



# 2022 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, each personally impacted by the debilitating effects of idiopathic hypersomnia (IH), came together to form the Hypersomnia Foundation, a non-profit organization dedicated to advocating for the unmet needs of people with IH and related sleep disorders. Through education, awareness, and advocacy, the Hypersomnia Foundation works to bring together the entire hypersomnia community, from people with IH and related disorders, to researchers, clinicians, industry, and more, to improve understanding, diagnosis and treatment of IH and related disorders.

Taking meaningful steps towards achieving these goals is especially urgent, given that IH is a disorder that is not well understood, and currently available treatments have limited effectiveness. For many people with IH, being active participants within their family, managing a home, holding down a job, or going to school is very difficult if not impossible.

Part of our mission is to connect the medical community, educational institutions, the general public, and the people affected by IH, through awareness, understanding, advocacy, and funding of needed research. Our goal is the development of better diagnostic tools, accurate diagnoses, improved treatments and increased accommodations for individuals at work and school.

The Hypersomnia Foundation is managed by an active, all-volunteer Board of Directors, a full-time Chief Executive Officer, Chief Operating Officer, Chief Financial Officer, and two corporate officers. Ten clinician-researchers sit on our Medical Advisory Board, chaired by Dr. David Plante, Associate Professor of Psychiatry at the Wisconsin School of Medicine and Public Health. Our Scientific Advisory Board has a membership of five researchers and is chaired by Dr. Thanh Dang-Vu, Associate Professor at Concordia University in Montreal, where he currently holds the University Research Chair in Sleep, Neuroimaging and Cognitive Health.

This year we were honored to have the AASM Foundation recognize our work with their 2022 Sleep Champion Award.



## **DAVID BURLEY APPOINTED AS CHAIR OF HYPERSOMNIA FOUNDATION BOARD OF DIRECTORS**

After years of being sleepy, David was diagnosed with idiopathic hypersomnia in his 20s. His story is like many others—a long journey with many unanswered questions. He hopes his non-profit background and passion for helping others can bring more awareness of IH and improved options for those living with it.



## **DR. ANNE MARIE MORSE JOINED THE HYPERSOMNIA FOUNDATION'S MEDICAL ADVISORY BOARD**

Dr. Morse is a board-certified and fellowship-trained pediatric neurologist. She currently serves as the Director of Child Neurology and Pediatric Sleep Medicine at Geisinger, Janet Weis Children's Hospital. Her clinical interests include sleep-wake disorders in neurologic disease, narcolepsy, hypersomnia disorders, and neuroimmunology. Her research interests include sleep-wake disorders in neurologic disease, hypersomnia disorders, and sleep-wake disorder phenotyping.

## **THE HYPERSOMNIA FOUNDATION WELCOMED CLAIRE WYLDs-WRIGHT AS CHIEF EXECUTIVE OFFICER AND LINDSAY JESTEADT AS CHIEF OPERATION OFFICER**



Claire Wylds-Wright, Grad Phys SRP, MCSP, MFA has been working in sleep advocacy for a decade following the onset of her daughter's diagnosis of narcolepsy in 2010 at the age of three. Claire trained as a physical therapist at St Thomas' Hospital, London, and practiced as a clinician in the British National Health Service and in private healthcare specializing in chronic pain management, community care, trauma, medico-legal representation and latterly senior management. She is well-versed on sleeping disorders and the impact of a pediatric diagnosis on the family unit and advocated for giving voice to children and their caregivers and exposing the under-recognized aspects of a pediatric sleep disorder diagnosis.



Lindsay Jesteadt, PhD began her career in education, focusing on Compliance, Special Education Policies and Procedures in the State of Florida. In 2014, following the abrupt onset of Type 1 Narcolepsy in her 4-year-old son, Lindsay began working ambitiously towards improving lives of children with narcolepsy and advising industry, patient advocacy organizations and supporting parents navigating the early years of childhood sleep disorders.



