (50%), obesity (24%), attention-deficit hyperactivity disorder (ADHD) (22%), high blood pressure (19%), hypothyroidism (17%), and obstructive sleep apnea (16%). Thirty-six percent of patients represented in the survey had been diagnosed with another sleep disorder (besides IH) in the past or at present, with obstructive sleep apnea (OSA) being the most common among them, with 22 percent reporting having received an OSA diagnosis at some point. Only four percent had a current diagnosis of narcolepsy type 2 (NT2), and three percent had a past diagnosis of NT2.

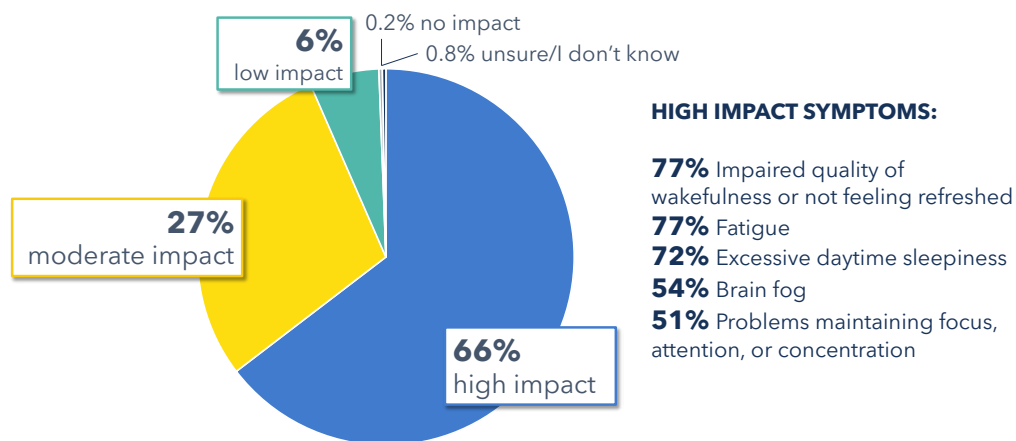
## Impact of IH and Most Burdensome Symptoms

Respondents were asked to rate the impact of IH over the past month, taking into consideration their current management and treatment regimens (described on pages 64-67). Two-thirds (66%) of respondents report a high impact, 27 percent report a moderate impact, and six percent report a low impact; only one respondent indicated having no effect on their life. Symptoms reported by at least 50 percent of respondents to have a high impact over the past month are impaired quality of wakefulness or not feeling refreshed (77%), fatigue (a lack of physical or mental energy, feeling tired, exhausted, or low energy) (77%), excessive daytime sleepiness despite adequate hours of sleep (72%), mental fogging or “brain fog” that continues past the transition from sleep to being awake (54%), and problems maintaining focus, attention, or concentration (51%).

**93% report moderate to high impact of IH symptoms on their life in the past month.**

FIGURE 7

### Impact of IH Symptoms on Life Over the Past Month



When asked to select only the 1-3 symptoms that have the most significant impact on life, excessive daytime sleepiness despite adequate hours of sleep was selected most often (by 67% of respondents), followed by impaired quality of wakefulness or not feeling refreshed (by 48%), mental fogging or “brain fog” that continues past the transition from sleep to being awake (by 38%), fatigue (a lack of physical or mental energy, feeling tired, exhausted, or low energy) (by 30%), and severe sleep inertia (also known as “sleep drunkenness”) (by 23%).

*"It's hard to pick just three. They are all so impactful on our daughter's life. Every aspect is affected. And we, as parents, miss her too. Because we enable her to function as best as possible or to whatever levels she wants, it means when she is at home, she only ever sleeps. So, we barely see her awake (I mean alert awake!)."*

*"There are symptoms I'm only just now discovering are associated with IH, and I do wish there was more awareness of what we might be facing that is part of the disorder to help us feel less like, 'Oh great, there's something else wrong.' Specifically, trouble regulating body temperature was something I only found out was related to IH in the last year, despite it being a major issue for me."*

When asked about the average number of hours they have slept within 24 hours over the past month, 27 percent stated sleeping 8-9 hours, 32 percent indicated sleeping 10 to 11 hours, and 22 percent reported sleeping 12 or more hours. When asked about the average number of hours they feel "alert and focused" within 24 hours, 28 percent reported 0 to 2 hours, 31 percent reported 3 to 4 hours, and 22 percent indicated 5 to 6 hours. Over the past month, 44 percent report experiencing severe sleep inertia 6 or 7 days per week when waking from nighttime sleep. Thirty-eight percent said that over the past month, sleep inertia lasts more than 60 minutes when waking from nighttime sleep. Open-text descriptions about the sensation of sleep inertia include the following:

*"I experience confusion, clumsiness, poor motor control, slurring or mumbling words, not being able to articulate my thoughts. I forget to take my medication and occasionally fall back to sleep or automatically do things without realizing I'm doing them."*

*"I'm awake, but in reality, I'm not really there. I take my medication, but later, I don't remember it, or the opposite: I don't take it but am sure I took it. I have an invisible force pulling me towards the bed, and I can't think clearly. My head is foggy, and I have to hold on to the stress in order to emerge. I often have memory problems and can't remember mornings unless I am given clues. Sometimes, I fall back asleep because I didn't even realize the alarm had gone off. I have a lot of difficulty speaking, physically. I'm moody and can be rude to people I love without meaning to. I often feel cold and feel like it takes twice as much effort to send the motor command to my muscles."*

One-third of all respondents (38% of those who indicated the question applied to them) reported noticing a relationship between IH symptoms and the menstrual cycle, menopause, or pregnancy.

*"A few days before her cycle, she has an increase in all her symptoms."*

*"During her menstrual cycle, her sleepiness, orthostatic intolerance, and heat/cold intolerance are more pronounced. She also sleeps longer, and sleep inertia is worse/longer lasting."*

*"The week before and the week of my menstrual cycle, there is nothing that can keep me awake. My medication basically becomes ineffective, and I am almost bedridden for two weeks out of each month."*

*"I have noticed that my IH symptoms become noticeably worse the week prior to the start of my menstrual cycle. Both my overnight sleep time and my EDS symptoms are ~25 percent worse than baseline."*

**54%**  
report  
**sleeping  
10+ hours**  
per 24-hour  
period

**59%**  
report just  
**0-4 hours  
feeling  
"alert and  
focused"**  
per 24-hour  
period

*"[S/he] wakes up completely unable to understand anything, angry with the same energy of a zombie."  
– Open-text description about the sensation of sleep inertia*

