hypersomnia foundation.org®

2021 ANNUAL REPORT

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.

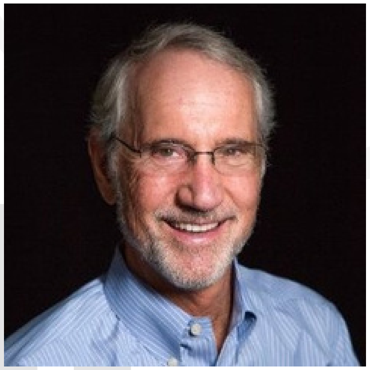
2021 BOARD HIGHLIGHTS

Board of Directors

The Hypersomnia Foundation **welcomed three new members** to our Board of Directors.

VERONICA MOORE is an experienced patient advocacy manager, health equity and inclusion advocate, and public health educator. More than half of her professional career has been dedicated to working with rare disease patient communities. In 2020, she was diagnosed with a hypersomnia. This diagnosis amplified her desire to passionately advocate for equitable access to diagnosis and treatment of hypersomnias among underrepresented communities.

MICHAEL SPARACE has been volunteering for the Hypersomnia Foundation for several years, especially helping with technology during in-person and virtual conferences and webinars. He is passionate about HF's work, as his wife has idiopathic hypersomnia.



CHIP WERNIG is deeply passionate about sleep disorders, being a parent of one daughter diagnosed with narcolepsy Type 1 and another diagnosed with IH. As a parent who has witnessed his daughters struggle with a sleep disorder, he is committed to support research efforts for finding a cure and to raise awareness so others will not feel isolated in their situations.

2021
HIGHLIGHTS

In 2021, we set out to strengthen the interconnection of our community by increasing our outreach at the individual, local, national, and global level and hosted a myriad of virtual events and workshops for the sleep community. Our work during this year was possible because of the generosity of our donors. We are grateful for their support.

VIRTUAL EDUCATIONAL EVENT
"YOUR BEST SELF: NEWS WAYS OF THINKING ABOUT DISABILTY & SUPPORT"

This virtual event discussed the emotional aspects of disability and how to choose the right support group - or even start your own. The event was moderated by Anjel Burgess, Esq., a prominent disability attorney and HF Board member who has represented numerous people with IH who are applying for disability; and Diana Kimmel, founder of the Hypersomnia Alliance and a well-known patient advocate in the IH community. (January 2021)

VIRTUAL FUNDRAISING EVENT
SLEEP/WAKE CYCLERS - RIDE FOR RESEARCH

Originally planned as an in-person fundraising event, we moved our first ever "Ride for Research" to a virtual day of riding and walking to raise money for research on idiopathic hypersomnia and related sleep disorders. Bikers of all ages participated in this day-long event. Whether they rode 2 miles or 200, on a bike trail, around your neighborhood, or on a stationary bike in your living room, our Sleep/Wake Cyclers team raised over $20,000 for research. (June 2021)

2021 HIGHLIGHTS

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 2021, over 3,500 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 4,612 at year end 2021.

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.

2021 HIGHLIGHTS

VIRTUAL EDUCATIONAL EVENT
"YOUR BEST SELF: GETTING YOUR MEDS"
This virtual educational event discussed how to reduce out-of-pocket cost for prescription medications and how to appeal insurance denials. The discussion and workshop was moderated by Laurie Todd, author of “Approved: Win Your Appeal in 5 Days," shared her unique approach to making insurance companies pay their fair share. Carla Dellaporta, Director of User Engagement at the non-profit Needymeds, shared resources to connect people to programs that will help them afford their medications and other healthcare costs. (June 2021)

SLEEPLAB MAGAZINE featured an article on the Hypersomnia Foundation, which highlighted our mission, free resources and educational materials, efforts to increase awareness of IH and other sleep disorders, and our CoRDS International Patient Registry. (September 2021)

