



ANNUAL REPORT 2019








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Message from the CEO

Diane Powell

As I write this, we are still in the midst of the Covid-19 pandemic. Much of the country is closed down, and the Hypersomnia Foundation's conference, planned for June in Philadelphia, has been cancelled.

Sadly, some nonprofits will not survive the shutdown, but I can assure you that the Hypersomnia Foundation is strong. We have always worked virtually, and mostly relied on volunteers, so we have very few fixed costs. We also have - always! - been careful stewards of the funds entrusted to us by our donors, as you will see in this report.

I hope you will be heartened and encouraged, as you look through these pages, to see that 2019 was an incredible year of exciting momentum towards greater awareness, more research, and increased clinical trials for new treatments of idiopathic hypersomnia and related rare sleep disorders.

While it is true that some of that work has been temporarily paused due to the pandemic, the HF Board continues to plan for a dynamic future. We will adapt to the new normal, whatever that is, and press forward on behalf of our community.

Wishing you and your families all the best,



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.

hypersomnia
foundation.org



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.

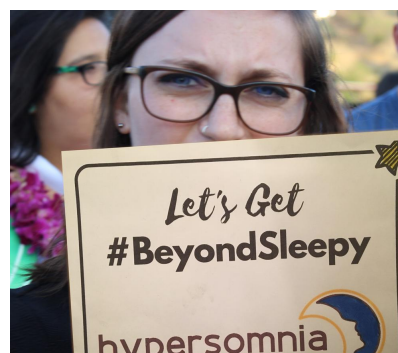
The Hypersomnia Foundation is managed by an active, all-volunteer Board of Directors, a Medical Advisory Board of nine physicians, chaired by Dr. Lynn Marie Trotti, Associate Professor of Neurology at Emory University, and a Scientific Advisory Board of five researchers chaired by Dr. David Rye, Professor of Neurology at Emory University.

Foundation Programs and Accomplishments



Our slogan “**Let’s get #BeyondSleepy,**” is 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.

We encourage spreading awareness of IH and the Hypersomnia Foundation by asking people to send us pictures with our "Let's Get #BeyondSleepy" sign while doing activities they would do more often if they could live their life #BeyondSleepy.



SOMNUSNOOZE

News, information, and research for the IH community.

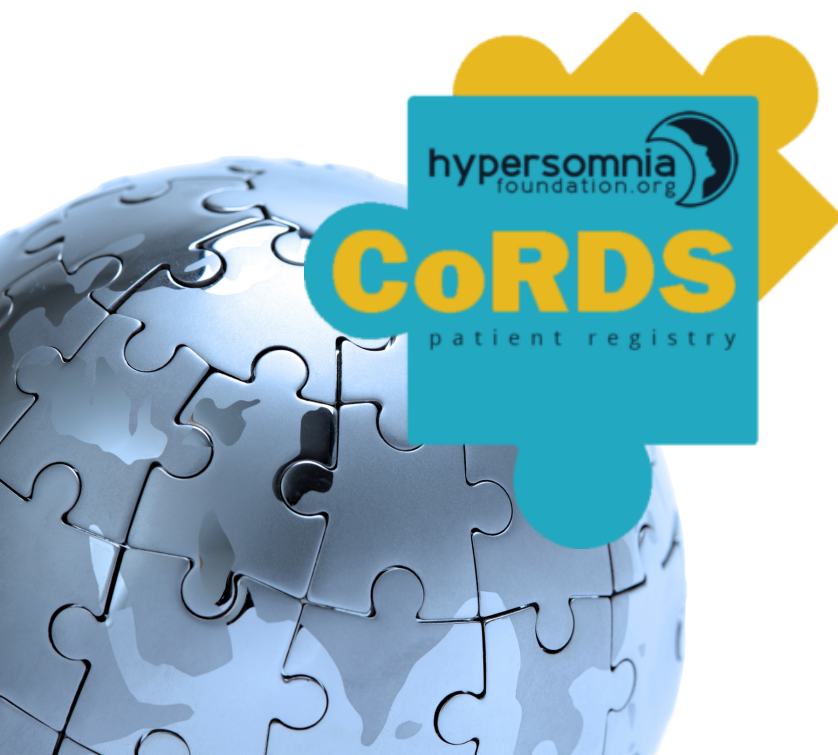


Our e-newsletter, **SomnusNooze**, is filled with information of interest to the hypersomnia community, including summaries of scientific articles on evolving treatments, research and basic understanding, as well as personal journeys, information about recruiting for clinical trials and registries, disability and strategies for coping, and support for caregivers. Our email subscribers have grown from 114 in 2014 to over 3,350 at year end 2019.