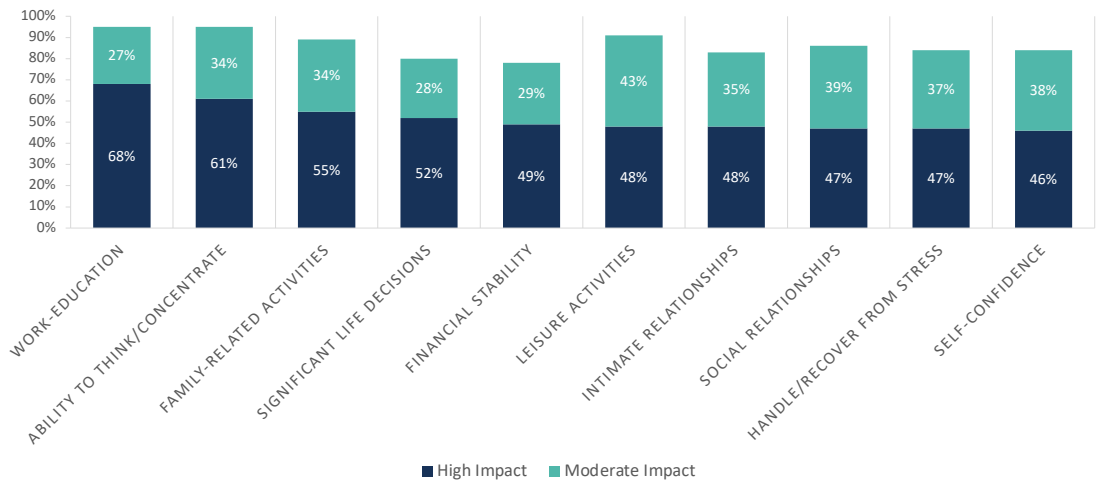
**68% of respondents indicated IH had a high impact on their work-related or educational activities.**

## Impact of Symptoms on Daily Life and Long-Term Outlook

As was heard during the meeting, survey responses reflect the wide-ranging impacts of IH symptoms on daily life. Based on survey responses, work-related or educational activities and responsibilities were the most affected areas of life, with 68 percent indicating a high impact and another 27 percent indicating moderate impact. The impacts on the ability to think, concentrate, process, or recall information had the second highest ratings, with 61 percent reporting high impact and 34 percent reporting moderate impact. The impacts on the ability to think, concentrate, process, or recall information had the second highest ratings, with 61 percent reporting high impact and 34 percent reporting moderate impact. The top 10 areas of life affected by IH are shown in the table below. Some of the many open-text responses describing the type and extent of impacts are included below:

FIGURE 8

### Impact of IH on Key Aspects of Life



*“EDS has impacted every aspect of my life. While I have been able to maintain a high-functioning, full-time job, I have no external life enjoyment. I come home from work and only want to sleep. My days off are spent sleeping. I am afraid to have children because I do not think I will have the wakefulness to care for them.”*

*“Her life is quite abnormal as a mother with a career. She works, which she must do to provide for her children and to have medical insurance to pay for her very expensive prescribed medications, and she sleeps. She is a wonderful mother, and her children bring her great joy, but they totally exhaust her.”*

*“He attended university classes but when he woke, he was on autopilot. He was overwhelmed by mid-semester and earned grades that didn’t reflect his ability because of his symptoms. He was medically discharged from school due to symptoms.”*

*"We filed an [accommodations request under the] Americans with Disabilities Act so he wouldn't lose his job. He doesn't go into work at normal times because he can't wake up, and he falls asleep at his desk sometimes. He struggles with executive functions; his brain is tired, and it affects all types of relationships, especially on the worst days."*

*"I am a band teacher. My job keeps me upright, moving around, and pretty consistently busy at work which really helps with IH symptoms and keeps me from falling asleep at work. Days when I have to do a lot of computer work are much harder to manage, and I often accidentally fall asleep. However, the mental load of the thousands of quick decisions teachers have to make takes a real mental toll on my worst IH days."*

When asked about conditions that make IH symptoms worse, respondents reported that emotionally demanding circumstances and stressful situations had the greatest impacts, with 55 percent indicating a significant worsening of symptoms under each set of conditions. Closely following that were mentally demanding tasks, with 49 percent indicating a significant worsening of symptoms. Physically demanding tasks were reported by 42 percent to cause significant worsening of symptoms. Additional open-text comments about what makes IH worse included these:

*"Too much interaction with people. Not sleeping well. Seasonal allergies."*

*"Emotional and physical stress or exhaustion. Continuous pressure, such as school. Lack of daytime napping causes a 'crash' where she'll sleep for 2 or 3 days and nights straight."*

*"Any kind of emotion – happy, sad, stress, anger."*

*"Being in situations where I have to be 'on' like work or meeting new people are very mentally fatiguing and are difficult to recover from."*

*"Pushing myself to live within society's expectations."*

Responses to the question, "What worries you most about your condition?" echoed sentiments heard during the meeting about the possible chronicity of feeling this way, impacts on long-term health and aspirations, effects on family members and other loved ones, and the possibility of progressing symptoms.

*"I'm fairly young and have struggled with this since I was a child, so my biggest worry is just that I will feel like this for the rest of my life and never be able to fully live it, as I have to balance doling out my energy between work and pleasure, with most of my energy going to work. It also greatly impacts my family planning as I do not want to have children and risk passing it along, having to go off of my medication for the duration of the pregnancy, and overall not having the energy to care for a child. My partner completely understands this, thankfully, but we have both wanted children, so we have been weighing the pros and cons of having children naturally versus adopting versus forgoing children altogether."*

*"Hurting myself when I'm alone or forgetting something important or dangerous, such as a lighted stove."*

*Sentiments shared about what worried respondents most about IH included effects on family members and other loved ones, and the possibility of progressing symptoms.*



Zachary Leader (on the right) with his siblings and pets

*"What I am actually capable of doing in life in terms of work, becoming a parent, etc. I am worried about what the future holds for me."*

*"Patient was determined by the court to be disabled as a very young adult due to the symptoms and receives Social Security benefits from their parents' Social Security, which are minimal. Patient is restricted by the number of hours that can be worked and cannot earn a salary or enough money for a retirement plan or to pay rent for independent living. Patient is financially dependent upon parents for the rest of the parents' and patient's lives. Being found to be disabled at a young age precludes a patient from earning enough money to pay into Social Security, so a good amount of money could be drawn on it in the future."*

**Ninety-seven percent of patients represented in the survey have been prescribed medication in the present or the past to manage IH.**

## TREATMENT EXPERIENCE

Ninety-seven percent of patients represented in the survey have been prescribed medication in the present or the past to manage IH. Over the past month, 83 percent of respondents have taken one or more prescription medications, 69 percent make adjustments to daily routines and lifestyle, 29 percent take one or more non-prescription medications, herbals, or supplements, and 27 percent use other approaches like meditation, psychotherapy, and massage. Four percent have not been doing anything to actively manage IH and its symptoms over the past month.

