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Improving the lives of people living with idiopathic hypersomnia and related sleep disorders through advocacy, education, awareness, and research

Biennial Report
2017/2018

Table of Contents

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OUR MISSION

To improve the lives of people with idiopathic hypersomnia and related disorders by advocating on their behalf, providing support, educating the public and healthcare professionals, raising awareness, and funding research into effective treatments, better diagnostic tools, and, ultimately, a cure for these debilitating conditions.

Message from the CEO

Diane Powell

This year the Hypersomnia Foundation marks its fifth anniversary! We are in the midst of an exciting period of growth, spurred on by the support of people with idiopathic hypersomnia (IH) and related sleep disorders, their families, our volunteers, and the sleep research community.

At our conference in Baltimore last June, I described HF as “small but mighty!” I am constantly in awe of our Board members and other volunteers, past and present, who have worked tirelessly to move the needle on awareness and research, and to support the IH community. Those with idiopathic hypersomnia have generously given us a lot of their precious wake time, and together we have accomplished so much.

Our Scientific and Medical Advisory Boards, chaired by Dr. David Rye and Dr. Lynn Marie Trotti, respectively, of Emory University, are comprised of world-class sleep physicians and researchers, and we are deeply grateful for their service. We are also very appreciative of the feedback and suggestions from our Patient Advisory and Advocacy Council (PAAC), which is comprised of volunteers (including people with IH and related sleep disorders, as well as their family members). We thank our corporate sponsors, whose generous support has allowed us to increase awareness of rare sleep disorders and expand our outreach worldwide. Last but not least, we thank our donors, whose loyal and generous support is the heart and soul of the Hypersomnia Foundation.

Indeed, our HF activities have multiplied so much that, for the first time, HF has hired a part-time Executive Director, Stephanie Wells, who joined us in September 2018. Her efforts and enthusiasm support the Hypersomnia Foundation’s day-to-day operations, allowing Board members to focus on long-term planning and future growth.

We are energized and excited as we look ahead to the future! This year, we plan to begin a series of single-day educational meetings around the country, giving more people the opportunity to meet one another and to hear from experts in the field. Our first-ever West Coast event is this June 29th in Seattle.

We also have accepted invitations to co-host a hypersomnias awareness event at the World Sleep Congress in Vancouver, and to present lectures and a patient panel at the conference of the Society of Behavioral Sleep Medicine in the U.S., both to be held in September 2019. In addition, we are reaching out to the professionals most likely to come in contact with sleepy people – such as family practitioners, school counselors and college health providers. By raising awareness of IH and related sleep disorders among these groups, we hope to shorten the time from first symptoms to a correct diagnosis, an all-too-common problem in our community.

We are proud to present this biennial report to share our accomplishments and to thank all of our supporters and donors who make our work possible. We hope to inspire you to be a part of our mission in whatever way you can, to help everyone get “Beyond Sleepy” so they can live fuller, more productive lives.

Diane

Diane Powell
April 2019

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 for which there are currently no FDA-approved treatments.

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 Medical Advisory Board of nine physicians, chaired by Dr. Lynn Marie Trotti, Associate Professor of Neurology at Emory University, and a Scientific Advisory Board of five researchers chaired by Dr. David Rye, Professor of Neurology at Emory University.

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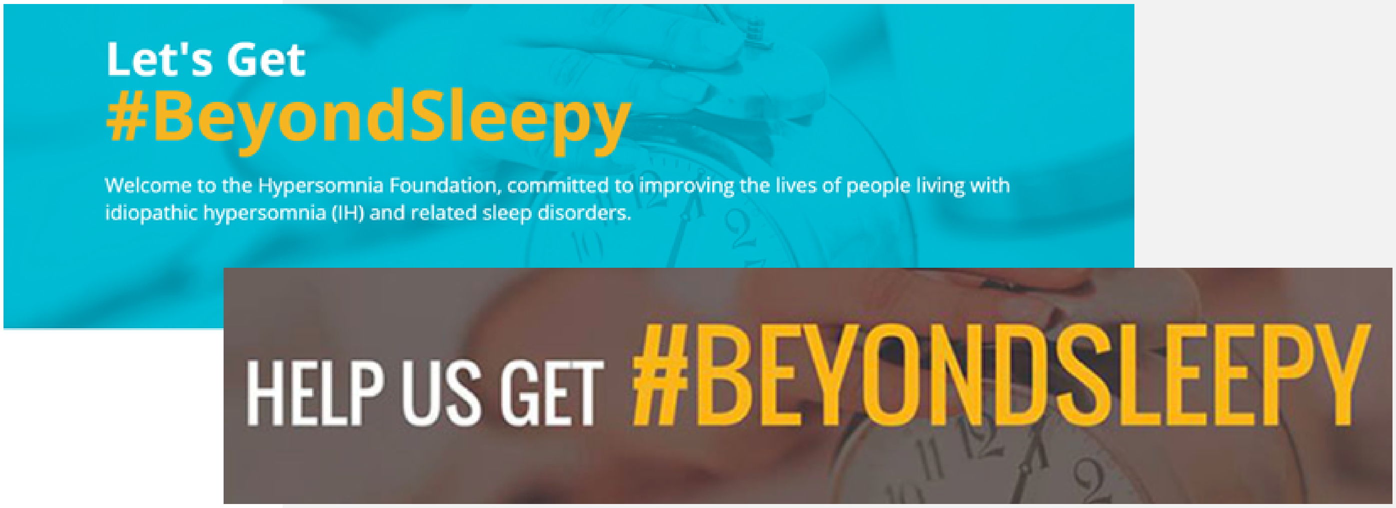
What We Do

The Hypersomnia Foundation's goals and objectives are:

- To increase community and physician awareness of idiopathic hypersomnia and the related disorders (hypersomnias).
- To provide a source of high quality, timely education and resources regarding idiopathic hypersomnia for people with sleep disorders, their supporters, and healthcare providers.
- To promote much-needed research into the causes and treatments of idiopathic hypersomnia, with a special focus on novel ideas with excellent potential for transforming the care of people with hypersomnias.
- To assist in translating new discoveries into improved outcomes and quality of life for people with hypersomnias.