# 2022 HIGHLIGHTS



## THE HYPERSOMNIA FOUNDATION AND THE AASM FOUNDATION AWARDED MARGARET BLATTNER, MD, PHD, WITH A 2022 STRATEGIC RESEARCH GRANT

As leaders in the sleep medicine field, the AASM Foundation and the Hypersomnia Foundation partnered to provide funding to the Strategic Research Grant program, in support of novel hypersomnolence research. Dr. Blattner received the 2022 Strategic Research Grant for her research, A Novel Protocol for Understanding and Diagnosing Idiopathic Hypersomnia, which recognizes that the current and most common methodology of diagnosing IH, a polysomnogram (PSG) and multiple sleep latency test (MSLT), may have poor sensitivity, specificity, and reliability. Dr. Blattner's research aims to help address the need to identify an accurate and reliable diagnostic tool for IH. *(September 2022)*

## I HAVE IH CAMPAIGN SURVEY RESULTS RELEASED

To address the low understanding of idiopathic hypersomnia, Jazz Pharmaceuticals partnered with the Hypersomnia Foundation to launch "I Have IH," a disease awareness campaign aimed at increasing knowledge of IH. As part of the campaign, Jazz and the Hypersomnia Foundation conducted two surveys. They surveyed healthcare providers to measure their perceptions and knowledge and also surveyed both people living with this disorder as well as their supporters, to learn the true impact on the lives of people with IH. "The results of this survey unveil important discoveries of the numerous barriers in a patient's idiopathic hypersomnia diagnosis journey, including misdiagnosis and lack of understanding by the healthcare community," said the Chief Executive Officer of the Hypersomnia Foundation. "We look forward to furthering our partnership with Jazz in order to increase awareness and reduce time to diagnosis for everyone living with this debilitating sleep disorder." *(March 2022)*

LET YOUR STORY  
**BE HEARD.**

Take the I Have IH survey now!

I Have

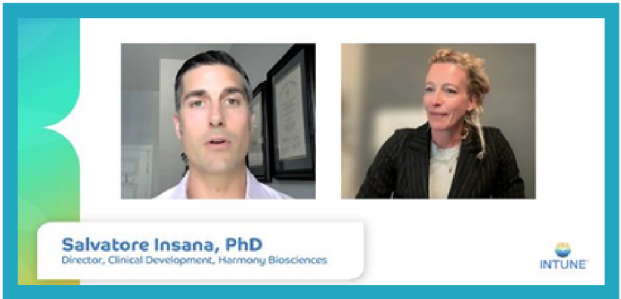


IDIOPATHIC  
HYPERSONNIA

hypersomnia  
foundation.org



Jazz Pharmaceuticals



## **HYPERSOMNIA FOUNDATION CEO INTERVIEWED SALVATORE INSANA, PHD, ABOUT THE INTUNE CLINICAL TRIAL**

Claire Wylds-Wright, HF CEO, interviewed Dr. Salvatore Insana, Director of Clinical Development at Harmony Biosciences, about the clinical study currently being conducted by Harmony Biosciences, to evaluate the safety and efficacy of pitolisant, an investigational medication for treating excessive daytime sleepiness (EDS) in people with idiopathic hypersomnia age 18 years or older. *(November 2022)*

## **HYPERSOMNIA FOUNDATION'S INDUSTRY OUTREACH OFFICER INTERVIEWED PHARMACEUTICAL LEADERS AT THE 2022 BEYOND SLEEPY CONFERENCE**



Andrew Powell, Hypersomnia Foundation's Industry Outreach Officer, spoke with Jennifer Gudeman, PharmD, Vice President of Medical and Clinical Affairs for Avelar Pharmaceuticals, and discussed Avelar's history of focusing drug delivery to historically unmet medical needs, their creation of "plain language summaries" so study and clinical trial details can reach a broader audience, and the importance of always listening to patients, and recognizing clinical trial participants as "medical heroes." *(July 2022)*

