



# 2023 ANNUAL REPORT

HF

# OUR MISSION AND VALUES

## OUR MISSION

The Hypersomnia Foundation engages, informs and champions our global community to improve the lives of people with idiopathic hypersomnia and related sleep disorders.

## OUR VALUES

- **PASSION:** We give voice to the significant unmet needs of the hypersomnia community, continuously striving to realize our dream of a cure.
- **VALIDATION:** We understand what it is like to live with an invisible disease. When you share your story, we believe you.
- **INCLUSIVENESS:** We believe all people with hypersomnias deserve timely diagnosis and effective treatment in order to live a healthier, more fulfilling life.
- **PARTNERING:** We strive to connect our patient community to multiple stakeholders who are critical to improving the lives of people with central hypersomnias. Clinicians, researchers, pharmaceutical companies, educators, regulators and legislators benefit from strong ties to each other and the patient community.
- **TRUST:** We are a trusted source of medical information for people with hypersomnia, their physicians and the general public. Your donations and shared medical information are fully protected and used only in accordance with your wishes.
- **DEDICATION:** Our team of volunteers and employees devote their time and professional skills—with unwavering focus—to the best interests of the hypersomnia community.

# WHO WE ARE

In 2014, three individuals deeply affected by idiopathic hypersomnia (IH) founded the Hypersomnia Foundation, a non-profit organization dedicated to advocating for people with IH and related sleep disorders. The Foundation's mission is to address unmet needs by fostering education, raising awareness, and uniting the hypersomnia community, including individuals with IH, researchers, clinicians, and industry partners, to enhance the understanding, diagnosis, and treatment of IH.

Progress in these areas is especially critical as IH remains poorly understood, and existing treatments offer limited effectiveness. For many with IH, daily tasks like participating in family life, managing a household, holding a job, or attending school are extraordinarily challenging.

The Foundation's efforts focus on connecting the medical community, educational institutions, the general public, and those impacted by IH through advocacy, awareness, and research funding. Its goals include improving diagnostic tools, achieving accurate diagnoses, enhancing treatments, and increasing accommodations for people with IH in educational and work settings.

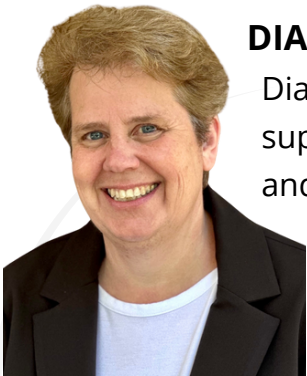
The Hypersomnia Foundation is led by an active, all-volunteer Board of Directors, along with a full-time CEO, COO, CFO, and two corporate officers. Its Medical Advisory Board, chaired by Dr. David Plante, Associate Professor of Psychiatry at the University of Wisconsin School of Medicine and Public Health, includes ten clinician-researchers. The Scientific Advisory Board, chaired by Dr. Thanh Dang-Vu, Associate Professor at Concordia University in Montreal, consists of five researchers focused on sleep, neuroimaging, and cognitive health.

As a strategic addition to the Hypersomnia Foundation Research Award Program, the Foundation partnered with the American Academy of Sleep Medicine Foundation (AASMF) to co-fund hypersomnia research. This collaboration significantly boosted hypersomnia grant applications to the AASMF, which subsequently funded additional IH grants independently. In 2023, this partnership generated \$663,320 in research funding, substantially increasing resources dedicated to advancing hypersomnia research. Our operating surplus is used to boost our reserve funds available to sponsor research and we are dedicated to leveraging those resources to maximize the difference we can make.

# 2023 LEADERSHIP HIGHLIGHTS

## HYPERSOMNIA FOUNDATION WELCOMED TWO NEW MEMBERS TO OUR BOARD OF DIRECTORS

The Hypersomnia Foundation added two accomplished new members to our Board of Directors: Robert “Bob” Ambrefe, RPh, and Diana Kimmel. Their combined experience and dedication will help further the foundation’s mission to improve the lives of those affected by hypersomnia.