### Prescription Medications

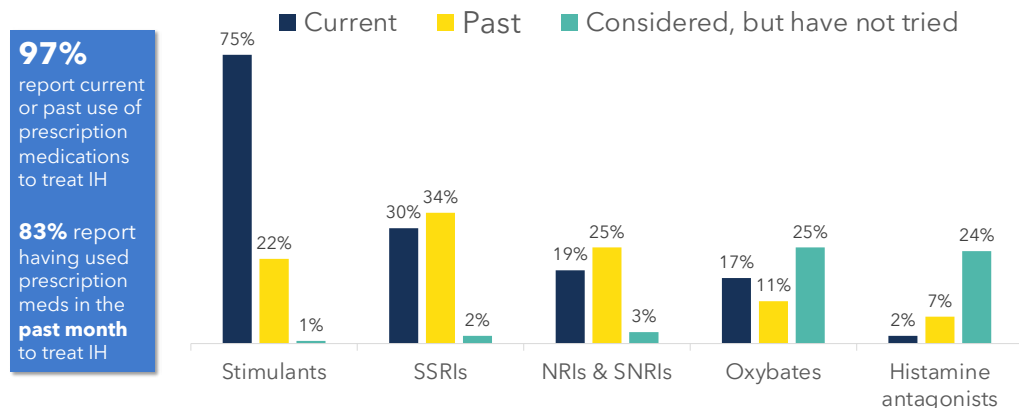
The most common medication types used by survey respondents are stimulants, with 75 percent currently taking one or more stimulants and 22 percent having used them in the past. Less than one percent had considered stimulants but not tried them. Selective serotonin reuptake inhibitors (SSRIs) are currently used by 30 percent of respondents, 34 percent have used them in the past, and two percent considered but had not yet tried SSRIs. Current use of selective and serotonin-norepinephrine reuptake inhibitors (NRIs and SNRIs) was reported by 19 percent, with 25 percent reporting past use and three percent had considered but never tried them.

FIGURE 9

### Experience with Medications by Class

*Note: Current use of all other medication classes fell below 15%*

For a list of medications included in each class for the purposes of this survey, please view the survey instrument at <https://bit.ly/IH-survey-instrument>





Oxybates, including the only medication approved by the FDA for the treatment of IH, Xywav, as a group, are currently being used by 17 percent of survey respondents, with 11 percent having past experience with this medication type. As was heard at the meeting, the use of oxybates outside the U.S. as a treatment for IH is limited. Looking only at survey respondents from the U.S., current use is reported by 25 percent, past use is reported by 14 percent, with 30 percent having considered oxybates but not yet tried this class of medicines.

Another class of medications, histamine antagonists, also has limited regulatory approval outside the U.S. For histamine antagonists, current use by respondents in the U.S. is two percent (2% globally, including U.S.), with past use reported by 7 percent (6% globally) and 24 percent having considered but not tried histamine antagonists (19% globally).

Respondents submitted open-text comments about their experience with prescription medications that reflected a dynamic effort to balance treatment benefits and downsides, including the following:

*"It would be nice to find a medication that actually works for her, lasting longer than 4-5 hours and effective for more than a few months."*

*"I just started medication and have seen some improvement. Cautiously optimistic at the moment."*

*"My current medication helps me so much. It has changed my life, but there are significant challenges and side effects."*

*"These medications usually lose their effectiveness and can be unpredictable sometimes. There is always some sort of hoop to jump through each time these medications need to be filled."*

*"Various antidepressants only helped with mood but did not improve fatigue."*



*"A downside of stimulant medications is that they promote alertness during the day but make it harder to fall asleep at night without a sleep aid, even when taken in the first half of the day."*

## Experience with Other Products, Lifestyle Adjustments, and Emotional Support

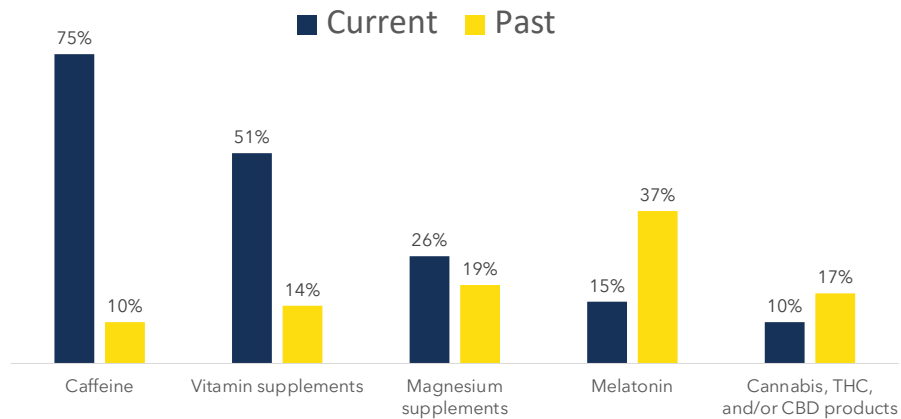
Caffeine was the top non-prescription product currently used by survey respondents, with 77 percent reporting current use and 10 percent reporting past use. One-half of respondents currently use vitamin supplements. Other approaches used, where current and past rates of use were similar, are shown in Figure 10, on the following page. Melatonin and cannabis, THC, or CBD-derived products had the highest levels of past use compared to current use, at 37 percent and 17 percent, respectively.

**75% of respondents reported taking one or more stimulants.**

**77% of respondents reported that they currently use caffeine to aid with treatment of their IH.**

FIGURE 10

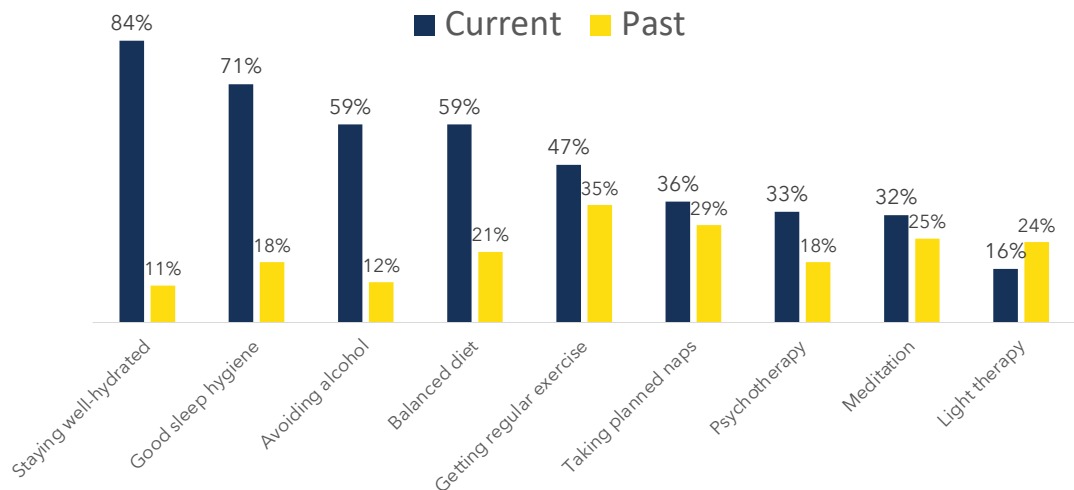
## Experience with Non-Prescription Products



The most utilized lifestyle adjustments include staying well hydrated (84%), practicing good sleep hygiene (71%), avoiding alcohol (59%), and following a well-balanced diet (59%). Past use for each of these approaches was about 20 percent or less. Getting regular exercise, taking planned naps, meditation, and light therapy were currently used by half to a quarter of respondents but had higher rates of past use than other types of lifestyle adjustments.