In 2019, we hosted two **outreach and awareness events** - one in Chicago and the other in Seattle, our first event on the West Coast. Over 125 people attended each educational event that included a day of presentations from leading sleep researchers and physicians, clinical trial updates, and advocacy opportunities. We also hosted casual "Meet and Greet" evening events encouraging networking for our attendees and speakers.



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.



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 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 **CoRDS Patient Registry** was launched. As of December 2019, over 2,000 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.

This past year we introduced our new initiative, **Advancing the Front Line**, raising awareness of hypersomnias among those who are most likely to come in contact with sleepy people. Our goal? To shorten the time between a sleepy person's first symptoms and a correct diagnosis.

As part of this initiative, we created our **"HINT" test** - a quick four-question screening test, to help school professionals, primary care providers, and others identify people who might have a sleep disorder and may need to see a sleep medicine expert for further evaluation.



We also developed a patient resource brochure, **Self-Advocacy Tips for People with Idiopathic Hypersomnia and Related Disorders**, that provides resources, tips, and ideas on how to effectively advocate for the needs of those with rare sleep disorders.

The "HINT" test and Self-Advocacy brochure are part of our series of free, downloadable materials available on our website, which include 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.

2019 Highlights

In 2019, the Hypersomnia Foundation was able to attend multiple conferences, spreading awareness and educating others about idiopathic hypersomnia and related sleep disorders. This was due to the generosity of donors and the following sponsors: Balance Therapeutics, Jazz Pharmaceuticals, Oppenheimer Investments, Pavilion Compounding Pharmacy, and Village Pharmacy at Lynnfield.



JANUARY – The Hypersomnia Foundation started 2019 celebrating our 5-year Anniversary! We are grateful to our founders who came together with a common goal to establish a non-profit organization dedicated to advocate, educate, and provide research and resources on behalf of people affected by idiopathic hypersomnia and related disorders.

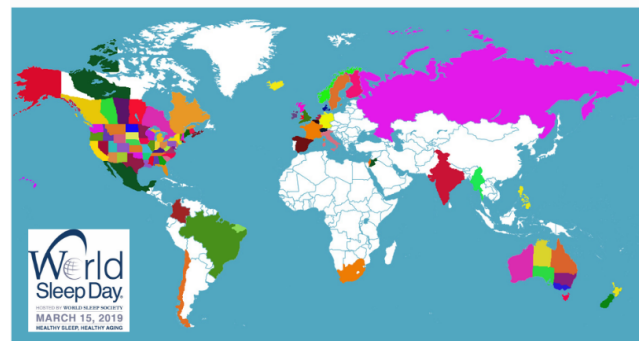
JANUARY - Diane Powell, Hypersomnia Foundation CEO/Chair and Dr. Lynn Marie Trotti, Hypersomnia Foundation Medical Advisory Board Chair, discussed the importance of our CoRDS Patient Registry Program in a podcast hosted by the Coordination of Rare Diseases at Sanford.



FEBRUARY – Dr. David Rye, Hypersomnia Foundation Scientific Advisory Board Chair, was featured on the television series “Your Fantastic Mind”. The episode interviewed people sharing their stories about living with idiopathic hypersomnia and discussed the latest research and potential treatments with Dr. Rye.