### DIANA KIMMEL

Diana has been an active volunteer with the Hypersomnia Foundation since its founding in 2013. She has supported conferences, online events, and has served on the Hypersomnia Foundation’s Patient Advocacy and Advisory Council (PAAC) since 2019. Following her own diagnosis of idiopathic hypersomnia (IH) in 2011, Diana focused on fostering a supportive community for those living with IH. She has organized monthly support group meetings in Atlanta since 2014, co-founded the Hypersomnia Alliance, and co-facilitates IH support retreats known as Snooze Cruises. Diana has presented at various conferences, reaching both those with IH and professionals in the medical and sleep medicine fields.



### ROBERT “BOB” AMBREFE, RPH

Bob brings extensive expertise from his 30-year career as a practicing pharmacist. He comes from a family of pharmacists and has experience in various pharmacy settings, including retail, hospital, and industry. His impressive background includes roles such as Associate Chief of Pharmacy for the VA in Boston, co-owner of the Village Pharmacy of Lynnfield, and management positions at Bristol Myers Squibb. Bob has also collaborated with physicians to compound Flumazenil for hypersomnia patients. Bob works with Alkermes in Waltham, Massachusetts, and has dedicated over 20 years to public health, serving as Chairman of the Board of Health in Middleton, Massachusetts.

# 2023 LEADERSHIP HIGHLIGHTS

## HYPERSOMNIA FOUNDATION JOINED HISTORIC SLEEP EQUITY CONVENING AT THE WHITE HOUSE



Rebecca King

Rebecca King, a board member of the Hypersomnia Foundation, and Claire Wylds-Wright, Hypersomnia Foundation CEO, joined a coalition of sleep advocates and organizations for the inaugural Sleep Equity Convening at the White House. This landmark event underscored the need for increased awareness, equitable access to sleep health resources, and continued advocacy for those affected by sleep disorders.

Reflecting on the experience, Rebecca stated, "It was an honor to represent the Hypersomnia Foundation at the first-ever White House listening session on sleep and sleep equity. Many were surprised to learn that one in five Americans has a sleep disorder, with most cases undiagnosed, posing significant health risks and impacting our nation's productivity. We also discussed the concerning disparity in sleep health among underrepresented groups, particularly Black and Hispanic communities, where sleep deprivation is a growing issue each year. There was some encouraging news as well. The American Heart Association has now included sleep in their 'Essential 8' elements for cardiovascular health, and new research is helping identify effective ways to reach Black men with information about obstructive sleep apnea (OSA) and other sleep disorders. This convening was a promising beginning to an essential conversation we look forward to continuing." (November 2023)

## HYPERSOMNIA FOUNDATION PARTICIPATES IN LIVE #IHAVEIH PANEL DISCUSSION

Claire Wylds-Wright, Hypersomnia Foundation CEO, was a guest panelist on a Jazz Pharmaceutical #IHAVEIH live LinkedIn event. The discussion featured perspectives from across the community on what it's like to live with and manage idiopathic hypersomnia, as well as important resources available to patients. (March 2023)



Claire Wylds-Wright

# 2023 PROGRAM HIGHLIGHTS

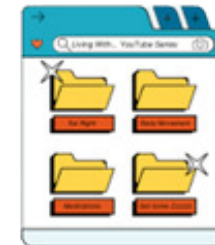


## THE HYPERSOMNIA FOUNDATION HOSTS MONTHLY VIRTUAL GET TOGETHERS

The Hypersomnia Foundation launched UNIGHT, a monthly virtual gathering focused on topics relevant to individuals with sleep disorders. Esteemed guest speakers for UNIGHT have included Dr. Lynn Marie Trotti, Dr. Anne Marie Morse, Dr. Yishan Xu, Dr. Jennifer Mundt, Dr. Michael Grandner, Dr. David Plante, Dr. Shelby Harris, and Hypersomnia Foundation Board member Anjel Burgess, JD. Discussion topics have covered a range of issues, including Behavioral Therapies for Hypersomnia, Disparities in Sleep Medicine, Navigating the Disability Process, Balancing Relationships in Central Disorders of Hypersomnolence, Workplace Accommodations for Hypersomnolence Disorders, Pregnancy and Parenting, and Legislative Advocacy.