VIRTUAL EDUCATIONAL EVENT
“REACHING EVERY PATIENT: A HEALTH EQUITY CONVERSATION”
Hosted by HF’s Diversity and Health Equity Task Force, this virtual roundtable discussed how we can help everyone with a rare sleep disorder get a proper diagnosis and treatment and why many communities are vastly underrepresented in patient registries and clinical trials. (November 2021)

2021 HIGHLIGHTS

VIRTUAL EDUCATIONAL EVENT
"DIAGNOSING HYPERSOMNIA DIFFERENTLY: A EUROPEAN PROPOSAL"

Dr. Gert Jan Lammers of Leiden University in the Netherlands, presented the new proposed diagnostic criteria for both narcolepsy and IH in patient care and research being used by some some European researchers, what the criteria is, how it differs from the standards currently used in the U.S., and what this means for patients. (May 2021)

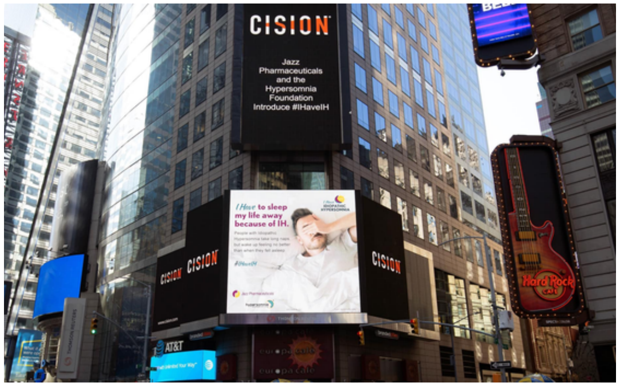
VIRTUAL MEET & GREET
“I'M NEWLY DIAGNOSED - WHAT DOES THIS MEAN?”

This interactive meeting was held for people who had been diagnosed within the last year with IH or a related sleep disorder. The informal and relaxed virtual conversation gave everyone a chance to talk informally and get meet one another. (May 2021)

NEW WEBPAGE
"SLEEPING/NAPPING IN YOUR CAR SAFELY"

Understanding how hard it can be for people with hypersomnias to stay awake all day, many had shared napping stories and strategies, which led us to ask - are we safe when we’re sleeping in our cars? This new webpage describes safety concerns and advice on how to minimize the risks of sleeping/napping in your car. (February 2021)

2021 HIGHLIGHTS

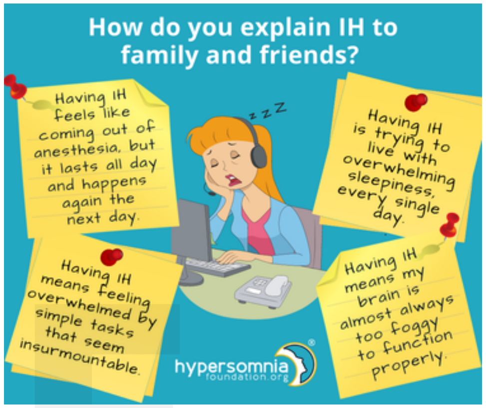


RAISING AWARENESS
#IHAVEIH CAMPAIGN

Jazz Pharmaceuticals worked closely with the Hypersomnia Foundation to raise awareness of idiopathic hypersomnia (IH) with our #IHaveIH campaign, which culminated with a billboard PSA in New York's Times Square. (March 2021)

NEW WEBPAGE
"DIAGNOSING NARCOLEPSY IN AFRICAN AMERICANS"

We updated the “Diagnosis” section of our “About Idiopathic Hypersomnia” webpage and the “Diagnosing Narcolepsy” section of our “About Related Sleep Disorders” webpage by adding information regarding the different presentation of hypersomnias in African Americans and the resultant importance of hypocretin testing for diagnosis. (February 2021)