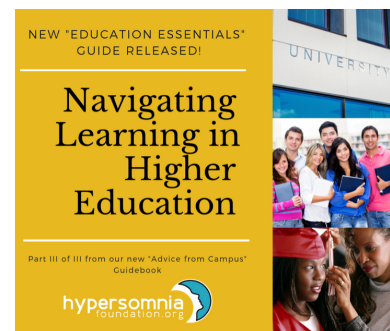
MARCH – The Hypersomnia Foundation recognized World Sleep Day® on March 15 by asking those suffering from idiopathic hypersomnia (IH) to tell us their location and help us track the need for worldwide IH support. By spreading global awareness, we hope researchers and pharmaceutical companies will structure their studies and demonstrate to legislators, in the United States and throughout the world, that the challenge of living with IH is global.

WHERE IN THE WORLD ARE PEOPLE WITH IH?
WE ARE EVERYWHERE!
hypersomnia
foundation.org



Celebrate World Sleep Day® by helping us raise #GlobalAwareness of idiopathic hypersomnia. Tell us where you are and we'll fill in the map! We want the world to know it's time to **Get #BeyondSleepy!**

MARCH / APRIL – We released three newly developed sections from our “Advice from Campus Guide” – part of our “Education Essentials” series for students with IH and their families. “Navigating Counseling Services on Campus” introduces the reader to Campus Counseling Centers explaining what they are and how they can be of help. “Navigating the Admissions Office”, written by a college admissions professional with IH, provides prospective students with a guide through the admissions process. “Navigating Learning in Higher Education”, written by a college professor with IH, provides advice about how to learn and manage homework assignments, what to tell their professors, what to do in class, and what to do outside of class when it comes to reading, writing, and studying.



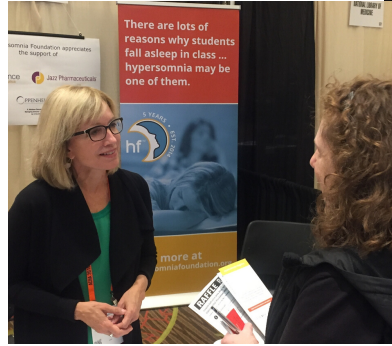
APRIL – The Hypersomnia Foundation was featured in two episodes of Wake Up Narcolepsy's podcast "Narcolepsy 360" which focused on idiopathic hypersomnia (IH). Betsy Ashcraft, Hypersomnia Foundation Board member, shared her journey as a parent of a child with IH and the challenges she faced trying to get a correct diagnosis for her son. Dr. David Rye, Hypersomnia Foundation Scientific Advisory Board Chair, discussed IH and its potential relation to type 2 narcolepsy and an update on current treatments.

APRIL - Thanks to generous donations, we were able to release the first in a series of videos from our 2018 Baltimore Conference. Hypersomnia Foundation Medical Advisory Board member Dr. Isabelle Arnulf presented “Women and Hypersomnia”, discussing the decisions women with sleep disorders must make about contraception, pregnancy, breastfeeding, and other issues unique to females.

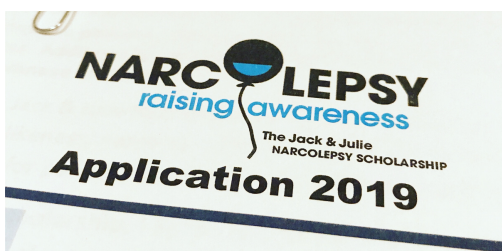


2018 June – Isabelle Arnulf, MD, HF MAB – “Women and Hypersomnia”
[Details](#) | [PPP Slides](#) | [Transcript](#)

MAY / JUNE - Hypersomnia Foundation CEO/Chair, Diane Powell, attended the American College Health Association's conference in Denver, Colorado. She spoke with college health providers from across the country to raise awareness that students habitually exhibiting excessive sleepiness in the classroom may be suffering from a sleep disorder.



JUNE – Hypersomnia Foundation Board members attended the American Academy of Sleep Medicine conference in San Antonio, Texas raising awareness of idiopathic hypersomnia (IH) and other rare sleep disorders with physicians, researchers, and sleep specialists from across the country. They also attended the American School Counselors Association Conference in Boston, Massachusetts educating K-12 counselors about IH and how to help sleepy students using HF's new "HINT Test." Board member Mary King attended the "Rare Disease Innovation and Partnering Summit," also in Boston, developing relationships with firms that recruit patients for medical trials.



