

# 2020 ANNUAL REPORT



hypersomnia  
foundation.org



HIF

# MESSAGE FROM OUR CHAIR

The year 2020 was like no other. The Hypersomnia Foundation had plans for a major conference in Philadelphia in June. We'd chosen a venue and had begun inviting speakers. Of course, all of that changed as the coronavirus spread across the world, the lockdowns began and events like ours had to be canceled.

Many nonprofits faced an uncertain future, but the ability of HF to continue to serve our community was never in doubt. We have always worked virtually, which keeps our overhead expenses low, and we are careful stewards of the donations entrusted to us.

Despite the worldwide lockdown, the Hypersomnia Foundation was able to keep our focus on improving the lives of people with IH and related disorders by advocating for more research and expanded treatment options. We also worked to support our community as they coped with the daily challenges of living with these disorders in the midst of a pandemic.

Now we are looking forward to the day when we can once again host an in-person event, gathering directly with our community of people with IH and related disorders, their supporters, doctors and researchers! I don't think any of us who lived through the pandemic will take those opportunities for granted ever again.

Lastly, January 2022 marks the end of my final term as a Board Member and as HF Chair & CEO. I am delighted to announce that Board Member David Burley will be taking over to lead the Foundation, and HF could not be in better hands! Thank you, to everyone, for all of your support over the last six years. It's been an incredible experience and a privilege to serve, and I am so proud of all that we have accomplished together. I look forward to continuing to support the Hypersomnia Foundation, as a donor and a member of our community. HF is growing and thriving!

**Diane Powell**



# 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.

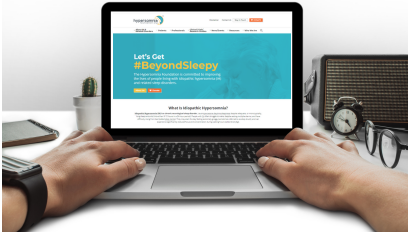
Part of our mission is to connect the medical community, educational institutions, the general public, and the people affected by IH, through awareness, understanding, advocacy, and funding of needed research. Our goal is the development of better diagnostic tools, accurate diagnoses, improved treatments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

The Hypersomnia Foundation is managed by an active, all-volunteer Board of Directors, a part-time executive director, two corporate officers, a Medical Advisory Board of nine clinician-researchers, 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.

# PROGRAMS AND ACCOMPLISHMENTS

## [www.HypersomniaFoundation.org](http://www.HypersomniaFoundation.org)

One of our significant accomplishments in 2020 was a complete redesign of the Hypersomnia Foundation website with the goal of making our site more user-friendly and creating easier access to information and supportive materials for those newly diagnosed with IH or a related sleep disorder. In addition to designing new web pages specifically for the newly diagnosed and for patients and supporters, we created new pages for healthcare providers and researchers. Our new website is reflective of our commitment to improving the lives of people living with idiopathic hypersomnia and related sleep disorders. It includes numerous free resources, including a Healthcare Provider Directory; Anesthesia/Hospital/Emergency Planning Guide and Care Plan; Medical Alert Cards; Education Essentials for Students; and more!



## 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 3,800 at year end 2020.



## Patient Advisory and Advocacy Council

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.



## 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 2020, over 3,000 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.

Help solve the puzzle.



## Board of Directors

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



**ANJEL BURGESS** is an attorney who specializes in the areas of Social Security Disability Law for adults and children, Veterans Disability and Guardianships. Anjel has been a guest speaker at multiple HF conferences, discussing her expertise on advising clients, including people who have idiopathic hypersomnia and related disorders, on their rights and obligations with respect to long-term disability. She has also written articles on Social Security Disability for our newsletter SomnusNooze.



**DAVID BURLEY** is the Chief Technology Officer at Upic Solutions, a non-profit service organization for United Way. Diagnosed with IH in his 20s, he is dedicated to increasing awareness of idiopathic hypersomnia and helping others navigate their sleep disorder journey. David's technology expertise will greatly benefit our efforts for increased awareness of IH and improved options for those living with a sleep disorder.

# 2020 HIGHLIGHTS

In early 2020, the Hypersomnia Foundation was planning a year of in-person workshops, meetings, and our annual conference. As the year went on, society found itself battered by a triple pandemic—COVID-19, racial and civil unrest, and an economic downturn. As people quarantined worldwide, and “in-person” shifted to “virtual,” we set out to strengthen the interconnection of our community by increasing our outreach at the individual, local, national, and global level. Our work during this unprecedented year was possible because of the generosity of our donors. We are grateful for their support.