FIGURE 11

## Experience with Lifestyle Adjustments



Comments about the use of non-prescription products and lifestyle adjustments reflect the range of experiences, positive and negative, that the same product or approach produced:

*"I drink a dangerous amount of caffeine to stay functioning, and it only really works in coffee form – energy drinks don't seem to have the same impact."*



Haley Wall

*"I gave up caffeine years before I was diagnosed, and it was one of the best things I could have done for my health. It was not actually helping with the EDS at all, and it was disrupting what sleep I was getting."*

*"Since starting on melatonin, I find it's a bit easier to wake up in the morning. Less sleep drunkenness."*

*"Tea is lovely, coffee on the bad days. Melatonin makes my symptoms worse."*

*"I use nicotine lozenges and gum to promote alertness and focus and walks at sunrise and sunset to assist circadian rhythms."*

*"Reducing carbohydrate intake – sugars, breads, pasta, etc. Found it's had a pretty big impact, although I don't follow a strict diet or cut it out completely."*

*"Son was found to be very low in vitamin D and is taking 10,000 u once per week. We have tried drug-free days as well as some nights where he allows himself to sleep as long as he needs to with no alarms set in the morning."*

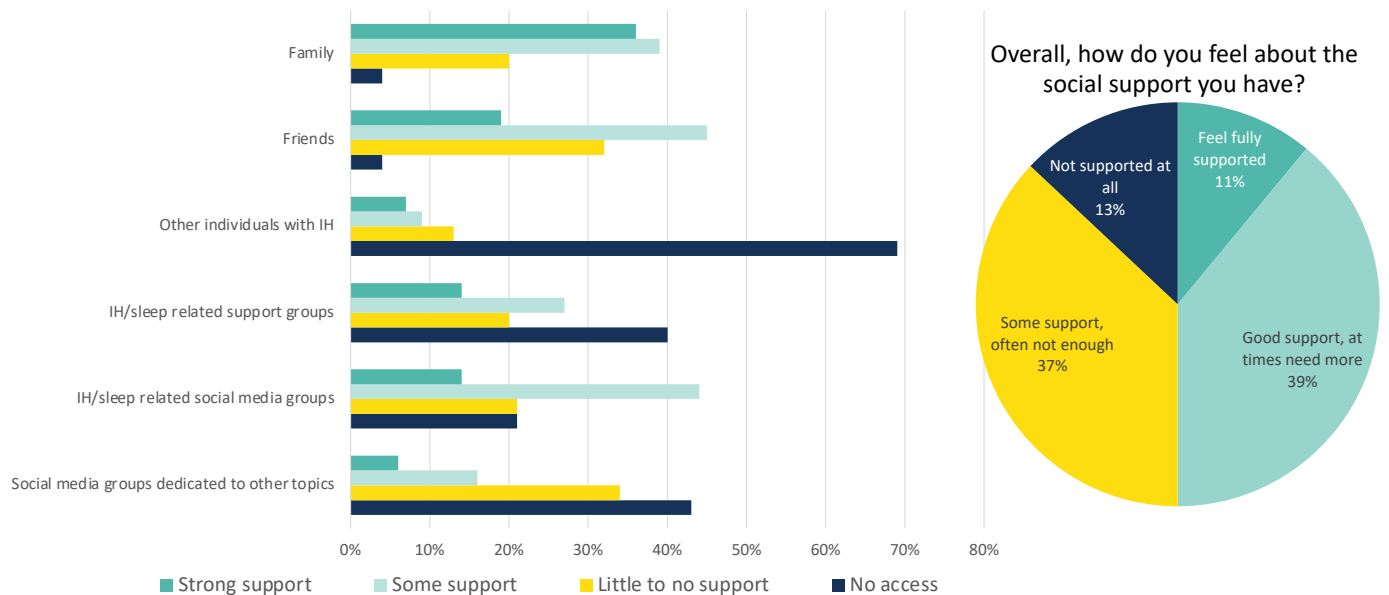
*"Exercise is absolutely critical in managing IH. My wife even uses a desk peddler, a stationary bike-like device under the desk to keep moving and help stay awake."*

**Just 11% of survey respondents report feeling fully emotionally supported for the challenges associated with IH.**

Emotional support for the challenges associated with IH – and the lack thereof that many people experience – was elevated by survey respondents. Just 11 percent of survey respondents report feeling fully supported, with 39 percent indicating they have good support but need more at times. Thirteen percent say they don't feel supported at all. The greatest source of strong support is family, as stated by 36 percent of respondents, although 24 percent report receiving little to no support from family or having no access to family. Friends provide strong support to 19 percent of respondents, with another 45 percent

FIGURE 12

### Sources of Emotional Support





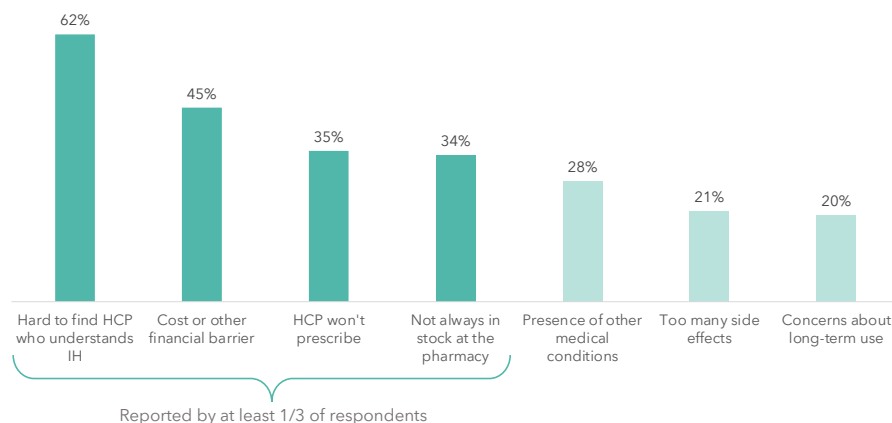
Raymond Meester with his daughter

indicating they receive some support from friends. While 16 percent say they receive strong or some support from individual friends with IH, 69 percent have no access. This echoes what was heard in planning the initiative and at the meeting, that many people had never interacted with another person with IH. Support groups and social media groups for IH or sleep-related topics provided support to 41 percent and 48 percent, respectively.