Foundation Programs and Accomplishments

We adopted our slogan “**Let’s get #BeyondSleepy**” as a metaphor intended to provoke a discussion and consideration of the many ways idiopathic hypersomnia affects people. We strive to “get beyond” life-altering symptoms, “get beyond” excessive sleep and sleepiness, “get beyond” the stigma, “get beyond” the lack of understanding, “get beyond” misdiagnosis and the prolonged time for diagnosis, and “get beyond” off-label treatments.



Our monthly e-newsletter, ***SomnusNooze***, is filled with information of interest to the hypersomnia community, including summaries of scientific articles on evolving treatments, research and basic understanding, as well as personal journeys, 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 2,900 at year-end 2018.

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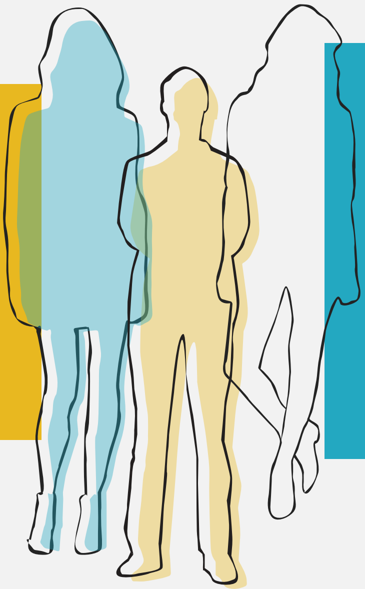
SOMNUSNOOZE

News, information, and research for the IH community

In 2017, we hosted our third conference. Focusing on "**Advocacy and Empowerment**," this multi-day event was held in Boston and provided the latest information on research, treatments, challenges, and issues facing people with idiopathic hypersomnia and related disorders. Seminars, workshops, and vendors provided information and resources for individuals with IH and related disorders, their supporters, physicians, and industry professionals. Sponsorship allowed us to reach a global audience through live streaming of our conference at no cost to viewers.

> *"It made me feel less alone. I got actual information that I can put to use in my life... I left feeling like I was being understood, people were doing things to help, and feeling more hopeful about my future."*
> *— 2017 Conference Attendee*



> *"There are very few times you can walk into a room and know that everyone there gets it, gets you, and is wholeheartedly accepting. That's how I felt at the meet and greet [social event] and conference. I also like learning about things relevant to my condition."*
> *— 2017 Conference Attendee*

We have created informational materials for individuals with idiopathic hypersomnia and healthcare professionals. Our website offers an **educational brochure** about IH and related disorders, a **handout of IH characteristics**, a **medical alert card**, an **anesthesia guide**, and **educational guides** for K-12 and college students who have IH. All of these materials can be downloaded and printed, free of charge.

Hypersomnia Registry

Research Award Program

EMERGENCY MEDICAL INFORMATION

Idiopathic hypersomnia (IH) is a neurological disorder characterized by excessive daytime sleepiness (often with associated cognitive dysfunction), despite getting a full night's sleep. People with IH may also experience

Other Information:

EMERGENCY MEDICAL INFORMATION

I have a rare disorder called idiopathic hypersomnia (IH)

My name:

Emergency Contact:

Emergency Phone #: Contact:

Doctor:

Medical Conditions:

Medication(s):

Allergies:

Blood Type: Organ Donor: _Y _N

"Idiopathic hypersomnia feels like going under general anesthesia. It's like being drugged. No matter how much sleep I get, I'm always desperately wanting more sleep, yet hating it with a passion."

What is Hypersomnia?

About Us

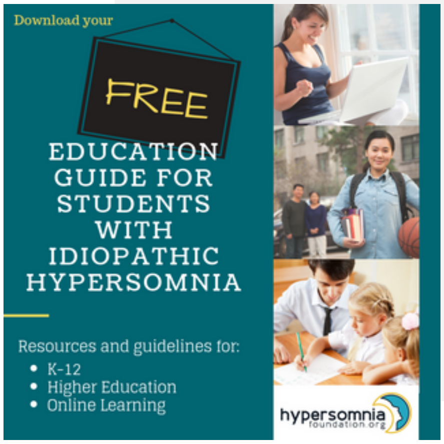
Do you sleep too much or have difficulty waking up or staying awake?

It Could Be Idiopathic Hypersomnia (IH)

IH is a chronic and often debilitating neurologic disorder

To better understand symptoms, treatments, and the diagnostic journey of individuals with hypersomnia disorders, we partnered with CoRDS (Coordination of Rare Diseases at Sanford) on an international patient registry specific to the variations of hypersomnia. After two years of development and essential support from the Foundation's Medical and Scientific Advisory Boards, the **Hypersomnia Foundation's Registry at CoRDS** was launched. As of March 2019, over 1,600 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 solve this complicated puzzle of rare sleep disorders.

From its inception, the Hypersomnia Foundation (HF) 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). This volunteer advisory group meets monthly by conference call and serves as a liaison between the hypersomnia community and the Board. The PAAC helps to ensure that the Board has a deep understanding of the concerns and needs of the hypersomnia community and how the Foundation's website, communications, and initiatives impact that community. In its advisory capacity, 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.