Andrew Powell, Hypersomnia Foundation's Industry Outreach Officer, spoke with Dr. Kelvin Tan, Chief Medical Officer for Jazz Pharmaceuticals, and discussed the importance of understanding and meeting patients' needs, Jazz Pharma's emphasis on getting medications to the public as soon as possible, and Jazz's dedication to partnering with patient advocacy organizations. *(July 2022)*







## THE HYPERSOMNIA FOUNDATION HOSTED A VIRTUAL MEET & GREET: WE'RE IN THIS TOGETHER

Understanding the challenge of managing life with a sleep disorder, community advocates Diana Kimmel (Hypersomnia Alliance), Christen Wernig (Colorado Narcolepsy & IH Support Group), Michael Sparace (Hypersomnia Foundation), Diane Powell (Hypersomnia Foundation), and Dr. John Harsh, a psychologist certified in sleep medicine, held a virtual discussion for people with IH, KLS, and narcolepsy and their supporters to share their experiences, their paths to understanding these sleep disorders, and practical ideas for coping. (January 2022)

## HYPERSOMNIA FOUNDATION HOSTED THE 2022 BEYOND SLEEPY CONFERENCE IN CHARLOTTE, NORTH CAROLINA

This three-day hybrid event was held for people with idiopathic hypersomnia and related sleep disorders, such as narcolepsy and KLS, and their supporters. Held in Charlotte, North Carolina, 586 people attended the conference - 140 people attended in-person and 446 participated virtually. This conference featured expert speakers covering the latest in research, treatments, and clinical trials; networking and discussion sessions, and served as a forum to connect people with rare sleep disorders with leading researchers and patient advocates in the sleep medicine field. The event included presentations by leading researchers in the sleep medicine field: Dr. David B. Rye, Dr. Lynn Marie Trotti, Dr. Thanh Dang-Vu, and Dr. Yves Dauvilliers.

Leading patient advocates moderated group discussions and break-out sessions, including,

- Christina Brundage, HF Patient Advisory and Advocacy Council Chair, and Veronica Moore, HF Board Member, who discussed raising awareness of hypersomnias in communities of color and under-resourced areas and what to expect when participating in a clinical trial.
- Rebecca King, HF Board Member, who moderated a discussion on Medicare and breaking down insurance barriers that prevent patients from obtaining their medications.
- Diane Powell, LCSW, former chair and CEO of the Hypersomnia Foundation, who led a break-out group for supporters for people with sleep disorders and how to cope and address stress.





### INTERNATIONAL PATIENT REGISTRY AT CORDS

To better understand symptoms, treatments, and the diagnostic journey of individuals with hypersomnia disorders, we partnered in 2015 with CoRDS (Coordination of Rare Diseases at Sanford) on an international patient registry specific to hypersomnias. After two years of development and essential support from the Foundation’s Medical and Scientific Advisory Boards, the Hypersomnia Foundation’s CoRDS Patient Registry was launched. As of December 2022, over 3,800 individuals with IH and related disorders (from nearly 30 countries) have registered with CoRDS, sharing their information and creating a vital database for researchers to help solve this complicated puzzle of rare sleep disorders.

### SOMNUSNOOZE

Our e-newsletter, SomnusNooze, is filled with information of interest to the hypersomnia community, including summaries of scientific articles on evolving treatments and other research, as well as personal journey stories, information about recruiting for clinical trials and registries, disability and strategies for coping, and support for caregivers. Our email subscribers have grown from 114 in 2014 to over 5,000+ at year end 2022.



### PATIENT ADVISORY AND ADVOCACY COUNCIL

The Hypersomnia Foundation (HF) has always sought the input of a broad swath of the hypersomnia community. In June 2016, the Board of Directors launched the HF Patient Advisory and Advocacy Council (PAAC), a volunteer advisory group that serves as a liaison between the hypersomnia community and the HF Board. The PAAC provides relevant and influential suggestions to increase awareness and understanding of the hypersomnias. Its informed and unique perspective ensures that the voices of the hypersomnia community are given opportunities to be engaged in the mission of the HF.