JUNE – The Hypersomnia Foundation was proud to partner once again with Project Sleep and their Jack & Julie Narcolepsy Scholarship Program, by providing \$1,000 scholarships to five high school seniors with idiopathic hypersomnia.

JUNE - The Hypersomnia Foundation presented Dr. Caroline Maness of Emory University with an HF Research Award for her proposal entitled “Investigating Cytokine Profiles in the Central Disorders of Hypersomnolence”, studying the potential role of inflammation as a cause or contributor to excessive daytime sleepiness and other symptoms of hypersomnia. Dr. Maness was the first recipient of our Research Award Program, which is funded through the generosity of our donors and designed to encourage research into idiopathic hypersomnia and other rare sleep disorders by individuals in the early stages of their professional careers.



JUNE – The Hypersomnia Foundation hosted a Patient Education Meeting in Seattle, Washington - our first outreach and awareness event on the West Coast. Guest speakers included Dr. David Rye of Emory University and Dr. Flavia Consens of University of Washington / Harborview Medical Center who shared research and treatment updates; Julie Flygare, President & CEO of Project Sleep, presented “Taking Action Through Advocacy” and Morgan Lam, CEO of Balance Therapeutics, and Deborah Hartman of Takeda Pharmaceuticals, each discussed their recent respective clinical trials. HF Board Member Rebecca King shared her current advocacy work for increased funding for sleep disorder research and HF Board member Sarah Beazley held an interactive workshop on “Effective Self-Advocacy” for people with IH and related sleep disorders.



During this event, Dr. Rye was presented with the first-ever Hypersomnia Foundation Impact Award in recognition of his pioneering research on idiopathic hypersomnia (IH) and for his vision and dedication to the IH community.



JULY – Hypersomnia Foundation (HF) Board member Rebecca King attended the American Academy of Family Physicians' National Conference of Family Medicine Residents and Medical Students, in Kansas City, Missouri, raising awareness of idiopathic hypersomnia (IH) and other rare sleep disorders with the medical students and residents in attendance.



AUGUST – The Hypersomnia Foundation released results from our "IH Prescription Drug Insurance Challenges" survey. We determined that coverage and cost barriers prevent 40% of people with idiopathic hypersomnia (IH) from taking the medication prescribed by the doctor. And almost 72% of people with IH have had their prescribed medications initially denied by their insurance company. Results reinforced the importance of why HF advocates for better prescription drug access and funds research to discover effective treatments for IH and related sleep disorders.

SEPTEMBER - Hypersomnia Foundation Volunteer Nicholas Tu and Board member Betsy Ashcraft attended the American Academy of Family Physicians Family Medicine Experience Conference in Philadelphia, Pennsylvania raising awareness of idiopathic hypersomnia, narcolepsy and other rare sleep disorders to the medical professionals, family physicians and medical students at this conference. Family physicians are often the first person someone sees when they suspect they might have a sleeping disorder. Increased awareness of sleep disorders among physicians can help lead to earlier diagnoses.



SEPTEMBER - The Hypersomnia Foundation teamed up with Global Genes, an international nonprofit advocacy group for individuals and families fighting rare diseases, to offer their free student resources and Global Genes RARE Toolkits on our website with our "Education Essentials Guides." Our goal is to help students with sleep disorders (as well as their families and their schools) succeed in their educational careers.



2019 Highlights *continued...*

SEPTEMBER - Hypersomnia Foundation (HF) Board members attended the World Sleep Congress in Vancouver, Canada, raising awareness, educating attendees about idiopathic hypersomnia (IH) and related sleep disorders and advocating for increased research and better treatments. HF was proud to sponsor the first, exploratory meeting of an International Hypersomnia Investigative Group (IHIG) at World Sleep Congress. Chaired by Hypersomnia Foundation Medical Advisory Board Members Dr. David Plante and Dr. Lynn Marie Trotti, this roundtable discussion among some of the top sleep researchers in the world was the first in a series of meetings to grapple with the issues of studying and treating idiopathic hypersomnia.