Download your

FREE

EDUCATION GUIDE FOR STUDENTS WITH IDIOPATHIC HYPERSOMNIA

Resources and guidelines for:
- K-12
- Higher Education
- Online Learning

Addressing the unmet educational needs of students with IH, the Hypersomnia Foundation developed a series of educational guides for students, families, and school administrators. The "**Education Essentials for Students with Idiopathic Hypersomnia**" provides information, direction, and support for students in K-12 and Higher Education.

2017 Highlights

February – **Rare Disease Day** – Research brings hope to people living with rare diseases. We supported a call to action throughout the hypersomnia community to register with CoRDS in order to better understand rare sleep disorders and the importance of research.

March – **World Sleep Day** – The Hypersomnia Foundation became a delegate for World Sleep Day by promoting hypersomnia awareness by means of a comparative analysis review of a scientific paper that discussed differences between narcolepsy type 1 (with cataplexy), narcolepsy type 2 (without cataplexy), and idiopathic hypersomnia. We created a table, which is now used globally, that sets forth, in layman's terms, this analysis.

April – **Sleep Awareness Week** – Hypersomnia Foundation Board Member Catherine Page-Rye was a guest on TopDocs Radio for a live radio broadcast discussing idiopathic hypersomnia – from diagnosis to treatment.

June – The Hypersomnia Foundation hosted its **#BeyondSleepy Conference** in Boston, built around the theme of empowerment for people with IH and related disorders.

July – HF released a list of standard **IH Characteristics**, vetted by our Medical Advisory Board, which is now used as a general reference, including by the NIH (https://rarediseases.info.nih.gov/diseases/8737/idiopathic-hypersomnia).

October – The Hypersomnia Foundation hosted an exhibit booth at the **World Sleep Congress** in Prague, Czech Republic. Attended by world clinical and scientific sleep medicine experts, this international conference provided an opportunity for the Foundation to promote idiopathic hypersomnia and its CoRDS hypersomnia registry.

December – Hypersomnia Foundation Board member, Catherine Page-Rye, and Medical Advisory Board Chair, Dr. Lynn Marie Trotti, were featured in a **Self Magazine** article on idiopathic hypersomnia, in which they described what it is like to live with this rare and debilitating disorder.

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2018 Highlights

January - **HypersomniaFoundation.org** – With the support from a grant from Trip Advisor, we formally launched our new website, a continually updated and comprehensive site providing the latest research updates, resources, a healthcare provider directory, medical terminology reference guide, and links to free education and support materials.

March – **Research Award Program** – The Hypersomnia Foundation launched a program to award idiopathic hypersomnia research funding to medical students, physician residents and fellows, postdoctoral fellows and other researchers.

April – The Hypersomnia Foundation received a grant from **Jazz Pharmaceuticals** to support its primary outreach, education, and awareness programs.

May – **Project Sleep's Jack and Julie Scholarship Program** – The Hypersomnia Foundation, in partnership with this scholarship program founded and administered by Project Sleep (a narcolepsy patient advocacy organization), provided funding for a scholarship awarded to a college-bound high school student diagnosed with IH.

June – The Hypersomnia Foundation hosted "**The Way Forward: #BeyondSleepy in Baltimore**," a conference to provide updated, timely, and quality information to people with IH and related disorders, their supporters, and healthcare professionals.

August – The Hypersomnia Foundation developed a **Medical Alert ID Card**, specifically for people with IH and available free of charge through our website. This ID card can also be distributed in medical practices, support groups, or health fairs, to help ensure that everyone with IH is prepared for an emergency situation.

September – With guidance from our Medical and Scientific Advisory Boards, we designed a free **Anesthesia Guide** that addresses anesthesia issues that may arise when a person with IH is facing surgery. Developed to be shared with a patient's medical team, the guide focuses on the anesthesia-related issues that must be considered before, during, and after a surgical procedure for someone with IH.

September – Researchers and patient advocacy groups, including the Hypersomnia Foundation, were invited to participate in the **7th International Symposium** on Narcolepsy in Massachusetts. The Hypersomnia Foundation was well represented by Drs. Rye, Trotti, Arnulf, Maski, and Ruoff; and Board Members Catherine Page-Rye and Mary King. Our representatives shared their latest research findings and patient advocacy initiatives which were summarized in *SomnusNooze:* https://www.hypersomniafoundation.org/7th-international-narcolepsy-symposium-includes-ih-part-1-of-2.

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CONFERENCE HIGHLIGHTS

In June 2018, the Hypersomnia Foundation hosted **The Way Forward: #BeyondSleepy** in Baltimore, a conference that provided updated, timely, and quality information to people with IH and related disorders, their supporters, pharmaceutical companies, and healthcare professionals.

Presentations covered the following topics:

- An overview of the current status of research and treatments by Dr. David Rye and Dr. Lynn Marie Trotti
- An explanation of how CoRDS collects data to be accessed by researchers, while carefully protecting privacy, by a senior research associate from CoRDS and an analysis of data from the international CoRDS registry by Dr. Trotti
- An interactive session discussing how patient data influence the design of clinical trials and how patients can best engage with the clinical trial process
- A panel discussion about patient engagement in the development process of new research and treatments, with questions drawn from attendees
- Information about preparation for, and seeking, long-term disability insurance coverage
- Ground-breaking research that included: 1) Women's issues (birth control, pregnancy, breastfeeding, and menopause) when diagnosed with IH; 2) Current understanding of how GABA(A) receptors differ in patients with IH; 3) Biomarkers that distinguish IH from narcolepsy; 4) Anesthesia concerns for people with IH when anticipating surgery
- Also, three group breakout sessions were offered separately for 1) people with IH and related disorders, 2) supporters, and 3) college-age students. Each session allowed time for discussion of the unique issues and challenges of its particular attendees.