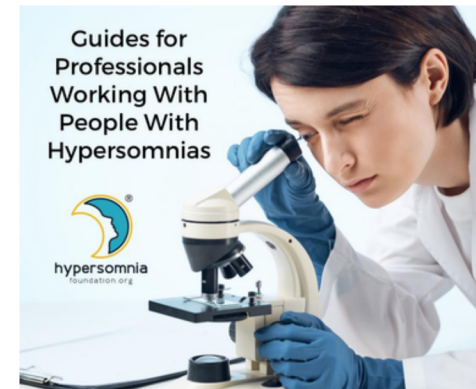


## HYPERSONMIA FOUNDATION MEDICAL ADVISORY BOARD PROVIDED UPDATES TO HF WEBSITE

As a kickoff to “Sleep Awareness Week 2022,” the HF Medical Advisory Board reviewed and updated the “Hormonal Therapy, Birth Control & Menstruation: Considerations for People Who Have Hypersomnias” webpage to include testosterone treatment and also updated of the “Treatment” webpage to include updated information about medications for idiopathic hypersomnia and narcolepsy. *(March 2022)*

## HF CREATES GUIDES FOR PROFESSIONALS WORKING WITH PEOPLE WITH HYPERSOMNIAS

Geared for the healthcare provider involved in research studies or the operation of sleep study centers and researchers, managers, and team members of a sleep or research study, HF created a series of “Guides for Professionals Working With People With Hypersomnias,” that include a “Guide for Sleep Study Centers and Research Study Sites,” “Guide for Researchers,” and “Guide to the Design of Survey Studies.” *(June 2022)*



## HYPERSONMIA FOUNDATION PARTNERED WITH HAYMARKET MEDICAL EDUCATION TO PROVIDE FREE CME CREDITS

HF hosted a complimentary accredited continuing education symposium for sleep specialists, psychiatrists, neurologists, and advanced-practice clinicians. The CME course entitled “A New Dawn for Better Outcomes in Patients With Idiopathic Hypersomnia: New Data, New Guidance, New Treatments” was presented at the SLEEP 2022 conference in Charlotte, NC. *(June 2022)*

# 2022 FINANCIALS

## STATEMENT OF ACTIVITIES FOR FISCAL YEAR ENDING DECEMBER 31, 2022

	Year Ended December 31, 2022			Year Ended December 31, 2021		
	Without Donor Restrictions	With Donor Restrictions	2022 Totals	Without Donor Restrictions	With Donor Restrictions	2021 Totals
<b>SUPPORT AND REVENUES</b>						
Contributions and Grants	\$ 85,607	\$ 448,746	\$ 534,353	\$ 145,065	\$ 261,618	\$ 406,683
Program Income	\$ 36,029	\$ -	\$ 36,029	\$ -	\$ -	\$ -
Interest Income	\$ 350	\$ -	\$ 350	\$ 303	\$ -	\$ 303
Net Assets Released from Restrictions						
Satisfaction of Program Restriction Expenditures	\$ 390,170	\$ (390,170)	\$ -	\$ 64,784	\$ (64,784)	\$ -
<b>TOTAL SUPPORT AND REVENUES</b>	<b>\$ 512,156</b>	<b>\$ 58,576</b>	<b>\$ 570,732</b>	<b>\$ 210,152</b>	<b>\$ 196,834</b>	<b>\$ 406,986</b>
<b>EXPENSES</b>						
Programs	\$ 437,465	\$ -	\$ 437,465	\$ 116,060	\$ -	\$ 116,060
Supporting Services:					\$ -	
General and Administrative	\$ 41,146	\$ -	\$ 41,146	\$ 12,760	\$ -	\$ 12,760
Fundraising	\$ 6,374	\$ -	\$ 6,374	\$ 2,421	\$ -	\$ 2,421
Total Supporting Services	\$ 484,985	\$ -	\$ 47,520	\$ 15,181	\$ -	\$ 15,181
<b>TOTAL EXPENSES</b>	<b>\$ 484,985</b>	<b>\$ -</b>	<b>\$ 484,985</b>	<b>\$ 131,241</b>	<b>\$ -</b>	<b>\$ 131,241</b>
<b>INCREASE IN NET ASSETS</b>	<b>\$ 27,171</b>	<b>\$ 58,576</b>	<b>\$ 85,747</b>	<b>\$ 78,911</b>	<b>\$ 196,834</b>	<b>\$ 275,745</b>
<b>NET ASSETS AT BEGINNING OF YEAR</b>	<b>\$ 456,542</b>	<b>\$ 424,973</b>	<b>\$ 881,515</b>	<b>\$ 377,631</b>	<b>\$ 228,139</b>	<b>\$ 605,770</b>
<b>NET ASSETS AT END OF YEAR</b>	<b>\$ 483,713</b>	<b>\$ 483,549</b>	<b>\$ 967,262</b>	<b>\$ 456,542</b>	<b>\$ 424,973</b>	<b>\$ 881,515</b>