During this event, World Sleep Society collaborated with several patient sleep organizations to host "Sleep EXPO 2019" - their first-ever, international summit for patients with sleep disorders.

The Hypersomnia Foundation, working in partnership with Wake Up Narcolepsy, presented "Understanding Narcolepsy and Hypersomnia: Insights and Perspectives", during a day of lectures, speaker panels, and Q&A sessions sharing the latest research on treatment options, the impact of rare sleep disorders, and strategies for living the fullest life possible.

HF Board member Rebecca King spoke about the increased diagnosis prevalence of narcolepsy and idiopathic hypersomnia at the World Narcolepsy Day Forum and also participated in Project Sleep's World Narcolepsy Day Pronouncement with Dr. Kiran Maski from the HF Medical Advisory Board, HF Scientific Advisory Board Chair Dr. David Rye, and HF Medical Advisory Board Chair Dr. Lynn Marie Trotti.





SEPTEMBER - HF Board members attended the Society of Behavioral Sleep Medicine conference in Birmingham, Alabama and provided educational sessions on idiopathic hypersomnia. Dr. Lynn Marie Trotti, Chair of HF's Medical Advisory Board, presented "Hypersomnia: Clinical Considerations", and HF Board Member Sarah Beazley organized and moderated a patient panel: "Living with Hypersomnia" with panelists Diana Kimmel, Megan Mallare and Rebecca King.

OCTOBER - The Hypersomnia Foundation hosted a Patient Education Meeting in Chicago, Illinois – our first outreach and awareness event in the Midwest. HF Board member Betsy Ashcraft moderated a Q&A session with HF Scientific Advisory Board Chair, Dr. David Rye, on hypersomnolence sleep disorders. HF Medical Advisory Board members Dr. Thien Thanh Dang-Vu presented "Beyond Sleepy: Structural and Functional Changes of the Default-Mode Network in IH" and Dr. David Plante shared his recent research on "Hypersomnolence Disorders and Depression."

Sessions also included presentations by HF Board members:

Amy Desmarais shared her personal journey of living with a rare sleep disorder, Sarah Beazley led an interactive workshop about advocating for yourself and your personal health, and Rebecca King discussed the importance of legislative advocacy for increased medical research funding.



OCTOBER - The Hypersomnia Foundation partnered with Wake Up Narcolepsy and sponsored five camperships for children ages 5 through 17 with idiopathic hypersomnia (IH) and their families at the Center for Courageous Kids' Camp in Scottsville, Kentucky. This unique opportunity allowed children with IH to meet other kids experiencing the same symptoms and challenges. HF Board members Sarah Beazley and Diane Powell attended this weekend event participating in peer-to-peer discussions with parents and families.



NOVEMBER - Hypersomnia Foundation Board member, Rebecca King, joined representatives from Project Sleep, Wake Up Narcolepsy, Narcolepsy Network, the Sleep Research Society and other patient advocates and organizations for a "Sleep Community Capitol Hill Advocacy Day" in Washington, DC. The group advocated for increased sleep disorder research funding at the National Institute of Health, the Veteran's Administration, and the Department of Defense, as well as re-invigorating vital public health initiatives focused on sleep at the Center for Disease Control.



Message from the Treasurer

Elizabeth (Betsy) Ashcraft

On behalf of the Hypersomnia Foundation (HF), I am pleased to provide this financial information for the HF for the fiscal year ending December 31, 2019.

Since its inception in 2014, the Foundation has been very fortunate to have generous donors--individuals, foundations and corporations--who have provided financial support for our various programs relating to Idiopathic Hypersomnia (IH) and related sleep disorders. In 2019, these programs included two Idiopathic Hypersomnia Education Days in Seattle and Chicago, IH awareness events at multiple conferences of medical and education professionals who see sleepy people, free online resources for people with IH and related sleep disorders, \$1,000 scholarships to five college-bound students who have IH, and our first-ever IH research award to Dr. Caroline Maness of Emory University. Last year was clearly a banner year for the HF!