Message from the Treasurer

Catherine Page-Rye

I am pleased to provide the statement of activities and financial position of the Hypersomnia Foundation (HF) for the fiscal years ending December 31, 2017 and December 31, 2018.

The Hypersomnia Foundation is fortunate to have generous donors who provide ongoing support for our programs, helping ensure the successful achievement of our mission and goals. Their generosity has placed the Foundation in a strong financial position to invest in the important work of increasing awareness of idiopathic hypersomnia in both the public arena and the medical community, through outreach, education, awareness, and research. The careful stewardship of funds has allowed us to actively participate in nationwide sleep conferences and educational events, sponsor an international hypersomnia-specific patient registry, whose data is accessible to researchers, and provide individuals, their families and supporters with free educational and other support materials. We have also launched a research award program, and we are hopeful that these awards will help unlock the mysteries of IH and pave the way for research that will discover optimal treatments.

During these past two years, the Hypersomnia Foundation was pleased to have received 1) a grant to restructure our website and social media outreach, 2) donations specifically to build our administrative infrastructure, which included hiring a part-time Administrative Assistant and Executive Director, and 3) sponsorships to help support the Hypersomnia Foundation's conferences.

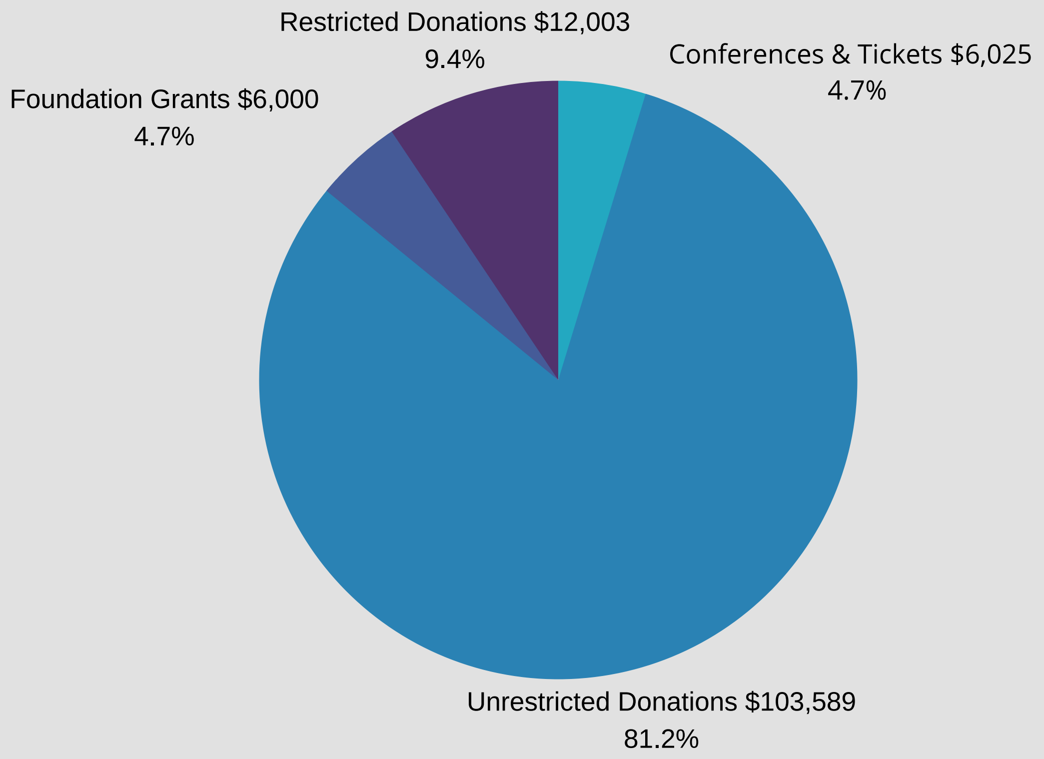
Moving forward, with the continued commitment of our donors, grant givers and sponsors, as well as with the vision and expertise of our Medical and Scientific Advisory Boards, and the energy and leadership of our Board of Directors, we are excited to make the necessary investments to fulfill our Foundation's mission and goals.

With heartfelt appreciation to all our donors, volunteers, staff, and researchers,