*“Living with a rare disorder is isolating. I’ve literally only met one other person in real life who has IH. I can count the number of people who have heard of it before I told them on one hand, and that includes the two sleep specialists I’ve seen since my diagnosis. People try to relate, but their regular life experiences might be something they could use to try to understand, but it’s not the same.”*

FIGURE 13

### Barriers to Accessing a Treatment



**62% of respondents have found difficulty finding a healthcare professional who understands IH and knows how to treat it.**

### Barriers to Treatment

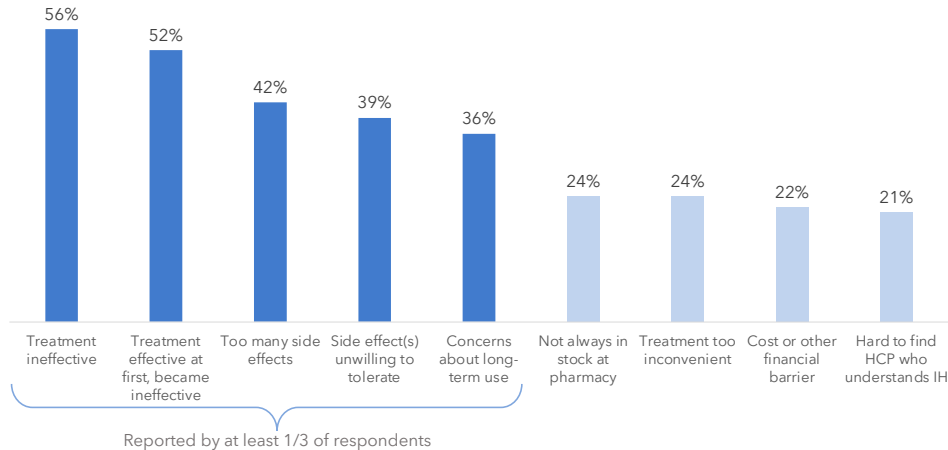
Describing barriers to accessing particular treatments, the top responses were: difficulty finding a healthcare professional who understands IH and knows how to treat it (62%), cost or other financial barriers (45%), healthcare professional unwilling to prescribe a particular treatment (35%), and medication not always in stock at the pharmacy (34%). The top reported barriers to sticking with a therapy are: treatment is ineffective (56%), loss of effectiveness over time (52%), too many side effects (42%), one or more side effects they’re unable to tolerate or unwilling to accept (39%), and concerns about long-term use (36%). Shortages, costs, and finding a healthcare professional who understands IH also factored into respondents’ ability to continue with treatment. These statistics are supported by comments submitted, including the following:

*“Doctors don’t know about IH, and the tests required by insurance companies in order to cover medication is a big problem.”*

*“The neurologist/sleep medicine doctor and the clinic/sleep lab is overburdened. We like him immensely, but response times and exceedingly long wait times for*

FIGURE 14

## Barriers to Sticking with a Treatment



*appointments/sleep studies are out of control. My daughter and our family suffered immensely waiting for appointments, a diagnosis, and finally, the receipt of her medication."*

*"She thinks Adderall is her preferred daytime stimulant, but due to the Adderall shortage, she is currently taking Dexedrine ER."*

*"The prescriptions that have been tried are completely ineffective, and the ones we want to try seem to take an act of god to even get a prescription."*

*"Fear of long-term use is huge. My PCP has little to no understanding of the condition and always seems alarmed at the prospect of me taking stimulants for life. But I'm at a loss as to any other options, so her alarm doesn't help. Because so many physicians are uninformed, the patient really has to take on a lot of the burden of navigating their own journey with treatment. A lot of physicians are happy to settle for 'a bit better' rather than striving for a complete solution, and they tell you that caffeine and naps are part of a good treatment plan. But that ignores the impact on the patient's life, especially work life!"*

*"Prior authorization for sodium oxybate took months, and I had to try, then fail, a bunch of other medications first."*

*"I take Xywav and have taken stimulants like Concerta in the past. The [Drug Enforcement Agency scheduling of these drugs] makes access to them difficult, and it makes doctors reluctant to prescribe them. Stimulants have been hard to find in pharmacies lately. Thankfully, I personally haven't been impacted too much, but I've seen lots of people with IH who are, and I'm worried I may be in the future. My insurance covers Xywav. It's been life-changing, but I'm worried about not getting it if insurance changes."*

*"Lack of approval from insurance because the drug is only approved for narcolepsy is the worst. A physician should be able to override in a peer-to-peer setting, but no."*

***"My PCP has little to no understanding of the condition and always seems alarmed at the prospect of me taking stimulants for life. But I'm at a loss as to any other options."***

*“There have been so many times when my medicine refill wasn’t processed or handled. Days without medicine that helps me function due to it not being in stock. Travel and rearranging appointments to get my prescriptions in time. So many calls to pharmacies.”*

*“Unfortunately, not a single drug is approved for IH in Germany. Therefore, only special outpatient clinics can prescribe off-label medications. In addition, health insurance companies sometimes refuse to cover the costs.”*

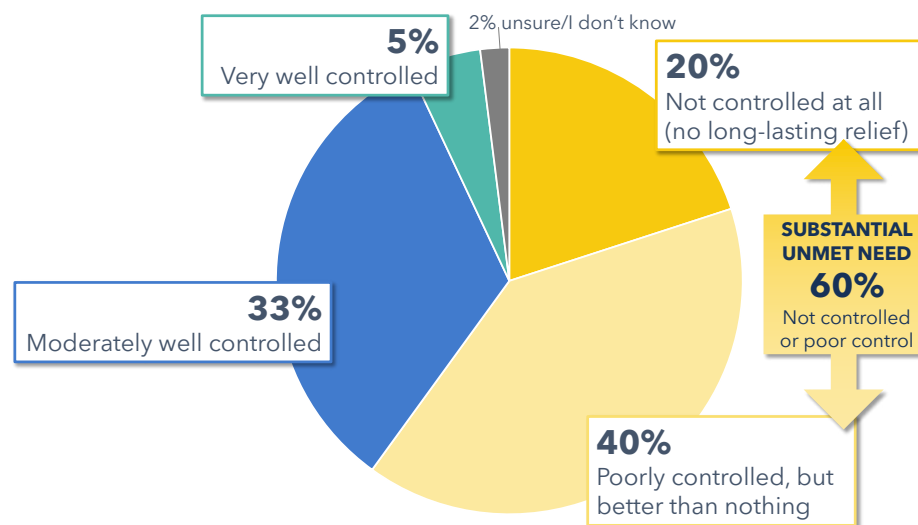
## Overall Treatment Satisfaction and Aspirations

Based on responses to the question, “How well controlled are IH and its symptoms based on treatment approaches available to you?” there remains a substantial level of unmet need among individuals with IH. Sixty percent indicated that IH is not controlled at all or is poorly controlled (“better than nothing”). One-third responded that it is moderately well-controlled, and just five percent indicated it is very well-controlled.