However, it is now the middle of 2020, and we are all dealing with the Covid-19 pandemic. While this crisis has adversely affected the activities and finances of all nonprofit organizations, including the HF, the Foundation remains financially stable. I am confident that, with the continuing support of our donors and careful stewardship of our finances, the Hypersomnia Foundation will remain fiscally strong as we navigate the remainder of 2020 and beyond.

Warm Regards,

Betsy Ashcraft
Treasurer, Hypersomnia Foundation

STATEMENT OF ACTIVITIES FOR FISCAL YEAR ENDING DECEMBER 31, 2019



REVENUE

Unrestricted Revenue --

Donations	\$161,802
Educational Meeting Ticket Sales	\$ 4,426
Corporate/Foundation Grant	\$ 8,000

TOTAL UNRESTRICTED REVENUE \$174,228

Restricted Revenue --

Donations for Executive Director	\$ 50,000
Corporate Grant for IH Panel Program	\$ 22,700
Donations for IH Research	\$ 5,000

TOTAL RESTRICTED REVENUE \$ 77,700

TOTAL REVENUE \$251,928

EXPENSES

Expenses from Unrestricted Revenue --

HF Educational Meetings	\$ 84,597
Outreach, Education & Awareness Activities	\$ 44,460
Professional Services (Legal, Accounting & Insurance)	\$ 7,075
State Registrations	\$ 6,549
Office & Administrative	\$ 11,048

TOTAL EXPENSES FROM UNRESTRICTED REVENUE \$153,729

Expenses from Restricted Revenue --

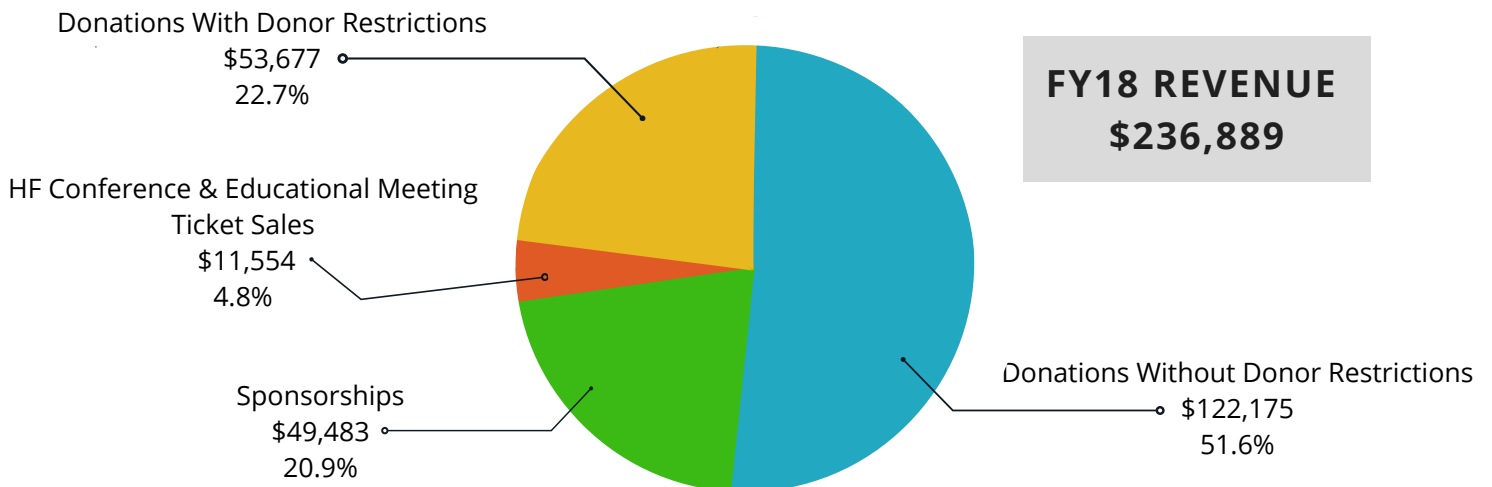
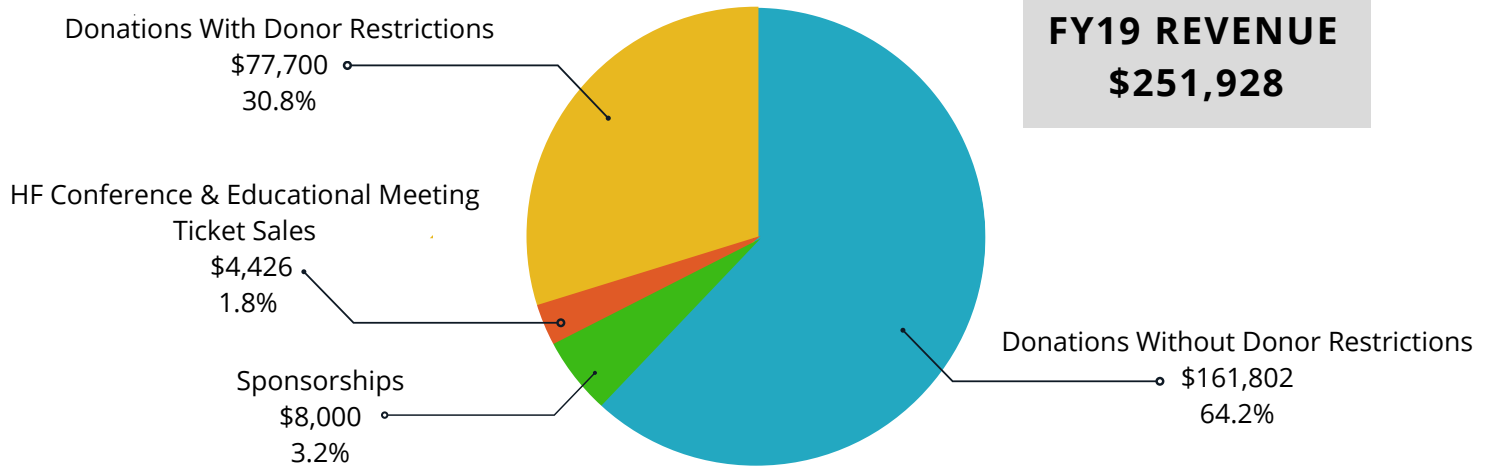
Part-Time Executive Director (salary & taxes)	\$ 44,316
HF Research Award Program	\$ 7,902