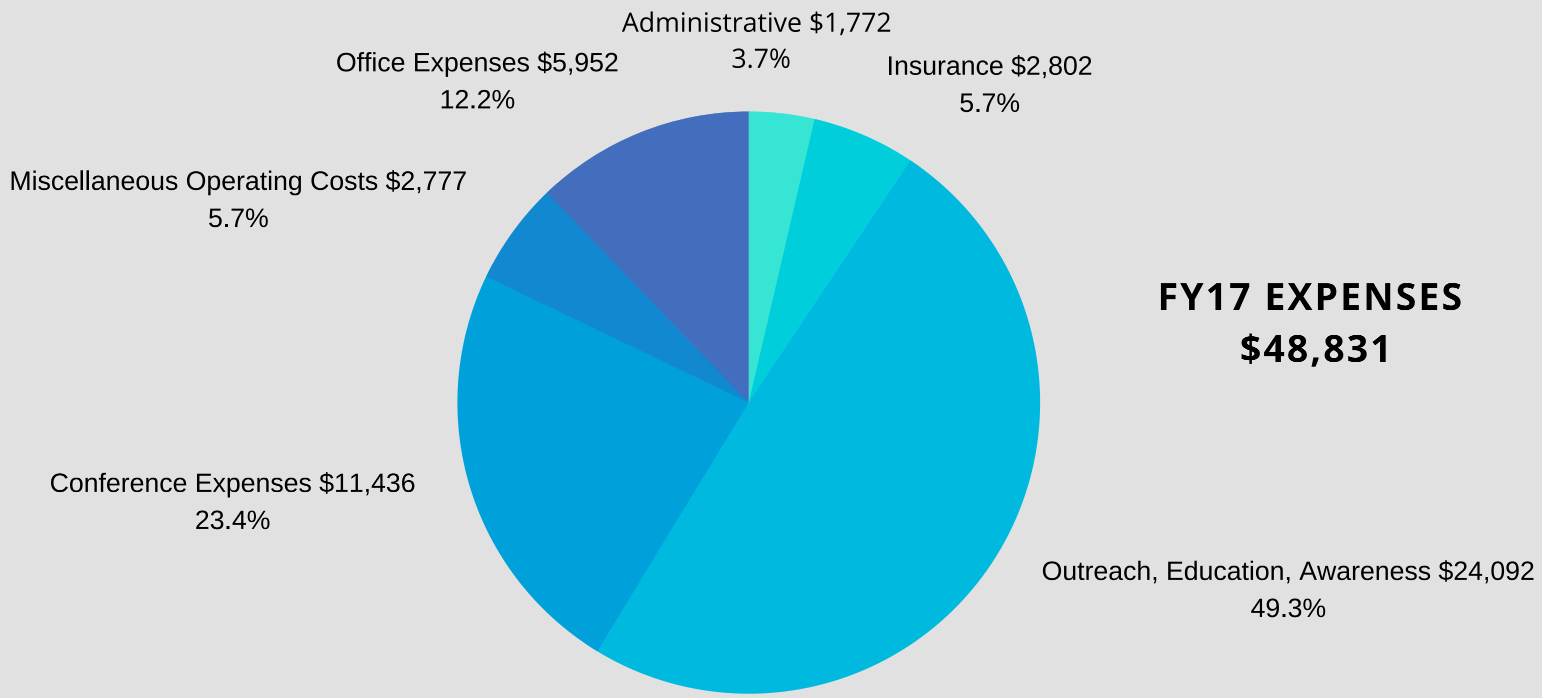
Catherine

Cat Page-Rye

2017 FINANCIAL SUMMARY



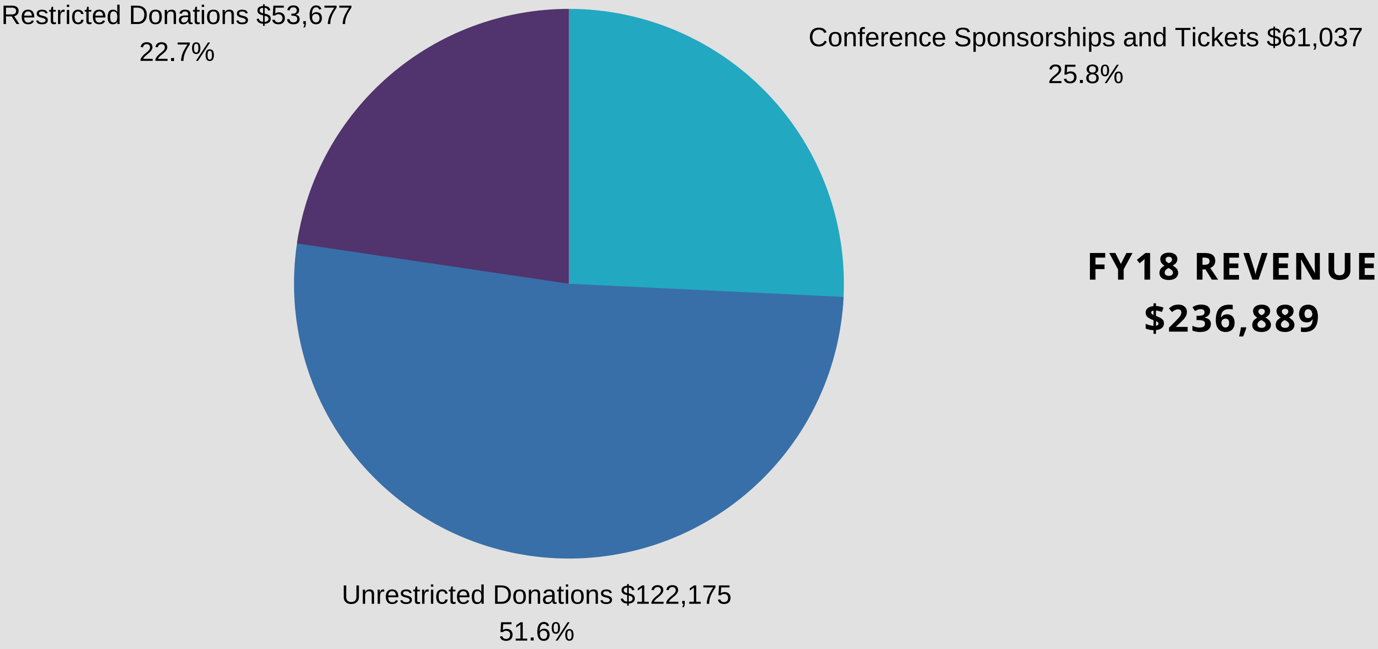
FY17 REVENUE
$127,617



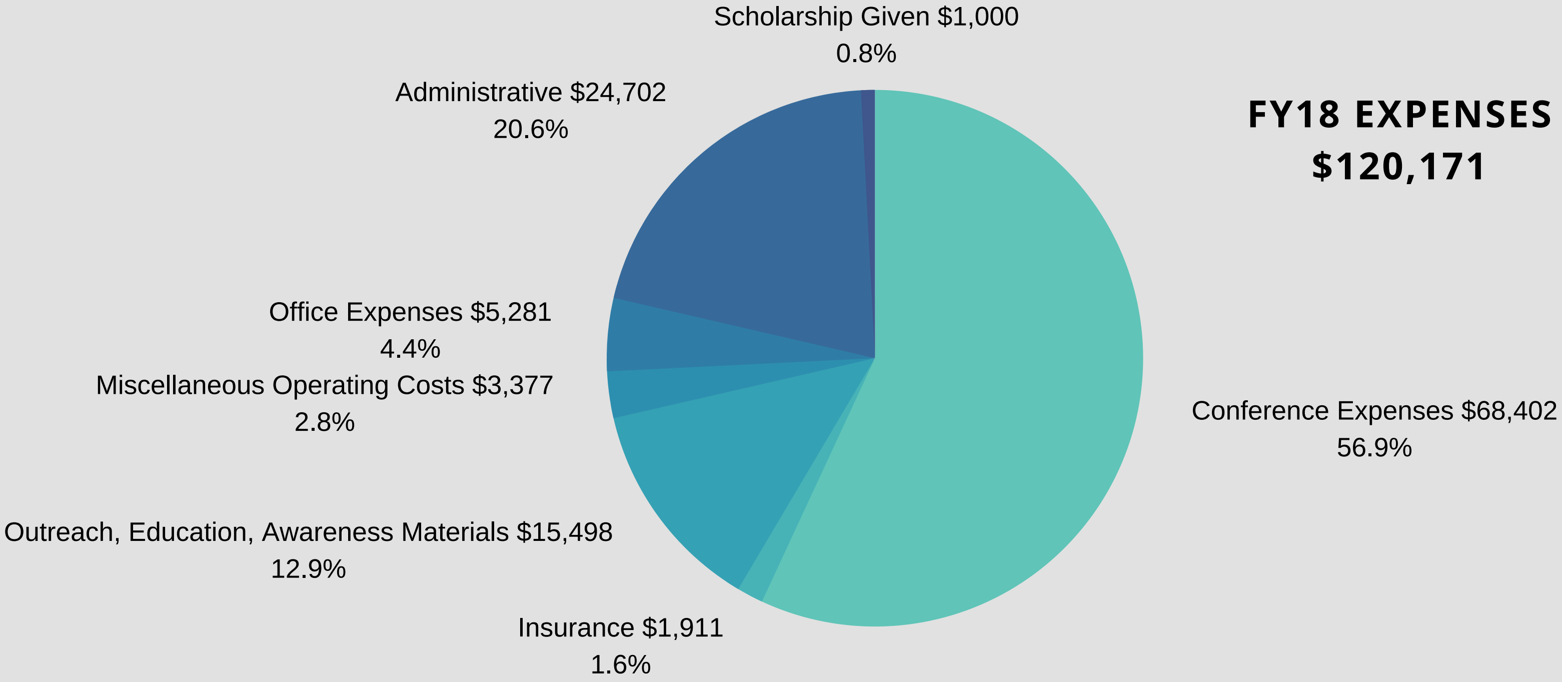
FY17 EXPENSES
$48,831

TOTAL NET REVENUE $78,786

2018 FINANCIAL SUMMARY



FY18 REVENUE
$236,889



FY18 EXPENSES
$120,171

TOTAL NET REVENUE $116,718

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STATEMENT OF ACTIVITIES FISCAL YEARS 2017 AND 2018

Revenue	**FY18**	**FY17**
UNRESTRICTED		
Conference Sponsorships and Tickets	$61,037	$6,025
Donations	$122,175	$103,589
Foundation Grants	$0	$6,000
Total Unrestricted	**$183,212**	**$115,614**
RESTRICTED		
Donations	$53,677	$12,003
Total Restricted	**$53,677**	**$12,003**
Total Revenue	**$236,889**	**$127,617**
Expenses		
UNRESTRICTED EXPENSES		
Administrative	$24,702	$1,772
Insurance	$1,911	$2,802
Outreach, Education, Awareness Materials		
Website, Newsletter, Videos, Handouts	$15,498	$24,092
Conference Expenses	$68,402	$11,436
Miscellaneous Operating Costs	$3,377	$2,777
Office Expenses	$5,281	$5,952
Scholarship Given	$1,000	$0
Total Expenses	**$120,171**	**$48,831**
Change in Net Assets	**$116,718**	**$78,786**

BOARD OF DIRECTORS 2019

Diane Powell