FIGURE 15

### How Well Controlled are IH and its Symptoms Based on Treatment Approaches Available to You?

**60% of respondents indicated that IH is not controlled at all or is poorly controlled (“better than nothing”).**



Responses to an open-ended question about what respondents have found that helps IH and its symptoms the most focus on medications, and often a combination of medications, used in parallel with lifestyle modifications. Many point to the insufficient degree of relief they experience. Representative comments include the following:

*“Having a sleep doctor that is willing to try new things or combinations and find something that works. From a medication standpoint, in one way Xywav, and in another way Vyvanse. Unfortunately, together they were too strong. Xywav and Sunosi together are too weak. But if your sleep doctor won’t try you on Xywav and Wakix, or Xywav and Concerta, or Xywav and low-dose Adderall, then you’re stuck unless you can find a new sleep doctor.”*

*“She structures her schedule with breaks and ensures she is home by 7 pm. This allows her to rest better. She limits her time in crowded and high-stimulus areas and now benefits from the use of noise-canceling earbuds.”*

*“Medicine helps him stay awake, but it’s just a Band-Aid. His symptoms are not controlled; it’s an everyday struggle.”*

*“What helps me the most is to reduce the workload (cognitive or physical) per week, but that’s not always possible. I sometimes have the impression that I have a limited reserve of energy compared to others and that as soon as it’s gone, I really struggle to do anything, or I get sick at the end of the day or week (headaches, drop in blood pressure, cold, hives, dizziness, flu...). When I have fewer things to do, things get better, and I manage my day-to-day life better.”*

*“Modafinil and family support. That’s all we can do. We’re here for her, and we always will be.”*

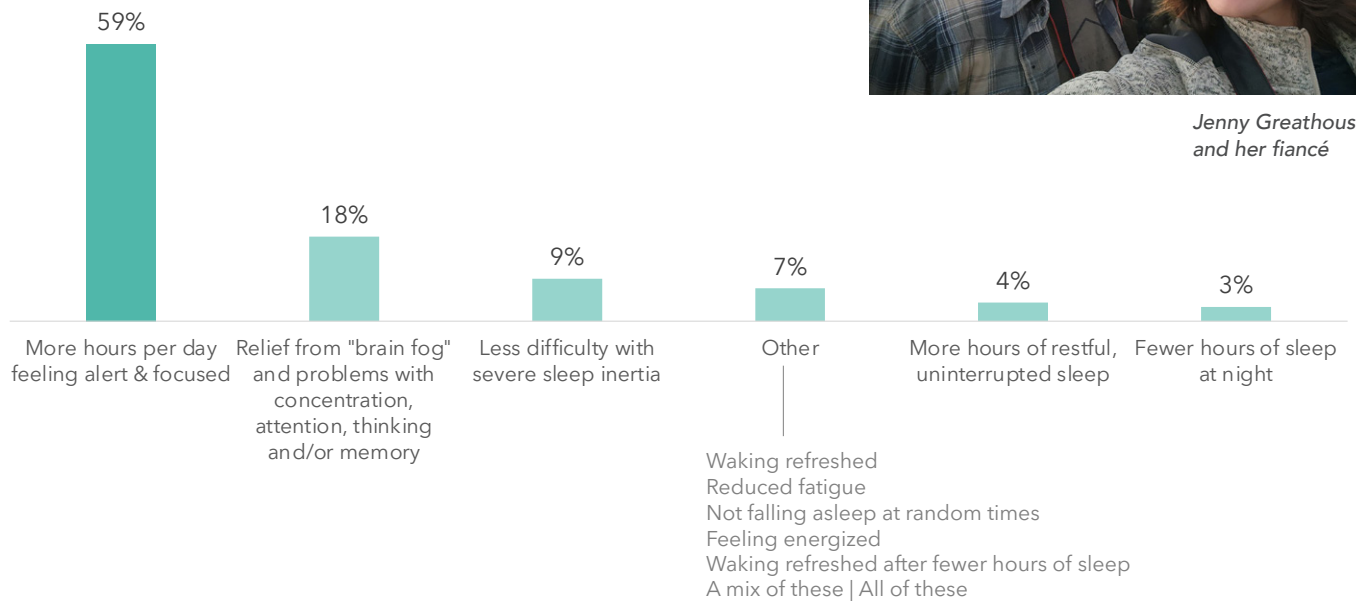
***“She limits her time in crowded and high-stimulus areas and now benefits from the use of noise-canceling earbuds.”***

The top treatment benefit sought by survey respondents is having more hours per day feeling alert and focused, with 59 percent endorsing that option when forced to select just one answer. Relief from brain fog was chosen by 18 percent of respondents, and nine percent selected less difficulty with sleep inertia. Other stated options were chosen by fewer than four percent each. Seven percent responded with “other” and a few of those statements follow below. Respondents were also asked what amount of improvement would make a meaningful difference; some of those answers are stated below. Many of the comments emphasized a desire for normalcy.

FIGURE 16

### Most Important Treatment Benefit

Respondents could select only one answer



Jenny Greathouse and her fiancé



*“I would love to be able to not be tired for just a few hours a day so that I can do things like normal people.”*

*“Twelve hours per day of wakefulness and focus at least five days per week to allow for full-time work including travel to and from work and time to complete basic self-care activities such as eating, showering, dressing, and cleaning.”*

*“I have far fewer usable hours in my day than an average person. This makes it hard to keep up with basic necessities, let alone to thrive. Even an hour or two a day reliably would be a significant improvement.”*

*“Not waking up feeling completely exhausted after more than average amounts of sleep.”*

*“Instead of her having 3 or 4 hours a day of feeling somewhat okay, 12 hours of feeling somewhat okay.”*

*“For me, it’s more than just more hours per day feeling alert and focused. That can be accomplished for most people with high enough doses of amphetamines. I think it’s about having more hours per day feeling alert and focused without increased anxiety, without increased heart rate and sometimes tachycardia, and without increased blood pressure. Maybe that will be possible with the orexin medications if and when they are approved.”*

*“Fifty percent more alertness would be very meaningful, but I would embrace any improvement.”*

*“If I had no brain fog, no sleep inertia, could stay awake during the whole day, and get up in the morning, it would be a huge improvement. This question just makes me more miserable, because it’s not going to happen.”*

*“Being fully present, awake with all emotions and brain cells awake for several hours in a row, where she can experience full joy, laughter and not feel exhausted from it – that would be bliss.”*



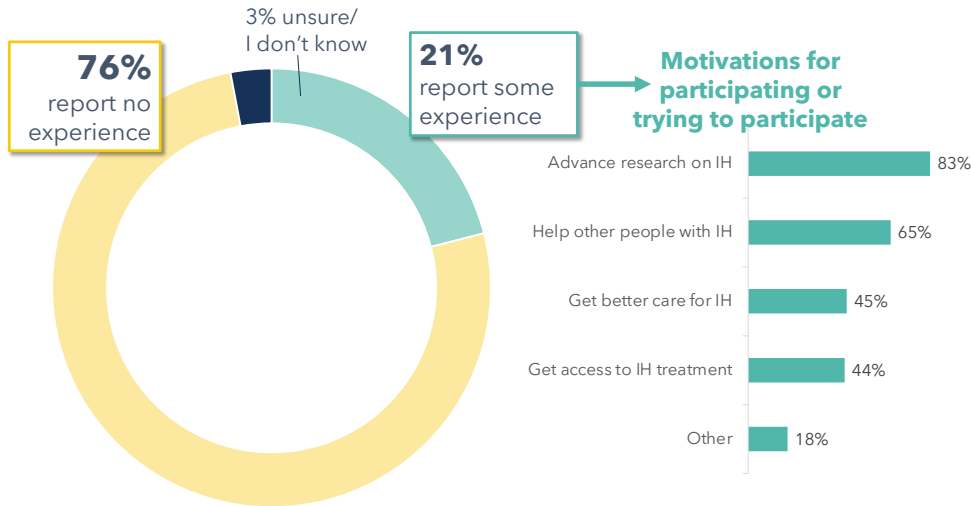
Becky Tallman

Twenty-one percent of survey respondents had experience participating or trying to enroll in a clinical trial. Of those with such experience, 83 percent were motivated by a desire to help researchers learn more about IH and its treatment, and 65 percent indicated an interest in helping other people diagnosed with IH. Getting access to better care or potential treatments motivated 45 and 44 percent, respectively. One individual stated that participating in a clinical trial “helped remove a financial barrier to getting diagnosed.” Others named searching for “relief” as a motivator; a few mentioned financial compensation.