TOTAL EXPENSES FROM RESTRICTED REVENUE \$ 52,218

TOTAL EXPENSES \$205,947

NET INCREASE IN NET ASSETS \$ 45,981

COMPARISON OF REVENUE CATEGORIES (FY 2019 versus FY 2018)



BOARD OF DIRECTORS 2020



Diane Powell
CEO/Chair



Elizabeth Ashcraft, JD
Treasurer



Sarah Beazley
Secretary



Michelle A. Emrich, MD



Mary King, EdD



Rebecca King

CORPORATE OFFICERS 2020



Evan Desmarais
Technical Officer



Andrew Powell, JD
Industry Outreach Officer

Board of Directors 2019

Diane Powell, CEO/Chair
Cat Page-Rye, Treasurer
Elizabeth Ashcraft, Secretary
Sarah Beazley
Amy Desmarais
Michelle A. Emrich, MD
Mary King, EdD
Rebecca King
Lisa Laribee, MA

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.

MEDICAL ADVISORY BOARD *continued...*



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. PhD

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



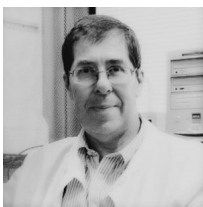
David Rye, MD, PhD - Advisory Board Chair

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

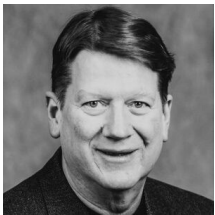
As Professor of Biophysics & Anaesthetics at London's Imperial College, Prof. Nicholas Franks has sought to understand how general anesthetic agents work at the molecular, cellular, and, most recently, neuronal network levels. Almost 40 years ago, he asked, "Where do general anaesthetics act?" and since 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.