CEO/Chair

Catherine Page-Rye
CFO/Treasurer

Elizabeth Ashcraft
Secretary

Sarah Beazley

Amy Desmarais

Michelle A. Emrich, MD

Mary A. King, EdD

Lisa Laribee, MA

Board of Directors 2017
Diane Powell, CEO/Chair
Cat Page-Rye, Treasurer
Celia King, MPS, Secretary
Elizabeth Ashcraft
Michelle A. Emrich, MD
Amy Haraden (Desmarais)
Mary King, EdD

Board of Directors 2018
Diane Powell, CEO/Chair
Cat Page-Rye, Treasurer
Elizabeth Ashcraft, Secretary
Celia King, MPS
Michelle A. Emrich, MD
Amy Haraden (Desmarais)
Mary King, EdD

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MEDICAL ADVISORY BOARD

Lynn Marie Trotti, MD, MSc – Advisory Board Chair
Dr. Trotti is Associate Professor of Neurology at Emory University in Atlanta, GA. She graduated from Baylor College of Medicine and completed her neurology residency, sleep fellowship, and Masters of Science in Clinical Research at Emory. Dr. Trotti's main area of research interest is the central disorders of hypersomnolence. She has completed two randomized controlled trials testing novel treatments for hypersomnolence and is currently funded by the NIH through a K23 grant to evaluate functional neuroimaging correlates of sleepiness and sleep inertia.