# 2022 FINANCIALS



## SCHEDULE OF FUNCTIONAL EXPENSES FISCAL YEAR ENDING DECEMBER 31, 2022

	Year Ended December 31, 2022				Year Ended December 31, 2021			
	Program Services	General and Administrative	Fundraising	Total 2022	Program Services	General and Administrative	Fundraising	Total 2021
Conferences space	\$ 56,059	\$ -	\$ -	\$ 56,059	\$ 20,258	\$ -	\$ -	\$ 20,258
Consulting	-	-	-	-	\$ 4,500	\$ 500	-	\$ 5,000
Dues and subscriptions	-	-	-	-	\$ 2,185	\$ 1,380	-	\$ 3,565
Employee compensation	\$ 157,549	\$ 27,426	\$ 4,070	\$ 189,045	\$ 38,772	\$ 2,107	\$ 1,264	\$ 42,144
Insurance	-	\$ 3,550	-	\$ 3,550	-	\$ 2,673	-	\$ 2,673
Legal, accounting and auditing	-	\$ 9,175	-	\$ 9,175	-	\$ 5,650	-	\$ 5,650
Marketing and outreach	\$ 25,975	-	-	\$ 25,975	\$ 500	-	-	\$ 500
Office expenses	\$ 12,129	\$ 659	\$ 396	\$ 13,184	\$ 124	\$ 11	-	\$ 135
Other fees	-	-	-	-	-	\$ 6	-	\$ 6
Other program expense	\$ 19,733	-	-	\$ 19,733	\$ 12,805	-	\$ 1,050	\$ 13,855
Payroll tax and other	\$ 13,271	\$ 336	\$ 1,908	\$ 15,515	\$ 3,266	\$ 178	\$ 107	\$ 3,550
Postage and delivery	\$ 1,318	-	-	\$ 1,318	\$ 549	-	-	\$ 549
Printing and reproduction	-	-	-	-	\$ 996	\$ 255	-	\$ 1,251
Registration fees	-	-	-	-	\$ 521	-	-	\$ 521
Scholarship and grants	\$ 112,500	-	-	\$ 112,500	\$ 25,000	-	-	\$ 25,000
Travel	\$ 8,523	-	-	\$ 8,523	-	-	-	-
Website	\$ 30,408	-	-	\$ 30,408	\$ 6,584	-	-	\$ 6,584
	\$ 437,465	\$ 41,146	\$ 6,374	\$ 484,985	\$ 116,060	\$ 12,760	\$ 2,421	\$ 131,241



# 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.



4514 Chamblee Dunwoody Road, #229, Atlanta, GA 39338  
info@HypersomniaFoundation.org | 678.842.3512

The Hypersomnia Foundation is a tax-exempt organization as set forth in Section 501(c)(3) of the Internal Revenue Code. Its Tax ID number (EIN) is 46-4162735.