## HYPERSOMNIA FOUNDATIONS PRODUCES NEW YOU TUBE SERIES

The Hypersomnia Foundation launched a new YouTube series titled "Living With...", hosted by HF CEO, Claire Wylds-Wright. Each episode of the series featured engaging conversations with sleep experts, researchers, clinicians, and individuals affected by idiopathic hypersomnia, exploring the daily realities of living with this condition. The goal of the "Living With..." series is to raise awareness about idiopathic hypersomnia, promote healthy sleep habits, and highlight the latest research in sleep medicine.



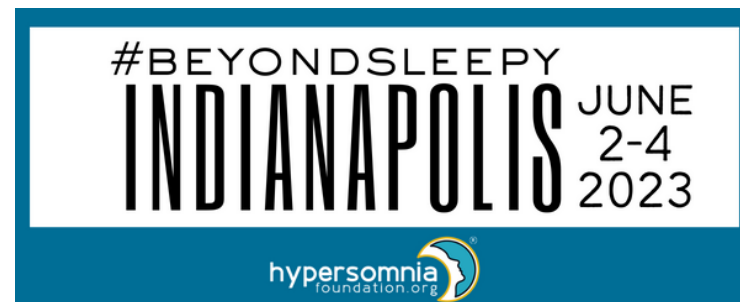
**NEW**  
**LIVING WITH...**

The series covered a variety of topics, including "Why are People with Idiopathic Hypersomnia Tired?" with Dr. Emmanuel Mignot; "Prioritizing the Patient Voice" with Dr. Anne Marie Morse; "Addressing the Complex Relationship of IH and Mental Health Conditions" with Dr. Lynn Marie Trotti; "A Helpful Guide for Patients" with Jelissa Suarez and Dr. Marisa Whalen; "Communicating the Need for Accommodations in Personal and Professional Life" with Victoria Kirby York; "The Woman Who Wouldn't Wake Up: Hypersomnia and the Science of Sleepiness" with Quinn Eastman; "Centering and Empowering the Patient Voice" with Veronica Moore; "Using Occupational Therapy Tools for Hypersomnia" with Haley Wall; and "Current and Future Treatments for Idiopathic Hypersomnia" with Dr. Thomas Scammell.

# 2023 PROGRAM HIGHLIGHTS

## HYPERSOMNIA FOUNDATION HOSTED THREE #BEYONDSLEEPY CONFERENCES

The Hypersomnia Foundation hosted a three-day conference in Indianapolis, Indiana bringing together individuals with idiopathic hypersomnia, narcolepsy, Kleine-Levin Syndrome, and their supporters. This engaging event offered numerous opportunities to learn, share experiences, discuss challenges, and connect with others. The agenda featured presentations on the latest research, treatments, and clinical trials, alongside networking and discussion sessions, a poolside evening reception, and ample opportunities for guests to reconnect with old friends and make new ones.



Key presentations included "Hypersomnia in Adulthood: What is the Role of the Family?" with Dr. Jennifer Mundt; "Reclaiming our Worth - Requesting Accommodations for Every Part of Our Lives" with Victoria Kirby-York; "Pregnancy + IH" with Dr. Lynn Marie Trotti and Amy Desmarais; "Setting Yourself Up for Success in School" with Jessamine Griewahn-Okita and Olivia Robinson; "Management of Pediatric Hypersomnolence" with Dr. Kiran Maski; and "Latest Research in IH" with Dr. Emmanuel Mignot. A total of 750 people attended, either in person or virtually, with presentations made available on the Hypersomnia Foundation's website afterward.

The Hypersomnia Foundation held two one-day hybrid conferences, creating valuable opportunities for individuals to connect with others navigating life with sleep disorders.



In March 2023, the Hypersomnia Foundation welcomed 6 in-person and 136 virtual attendees to the #BeyondSleepySatellite: Together in Salt Lake City, Utah. The keynote speaker, Dr. Chris Hammond, delivered a presentation on "Hypersomnia: Assessment and Management." Hypersomnia Foundation Board members Anjel Burgess, JD, spoke on "Idiopathic Hypersomnia and Social Security Disability: What You Need to Know," while Rebecca King presented "The Game of Life." Amy Desmarais, HF's Treasurer and Chief Financial Officer, shared insights in her talk, "Living with Idiopathic Hypersomnia."