Isabelle Arnulf, MD, PhD
Having authored more than 150 publications in peer-reviewed scientific journals, Dr. Arnulf is one of the world's leading experts on all forms of hypersomnia, including narcolepsy, idiopathic hypersomnia, and Kleine-Levin syndrome.
She is also Professor of Neurology at the Sorbonne Universités, Pierre and Marie Curie University, and head of the Sleep Disorder Service at the Pitié-Salpêtrière University Hospital in Paris, France. Dr. Arnulf trained with Dr. Michel Jouvet, who studied the function and mechanism of REM sleep soon after its discovery, and completed a postdoctoral fellowship with Dr. Emmanuel Mignot at Stanford University. Dr. Arnulf is the past-president of the French Sleep Society.

Thanh Dang-Vu, MD, PhD
Dr. Dang-Vu is Associate Professor at Concordia University in Montreal, where he currently holds the University Research Chair in Sleep, Neuroimaging and Cognitive Health. He is also an attending neurologist and the Associate Director for Clinical Research at the Institut Universitaire de Gériatrie de Montréal, a Clinical Assistant Professor of Neuroscience at the University of Montreal, and an Adjunct Professor of Neurology and Neurosurgery at McGill University.
Dr. Dang-Vu received his MD and PhD from the Université de Liège in Belgium, and completed post-doctoral fellowships in the Department of Neurology at the Massachusetts General Hospital and Harvard Medical School, as well as at the Center for Advanced Research in Sleep Medicine at the Université de Montreal. His research is focused, in part, on the pathophysiology of sleep disorders using multimodal neuroimaging and EEG, including his team's 2017 brain imaging study, which found that participants with IH showed regional cerebral blood flow differences compared to participants without IH.

Ana Krieger, MD
Dr. Krieger is Associate Professor of Clinical Medicine in the Departments of Medicine, Neurology, and Genetic Medicine at Weill Cornell Medical College. She is board certified in sleep medicine and the Medical Director of the Weill Cornell Center for Sleep Medicine. Dr. Krieger also holds board certification in internal medicine and pulmonary medicine, and is a faculty member in the Division of Pulmonary and Critical Care Medicine, Department of Medicine, at Weill Cornell Medical College and an Associate Attending at the New York Presbyterian Hospital/Weill Cornell Medical Center and at Rockefeller University Hospital. Over the past 17 years, Dr. Krieger has been actively involved in clinical care and education, training sleep specialists, and conducting collaborative multidisciplinary research projects in sleep medicine. Dr. Krieger is a Robert Wood Johnson Scholar, a Fellow of the Royal Society of Medicine, and a Fellow and Policy Advisor at the New York Academy of Medicine.

Kiran Maski, MD, MPH
Dr. Maski is an assistant professor at Harvard Medical School and a child neurologist and sleep medicine specialist at Boston Children's Hospital. She received her medical degree from the University of Wisconsin, completed her general pediatric residency at Tufts-New England Medical Center, and received her pediatric neurology residency and pediatric sleep fellowship training at Boston Children's Hospital (BCH). She now runs the Neurology Sleep Clinic at BCH and is the assistant program director for the Child Neurology Residency. Dr. Maski's clinical work and research is focused on pediatric narcolepsy. Dr. Maski has created a hypersomnia clinic at BCH where she sees children and young adults with central nervous system hypersomnia conditions from all over the world. Dr. Maski currently serves as the Chairperson of the American Academy of Sleep Medicine Task Force for the Treatment of Central Nervous System Hypersomnias.

Jason Ong, PhD
Dr. Ong is an Associate Professor of Neurology at Northwestern University Feinberg School of Medicine. He received his PhD in clinical psychology from Virginia Commonwealth University and completed a fellowship in Behavioral Sleep Medicine at Stanford University Medical Center. His primary research interest involves demonstrating the effectiveness and value of behavioral treatments for sleep disorders, including cognitive-behavioral therapy and mindfulness meditation. Specifically, Dr. Ong is interested in the psychosocial impact of hypersomnia, and his lab has been developing an intervention to aid in coping with chronic hypersomnia. Additional research interests include the impact of sleep disturbance on chronic health conditions. His clinical interest is aimed at delivering empirically supported behavioral treatments to patients with sleep disorders, which complements and informs his clinical research. Dr. Ong is also the immediate past-president of the Society for Behavioral Sleep Medicine.

MEDICAL ADVISORY BOARD *continued....*

David Plante, MD
Dr. Plante is Assistant Professor of Psychiatry at the University of Wisconsin School of Medicine and Public Health. He is a Fellow of the American Academy of Sleep Medicine, member of the Sleep Research Society, and Program Director for the University of Wisconsin Sleep Medicine Fellowship. His current research uses high-density electroencephalography to study sleep and wakefulness in hypersomnia and affective disorders.

Chad Ruoff, MD
Dr. Ruoff is an Adjunct Clinical Assistant Professor at the Stanford Center for Sleep Sciences and Medicine. He is board certified in sleep medicine, obesity medicine, and internal medicine, and he is a Sleep and Obesity Medicine Associate at Southern California Permanente Medical Group. Dr. Ruoff's career in sleep medicine began as a sleep technologist in 1998, while completing his undergraduate education at Georgetown University. He received his internal medicine training at Baylor College of Medicine and then completed a sleep medicine fellowship at Stanford University in 2011, after which he joined the Stanford sleep faculty. He has developed a strong interest in the clinical evaluation and treatment of CNS hypersomnias.