FIGURE 17

### Experience Participating or Trying to Enroll in a Clinical Trial for an IH Treatment - Motivations for Participating

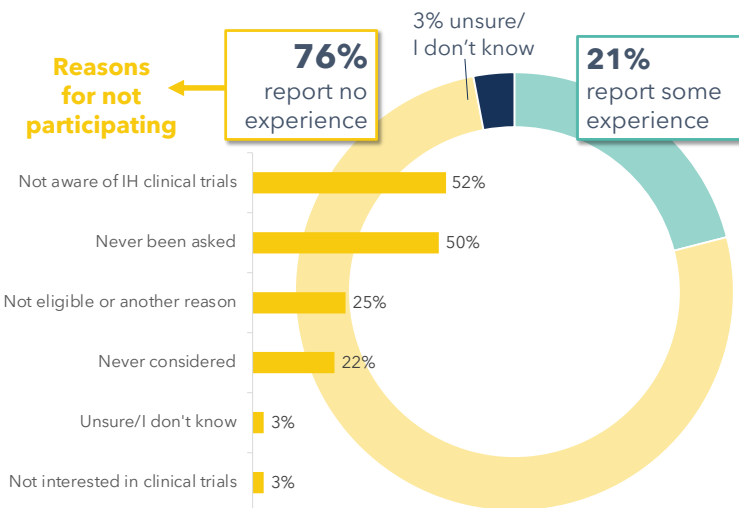


**21% percent of survey respondents had experience participating or trying to enroll in a clinical trial. Of those with such experience, 83 percent were motivated by a desire to help researchers learn more about IH and its treatment.**

Among the 76 percent who had no experience with clinical trials, the top reason was lack of awareness of clinical trials for IH (52%) and/or never having been asked to participate in a clinical trial for IH (50%). One-fourth considered a clinical trial but did not pursue it because they were ineligible or for other reasons; a similar percentage (22%) replied that they had never considered clinical trial participation. Only three percent indicated a lack of interest as the reason.

FIGURE 18

### Experience Participating or Trying to Enroll in a Clinical Trial for an IH Treatment - Reasons for Not Participating



*"IH takes a toll on a person and their spouse. We just live every day the best we can, hoping for better and more effective treatment one day."*



Melanie Bradley

*"I just wish there was more research about this as it will affect my family in future generations."*

## FINAL THOUGHTS

The final question of the survey invited respondents to provide any other comments about their experience with IH or ways their life has been affected by IH that they had not shared elsewhere in the survey. Responses reflected several key themes heard during the meeting and borne out by the data summarized above: the totality of the impact of IH on their lives and the people around them, a desire for more awareness, understanding, empathy, and better treatments and care, feelings of hopelessness about the future burdened by IH, and expressions of optimism for future progress inspired by the Illuminate Hypersomnia initiative. A few of these statements are provided below:

*"Life's potentials have been erased for the patient. Chances of finding a life partner are significantly diminished. Financial future is dismal. Parents' lives have been flipped upside down; retirement is not possible nor are vacations. Finances must be protected for the patient's future."*

*"Our life has been affected financially and mentally. IH takes a toll on a person and their spouse. We just live every day the best we can, hoping for better and more effective treatment one day."*

*"I just wish people could understand how freaking hard I have to work to just be AWAKE. I wish I had better words to describe it than 'excessive daytime sleepiness' because that just sounds like 'tired all the time', and most people feel a degree of that, but it's more than that, and the 'everyone is tired' garbage is absolutely frustrating."*

*"I was told over and over again to lose weight, do yoga, it's a mental health issue, or reduce your stress. Guess what? I did exactly all of it, and it never helped at all. I spent lots of \$\$\$ and lost decades looking for an answer."*

*"My husband's mom passed away after falling asleep at the wheel of her car. She also had IH, and I just wish there was more research about this as it will affect my family in future generations. We cope as a family dealing with it but it's a heavy burden."*

*"Thank you for raising awareness. My hope is that all medical providers will include testing for or at least ask diagnostic questions about IH and sleep disorders as part of evaluating patients who seek treatment for cognitive issues, mental health struggles, and fatigue. In my experience, no provider has ever suggested a sleep disorder should be investigated for my symptoms or my daughter's. I had to propose it and then convince them to pursue a sleep disorder evaluation. All medical and mental health providers I have seen when I described my symptoms defaulted to testing for allergies, anemia, thyroid, hypoglycemia, ADHD, depression, hormone imbalances, recommending lifestyle changes, etc., without suggesting a sleep disorder evaluation."*



*"Thank you for doing this study. It keeps hope alive for more treatments, if not a cure one day."*

# Acknowledgements

Sleep Consortium expresses its gratitude to all who have enhanced the Illuminate Hypersomnia initiative, especially the hundreds of IH community members who participated in the meeting, the survey, and/or by submitting written comments.

## MEETING SPEAKERS

### Presenters and Discussion Starters

Community-member presenters and “discussion starters” dedicated considerable time to reflect and prepare to speak to the challenges, expectations, and hopes of the IH community as a way of inviting an even broader range of experiences through the moderated discussion at the April 11, 2024, EL-PFDD meeting. We deeply appreciate their contributions, courage, and commitment to the success of this initiative.

**Sam Bell**, Chicago, Illinois

**Rebecca Bonnar**, New York, New York

**Beth Boyce**, Hood River, Oregon

**Michelle Chadwick**, Brisbane, Australia

**Kathleen Collins**, Memphis, Tennessee

**Shelly Gonzalez**, St. Louis, Missouri

**Jenny Greathouse**, Leroy, West Virginia

**Gemma Jones**, Horsens, Denmark

**Diana Kimmel**, Sugar Hill, Georgia

**Steve Koch**, Plano, Texas

**Robin Leader**, Greenwich, Connecticut

**Suzanne Lecours**, Toronto, Canada

**Raymond Meester**, Lincoln, Nebraska

**Michael Sparace**, Atlanta, Georgia

**Jelissa Suarez**, Charleston, South Carolina

**Becky Tallman**, Navarre, Florida

**María Vargas**, Mexico City, Mexico

**Haley Wall**, El Paso, Texas

### Introductory Speakers and Moderators

Thank you to these individuals for providing important context at the beginning of the EL-PFDD meeting and for guiding the conversation, incorporating perspectives from those calling in during the meeting, and from written comments submitted in advance of and during the meeting.