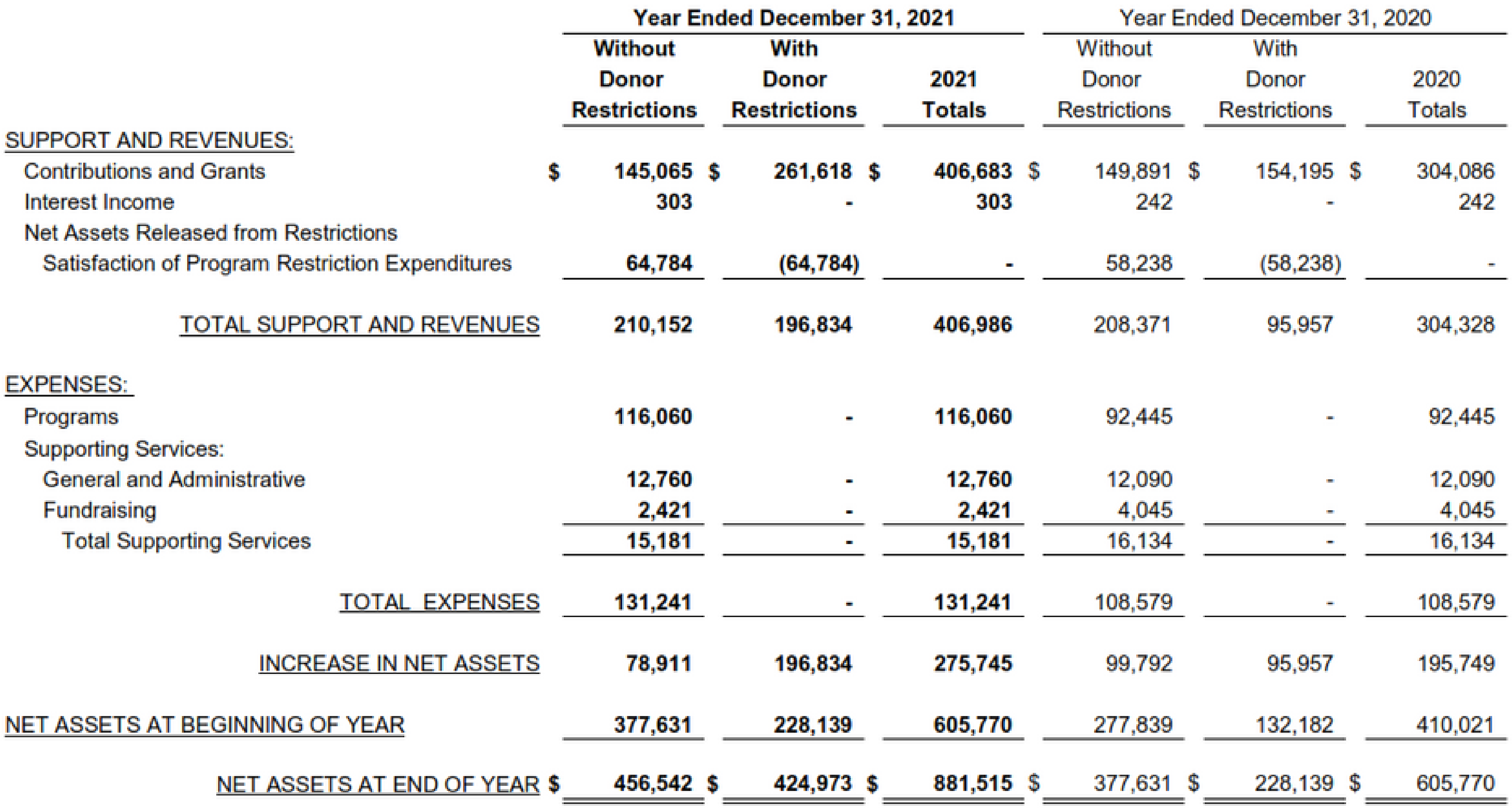


RAISING AWARENESS
"HOW TO EXPLAIN IH"

It is often difficult for people who have idiopathic hypersomnia to describe how profoundly it impacts their lives every single day. Working with our PAAC members, we created a “How do you describe IH to family and friends?" social media campaign to help people better understand IH and related sleep disorders. (March 2021)