Mandeep Singh, MBBS, MD, MSc, FRCPC
Dr. Singh completed his Anesthesiology training at the University of Toronto, and later completed his Sleep Medicine fellowship training at the University of Toronto. He has the distinction of being the first Canadian physician to be dual-specialized in Sleep Medicine and Anesthesiology. He also completed a Masters in Clinical Epidemiology and Health Sciences Research from the University of Toronto. His current research interests include evaluating the perioperative (before and after surgery) outcomes in patients with sleep disorders, including disorders of daytime hypersomnolence. Dr. Singh is one of the authors of an article published last year about the anesthesia concerns for patients with idiopathic hypersomnia (IH) who are considering surgery.

SCIENTIFIC ADVISORY BOARD

David Rye, MD, PhD - Advisory Board Chair
Dr. Rye is Professor of Neurology at Emory University, board certified in Neurology and Sleep Medicine. He has received the American Academy of Neurology's Sleep Science Award and the Sleep Research Society's Outstanding Scientific Achievement Award for the discovery of the genetic contributions of restless legs syndrome. He has also received Narcolepsy Network's Researcher of the Year Award, which recognizes the Emory team's more recent contribution to our understanding of the origins of and treatments for hypersomnia. He and the Emory team are making new discoveries into the origins and treatments of hypersomnia that are transforming the way medicine is practiced.

Dale M. Edgar, PhD
During his 15 years at Stanford University's School of Medicine, Dr. Edgar achieved international recognition as a leader in discovering how the brain and its chemistry modulate sleep/wake and bodily rhythms. In 2000, Dr. Edgar co-founded Hypnion, Inc. — a spin-out of the unique technologies that he developed at Stanford. At Hypnion, he led preclinical and clinical research teams tasked with developing novel medicines to treat insomnia and disorders of excessive sleepiness. In 2007, Dr. Edgar became Chief Scientific Leader of Discovery Sleep Research at Lilly, focusing on innovative medicines for sleep disorders and sleep-related comorbidities in psychiatry, pain, neurodegenerative disease, and metabolic disease. Dr. Edgar is now co-founder and senior vice president of research at Novion Pharmaceuticals, a start-up neuroscience biotechnology company focused on the discovery and development of novel treatments for sleep disorders.

Professor Nicholas Franks, FRSB, FRCA, FMedSci, FRS
As Professor of Biophysics & Anaesthetics at London's Imperial College, Prof. Nicholas Franks has sought to understand how general anesthetic agents work at the molecular, cellular, and, most recently, neuronal network levels. Almost 40 years ago, he asked, "Where do general anaesthetics act?" and since then has been pursuing the answer through funded studies in his laboratory. Along the way, he expanded his research to better understand the relationships among anesthesia, consciousness, and sleep and answered the question, "Do sedatives engage natural sleep pathways?" Prof. Franks recently identified the exact binding location of propofol to the GABA-A receptor. In 2007, he was elected Fellow of the Royal College of Anaesthetists and, in 2011, Fellow of the Royal Society. He has been awarded the Ebert Prize of the American Pharmaceutical Association, the Gold Medal of the Royal College of Anaesthetists, and the Excellence in Research Award from the American Society of Anesthesiologists.

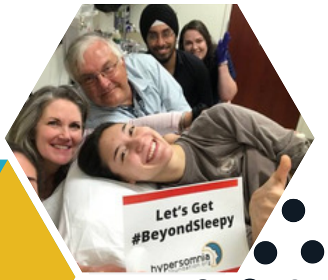
SCIENTIFIC ADVISORY BOARD *continued....*

Jeff Gulcher, MD, PhD

Jeff Gulcher, MD, PhD, is Chief Scientific Officer for WuXi NextCODE. Previously he was Chief Scientific Officer and co-founder of deCODE Genetics. Dr. Gulcher was on staff in the Department of Neurology at Beth Israel Hospital and Harvard Medical School from 1993 to 1998. He received his PhD and MD from the University of Chicago in 1990 and completed his neurology residency at Brigham and Women's Hospital and Beth Israel Hospital of Harvard Medical School in 1996. He received a Bachelor's Degree in Chemistry/Physics from Michigan State University in 1981. He has co-authored 198 peer-reviewed publications on the genetics of common/complex diseases.

James M. Krueger, PhD

Dr. Krueger is Regents Professor of Neuroscience in the Elson S. Floyd College of Medicine at Washington State University. Awards include election to the Washington State Academy of Sciences, Doctorem Medicinae Honoris Causa from the University of Szeged, the Distinguished Scientist Award from the Sleep Research Society, and the Senator Jacob Javits Award in the Neurosciences from the NIH. Dr. Krueger's research, funded by the NIH for nearly three decades, is focused on the biochemical regulation of sleep, molecular mechanisms responsible for the effects of infectious diseases and inflammation on sleep, sleep function, and brain organization of the initiation of sleep. His 350 peer-reviewed publications cover the gamut from sleep function to sleep and cytokines, and to physiological markers of localized sleep. His latest research documents his theoretical predictions that sleep originates in small neural networks, discoveries that open the door to a deeper appreciation of the genetic, molecular, and electrical aspects of sleep disorders.



LOOKING FORWARD

We will continue to:

- increase our outreach, education, awareness, and advocacy efforts to improve the quality of life for people with IH and related sleep disorders
- 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 sleep disorder community

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