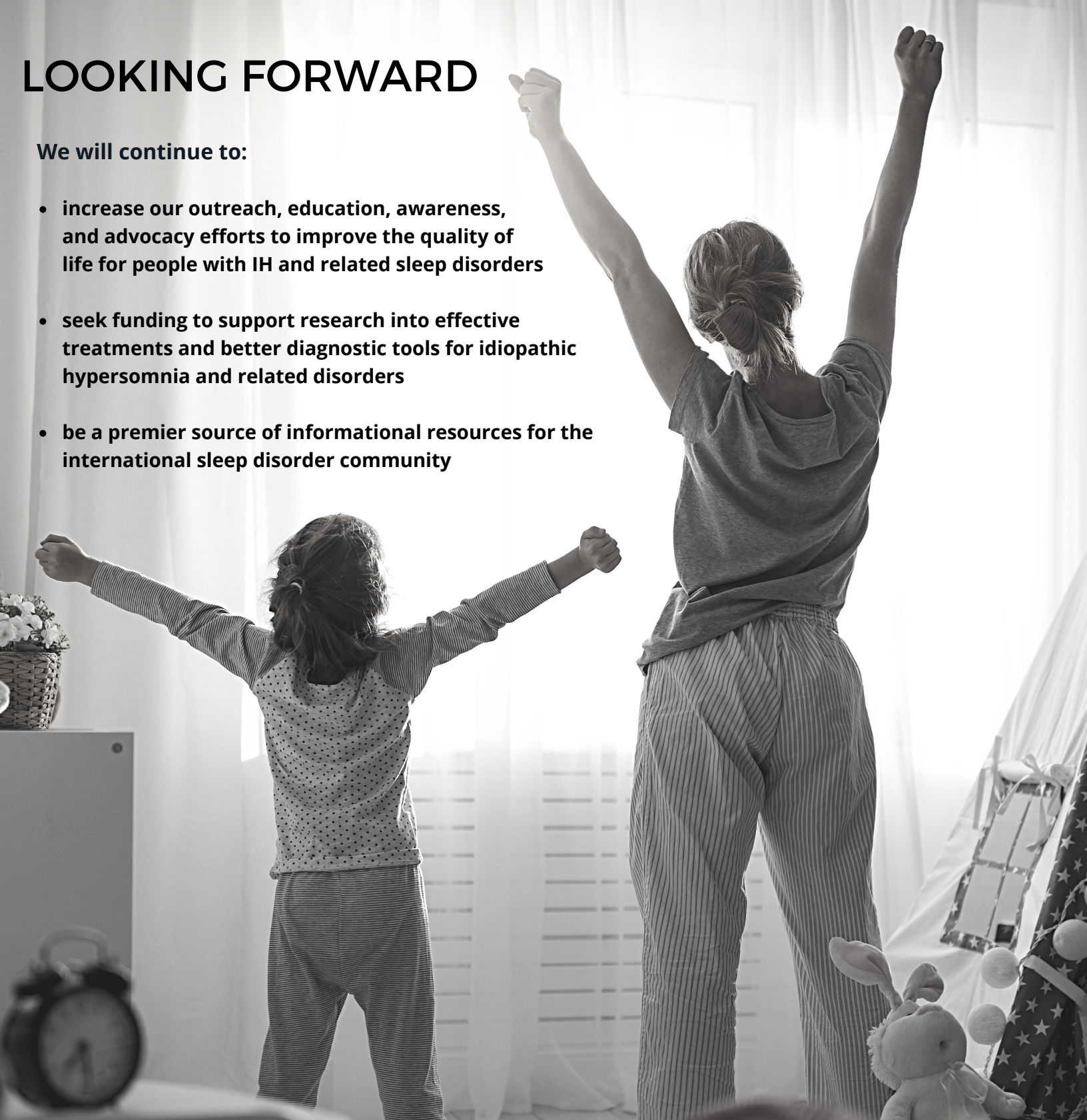
James M. Krueger, PhD

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 international sleep disorder community



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