2021 FINANCIALS

STATEMENT OF ACTIVITIES FOR
FISCAL YEAR ENDING DECEMBER 31, 2021



	Year Ended December 31, 2021			Year Ended December 31, 2020		
	Without Donor Restrictions	**With Donor Restrictions**	**2021 Totals**	Without Donor Restrictions	With Donor Restrictions	2020 Totals
SUPPORT AND REVENUES:						
Contributions and Grants	**$ 145,065**	**$ 261,618**	**$ 406,683**	$ 149,891	$ 154,195	$ 304,086
Interest Income	**303**	**-**	**303**	242	-	242
Net Assets Released from Restrictions						
Satisfaction of Program Restriction Expenditures	**64,784**	**(64,784)**	**-**	58,238	(58,238)	-
TOTAL SUPPORT AND REVENUES	**210,152**	**196,834**	**406,986**	208,371	95,957	304,328
EXPENSES:						
Programs	**116,060**	**-**	**116,060**	92,445	-	92,445
Supporting Services:						
General and Administrative	**12,760**	**-**	**12,760**	12,090	-	12,090
Fundraising	**2,421**	**-**	**2,421**	4,045	-	4,045
Total Supporting Services	**15,181**	**-**	**15,181**	16,134	-	16,134
TOTAL EXPENSES	**131,241**	**-**	**131,241**	108,579	-	108,579
INCREASE IN NET ASSETS	**78,911**	**196,834**	**275,745**	99,792	95,957	195,749
NET ASSETS AT BEGINNING OF YEAR	**377,631**	**228,139**	**605,770**	277,839	132,182	410,021
NET ASSETS AT END OF YEAR	**$ 456,542**	**$ 424,973**	**$ 881,515**	$ 377,631	$ 228,139	$ 605,770

2021 FINANCIALS

SCHEDULE OF FUNCTIONAL EXPENSES
FISCAL YEAR ENDING DECEMBER 31, 2021

	Year Ended December 31, 2021				Year Ended December 31, 2020			
	Program Services	**General and Administrative**	**Fundraising**	**Total 2021**	Program Services	General and Administrative	Fundraising	Total 2020
Employee compensation	**$ 38,772**	**$ 2,107**	**$ 1,264**	**$ 42,144**	$ 38,772	$ 2,107	$ 1,264	$ 42,144
Payroll tax and other	**3,266**	**178**	**107**	**3,550**	3,230	176	105	3,511
Office expenses	**124**	**11**	**-**	**135**	347	98	49	494
Conferences	**20,258**	**-**	**-**	**20,258**	6,307	-	-	6,307
Postage and delivery	**549**	**-**	**-**	**549**	1,067	119	-	1,186
Printing and reproduction	**996**	**255**	**-**	**1,251**	839	93	-	932
Insurance	**-**	**2,673**	**-**	**2,673**	-	1,406	-	1,406
Travel	**-**	**-**	**-**	**-**	133	-	-	133
Other professional fees	**12,805**	**-**	**-**	**12,805**	6,335	-	-	6,335
Legal, accounting and auditing	**-**	**5,650**	**-**	**5,650**	-	7,400	-	7,400
Registration fees	**521**	**-**	**-**	**521**	2,787	-	-	2,787
Dues and subscriptions	**2,185**	**1,380**	**-**	**3,565**	515	667	312	1,494
Other fees	**-**	**6**	**-**	**6**	-	24	-	24
Scholarship and grants	**25,000**	**-**	**-**	**25,000**	14,000	-	-	14,000
Marketing and outreach	**500**	**-**	**-**	**500**	527	-	-	527
Consulting	**4,500**	**500**	**-**	**5,000**	-	-	-	-
Website	**6,584**	**-**	**-**	**6,584**	16,200	-	2,314	18,514
Other program expense	**-**	**-**	**1,050**	**1,050**	1,385	-	-	1,385
	$ 116,060	**$ 12,760**	**$ 2,421**	**$ 131,241**	$ 92,445	$ 12,090	$ 4,045	$ 108,579

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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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.