In September 2023, HF hosted #BeyondSleepySatellite: Together in Philadelphia with 63 in-person and 250 virtual attendees. Highlights included a presentation on "Uncovering the Real-World Impact of Idiopathic Hypersomnia" by Marisa Whalen, PharmD, and an update on a clinical study with KP1077 in adults with idiopathic hypersomnia, presented by Dr. Rene Braeckman and Christopher L. Drake, PhD, FAASM.



# 2023 FINANCIALS



## STATEMENT OF ACTIVITIES FOR FISCAL YEAR ENDING DECEMBER 31, 2023

|                                                   |           |                   |
|---------------------------------------------------|-----------|-------------------|
| <b>SUPPORT AND REVENUE</b>                        |           |                   |
| Contributions (Individual)                        | \$        | 213,135.71        |
| Contributions (Foundations)                       | \$        | 105,507.96        |
| Grants (Non-Restricted Pharmaceutical)            | \$        | 265,000.00        |
| Grants (Restricted Pharmaceutical)                | \$        | 230,000.00        |
| Program Income                                    | \$        | 75,040.78         |
| Product Sale Income                               | \$        | 638.28            |
| Interest Income                                   | \$        | 28,083.47         |
| <b>TOTAL SUPPORT AND REVENUE</b>                  | <b>\$</b> | <b>917,406.20</b> |
| <b>EXPENSES</b>                                   |           |                   |
| Research Grant Award                              | \$        | 50,000.00         |
| Scholarships to Individuals                       | \$        | 5,000.00          |
| Salaries and Related Expenses                     | \$        | 290,542.04        |
| Contract Services (Accounting, Professional Fees) | \$        | 94,486.82         |
| Reconciliation Discrepancies                      | \$        | 561.04            |
| Office Expenses                                   | \$        | 10,937.74         |
| Travel and Accommodations                         | \$        | 74,679.76         |
| Conferences and Meetings                          | \$        | 137,003.20        |
| Marketing, Website, and Non-Employee Insurance    | \$        | 71,264.46         |
| <b>TOTAL EXPENSES</b>                             | <b>\$</b> | <b>734,475.06</b> |
|                                                   |           |                   |
| <b>NET REVENUE</b>                                | <b>\$</b> | <b>182,931.14</b> |



# 2023 FINANCIALS

## SCHEDULE OF FUNCTIONAL EXPENSES FISCAL YEAR ENDING DECEMBER 31, 2023

|                             | Program Services     | General and Administrative | Fundraising         | TOTAL                |
|-----------------------------|----------------------|----------------------------|---------------------|----------------------|
| Conferences and Meetings    | \$ 137,003.20        | \$ -                       | \$ -                | \$ 137,003.20        |
| Employee Compensation       | \$ 217,906.53        | \$ 58,108.41               | \$ 14,527.10        | \$ 290,542.04        |
| Insurance (non-employee)    | \$ -                 | \$ 3,727.00                | \$ -                | \$ 3,727.00          |
| Legal, Accounting, Auditing | \$ -                 | \$ 94,486.82               | \$ -                | \$ 94,486.82         |
| Marketing and Outreach      | \$ 32,753.47         | \$ -                       | \$ 3,639.28         | \$ 36,392.75         |
| Office Expenses             | \$ -                 | \$ 9,944.72                | \$ 993.02           | \$ 10,937.74         |
| Scholarships and Grants     | \$ 55,000.00         | \$ -                       | \$ -                | \$ 55,000.00         |
| Travel                      | \$ 74,679.76         | \$ -                       | \$ -                | \$ 74,679.76         |
| Website                     | \$ 29,350.64         | \$ -                       | \$ 1,544.77         | \$ 30,895.41         |
| Reconcile Discrepancies     | \$ -                 | \$ 561.04                  | \$ -                | \$ 561.04            |
| Other                       | \$ -                 | \$ 249.30                  | \$ -                | \$ 249.30            |
| <b>TOTAL</b>                | <b>\$ 546,693.60</b> | <b>\$ 167,077.29</b>       | <b>\$ 20,704.17</b> | <b>\$ 734,475.06</b> |

# LOOKING FORWARD

We will continue to:

- Increase our outreach, education, and awareness;
- Seek funding to support research into effective treatments and better diagnostic tools for idiopathic hypersomnia and related disorders;
- Be a premier source of informational resources for the international sleep disorder community and advocacy efforts to improve the quality of life for people with IH and related sleep disorders.



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