FDA Perspective: **Tiffany Farchione, MD, FAPA**, Director of the Division of Psychiatry, Center for Drug Evaluation and Research, U.S. Food and Drug Administration (FDA)

Clinical Overview: **Lynn Marie Trotti, MD, MSc**, Associate Professor of Neurology, Emory University

Moderators: **Lindsay Jesteadt, PhD**, Co-Founder and CEO, Sleep Consortium, and **K. Kimberly McCleary**, Founder and CEO, The Kith Collective

## SURVEY CONTRIBUTORS, REVIEWERS, AND TESTERS

The project team extends thanks to those who helped shape the Illuminate Hypersomnia survey, reviewed early drafts, and tested it, making it better each step of the way. This group includes people living with IH, care partners to adults and children with IH, and medical specialists who provide care to people with IH.

|                     |                  |                       |
|---------------------|------------------|-----------------------|
| Jennifer Beard      | Katie Kellerman  | Robert Stone          |
| David Burley        | Diana Kimmel     | Jelissa Suarez        |
| Michelle Emrich, MD | Rebecca King     | Lynn Marie Trotti, MD |
| Alexis Gallagher    | Kiran Maski, MD  | Victoria Kirby York   |
| Christine Ingrassia | David Plante, MD |                       |
| Acacia Kapusta      | Michael Sparace  |                       |

## INITIATIVE PARTNERS

Sleep Consortium thanks these partners of the Illuminate Hypersomnia initiative for their enthusiastic and active support with community outreach:



## CORPORATE SPONSORS

Thank you to these generous sponsors for their unrestricted educational grants in support of the Illuminate Hypersomnia initiative:



## ILLUMINATE HYPERSOMNIA INITIATIVE TEAM

Working on behalf of their respective organizations and collectively as a cohesive team, these women dedicated their skills, experience, and insights to planning and delivering the Illuminate Hypersomnia initiative.

### Sleep Consortium

**Lindsay Jesteadt, PhD**, Co-Founder and CEO

**Claire Wylds-Wright, Grad Phys, MCSP, MFA**, Co-Founder and CXO

### Kith Collective

**K. Kimberly McCleary**, Founder and CEO

**Samantha Mayberry**, Director of Client Services

**Megan Feeny, MPH**, Community Engagement Specialist

## FURTHER ACKNOWLEDGEMENTS

The Project Team is grateful for the following contributors to the execution of the Illuminate Hypersomnia initiative.

**Paul Cooper** of **Face to Face Strategies** for planning and moderating quarterly meetings of Sleep Consortium's Corporate Advisory Council.

**John Dudley** and his team at **Dudley Digital Works** for creative and technical services to broadcast the meeting and preserve it for on-demand viewing.

**Ethan Gabbour**, Patient-Focused Drug Development Program Staff, Center for Drug Evaluation and Research, **U.S. Food and Drug Administration**, for providing guidance, counsel, and encouragement through the entire planning process, including review of the draft survey and meeting report.

**Julie Rathjens** of **Hello Brand** for the design of the Illuminate Hypersomnia logo, production of other creative materials and outreach images, and for the layout and graphic design of this report.

**Elizabeth Windom** and **Julia Windom** of **Windhaven Productions** for coordinating social media and select video recordings for this initiative.



Lindsay Jesteadt,  
Claire Wylds-Wright,  
Sam Mayberry,  
and Kim McCleary  
preparing for the  
meeting

## APPENDIX

Scan to watch  
the meeting  
recording:



### AGENDA – APRIL 11, 2024 *(all times are Eastern U.S. Daylight Time)*

- 12:00 pm Welcome Remarks**  
*Lindsay Jesteadt, PhD, Sleep Consortium*
- 12:05 pm Opening Remarks from FDA: Value of PFDD in IH**  
*Tiffany Farchione, MD, FAPA, U.S. Food and Drug Administration (FDA)*
- 12:10 pm Overview of IH and Current Treatments**  
*Lynn Marie Trotti, MD, MSc, Emory University*
- 12:25 pm Overview of Discussion Format & Selected Results from the Illuminate Hypersomnia Survey**  
*Moderator, Kim McCleary, Kith Collective*
- 12:35 pm Topic 1: Living with IH – Symptoms and Daily Impacts**  
*Series of presentations by members of the global IH community*
- 1:00 pm Facilitated Discussion: Topic 1**  
*Discussion starters and other people affected by IH in the viewing audience*
- What symptoms have the greatest impact on your life?
  - How does IH affect your life?
  - How has IH changed over time?
  - What worries you most about living with IH?
- 2:00 pm Break**
- 2:15 pm Topic 2: Perspectives on IH Current and Future Approaches to Treatment**  
*Series of presentations by members of the global IH community*
- 2:45 pm Facilitated Discussion: Topic 2**  
*Discussion starters and other people affected by IH in the viewing audience*
- What are you currently doing to help manage IH?
  - How has your approach to managing IH changed over time?
  - What are the most significant downsides to treatment?
  - Short of a cure, what specific things would you look for in an ideal treatment for IH? What would you consider to be a meaningful improvement in your condition that a treatment could provide?
- 3:50 pm Closing Remarks and Themes Heard from the IH Community**  
*Kim McCleary and Lindsay Jesteadt, PhD*
- 4:00 pm Adjourn**

## ABOUT THE SLEEP CONSORTIUM



Sleep Consortium is a registered not-for-profit (501(c)(3)) organization created to accelerate next-generation research, disease understanding, and therapy development for those living with Central Disorders of Hypersomnolence (CDoH), including IH and related diseases. Sleep Consortium works to advance sleep health through innovation and patient empowerment.

### Our Mission

Through ethical data sharing practices, leveraging artificial intelligence and machine learning, Sleep Consortium is re-imagining data collection by creating a global comprehensive, federated database of CDoH omics and clinical data which aims to:

- Reduce diagnostic delays in all communities across the world by identifying new patients with sleep-related phenotypes
- Improve therapeutic options and access for all patients experiencing symptoms of disordered sleep and sleep/wake instability
- Identify the relationship of symptoms of CDoH across other rare and non-rare disease spaces
- Increase the understanding of CDoH in under-represented populations
- Power patient progress by leveraging break-through technology
- Elevate the patient voice by providing a platform for people living with CDoH, and their caregivers to engage with community members, partnering patient advocacy organizations, industry, and government agencies.

### Stay In Touch

 [sleepconsortium.org](https://sleepconsortium.org)

 [PFDD@sleepconsortium.org](mailto:PFDD@sleepconsortium.org)

 [@SleepConsortiumPFDD](https://www.youtube.com/@SleepConsortiumPFDD)

 [@ConsortiumSleep](https://twitter.com/ConsortiumSleep)

 [@sleep\\_consortium](https://www.instagram.com/sleep_consortium)

 [linkedin.com/company/sleep-consortium-inc/](https://www.linkedin.com/company/sleep-consortium-inc/)

# **Illuminate** **Hypersomnia**

*Shining light on the lived experience of IH*

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 Sleep Consortium

VOICE OF THE PATIENT