## RESEARCH AND ADVOCACY

The Hypersomnia Foundation selected the second recipient of our Research Award Program, Todd M. Bishop, PhD, of the Veterans Health Administration (VHA), for his study of idiopathic hypersomnia among U.S. veterans. Dr. Bishop and his research team is developing and validating a method for the accurate identification of cases of IH within the VHA electronic medical record. They are gathering data on the number of veterans with idiopathic hypersomnia, examining patterns of treatment, and exploring other health conditions (co-morbidities) among this population, with an emphasis on identifying suicide risk factors. (March 2020)



A research paper was published using the valuable dataset from our International Patient Registry at CoRDS. The paper, entitled “Disease Symptomatology and Response to Treatment in People With Idiopathic Hypersomnia: Initial Data From the Hypersomnia Foundation Registry,” examines idiopathic hypersomnia symptoms and treatments. (September 2020)

## RESEARCH AND ADVOCACY

The Hypersomnia Foundation joined other rare disease organizations endorsing EveryLife Foundation for Rare Diseases' statement asking Congress to develop drug-pricing proposals that incentivize innovation for rare diseases. (January 2020)



The Hypersomnia Foundation participated in a “Request for Information” from the U.S. National Institutes of Health, which asked for data on Racial Disparities in Hypersomnia Disorders. We believe there are significant

disparities in hypersomnia diagnosis and treatment. We therefore analyzed the demographic data on those who have chosen to participate in our international patient registry at CoRDS and found that the racial/ethnic breakdown in CoRDS does not match the U.S. population. This information led us to believe that barriers may disproportionately affect specific racial/ethnic groups and that it is the responsibility of HF’s Board to examine diversity issues more closely and to raise awareness and reach undiagnosed patients. (October 2020)



Working on behalf of everyone concerned about accessing medications during the pandemic, the Hypersomnia Foundation signed onto a letter sent nationwide urging governors, insurance commissioners, Medicaid directors, and executive directors of boards of pharmaceutical companies to protect rare disease patients and high-risk populations during the COVID-19 crisis. (April 2020)

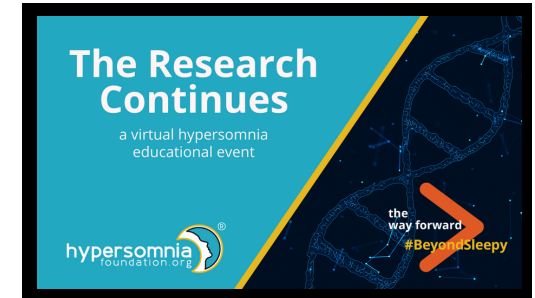


# 2020 HIGHLIGHTS

## EDUCATION, OUTREACH, AND AWARENESS

The Hypersomnia Foundation held its first virtual educational event, “The Research Continues,” which included presentations by and live Q&A with:

- HF’s 2019 Research Award Recipient, Dr. Caroline Maness, who provided an update on her research “Cytokine Profiles in the Central Disorders of Hypersomnolence.”
- HF’s 2020 Research Award Recipient, Dr. Todd Bishop, who provided an update on his research “Hypersomnia and Our Heroes: Studying IH and Behavioral Disorders in the U.S. Veteran Population.”
- Christina Brundage, Hypersomnia Foundation Volunteer and IH Patient Advocate, who shared her personal experiences in “Christina’s Story: Volunteering for IH Clinical Trials.”
- Dr. Marisa Whalen, Associate Director, Medical Affairs at Jazz Pharmaceuticals, who provided updates on research studies in “Unlocking Pharmaceutical Discoveries: Developing Meaningful Treatments That Address Patient Needs.” (October 2020)



Our “Do you receive texts like these?” awareness campaign during “Sleep Awareness Week” encouraged people who struggle with excessive daytime sleepiness, despite having a full night’s sleep, to talk to their physicians about the possibility of having a sleep disorder. (March 2020)

During Sleep Awareness Month, Jazz Pharmaceuticals shared a quote from our Chair and CEO, Diane Powell, on the importance of building awareness of often overlooked sleep disorders and bringing attention to idiopathic hypersomnia. (March 2020)



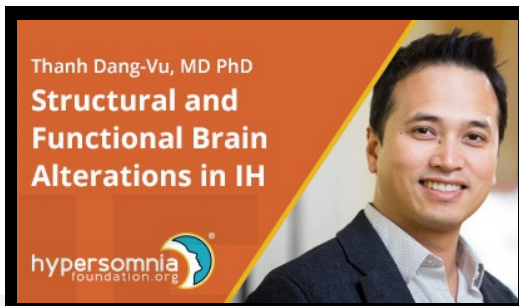
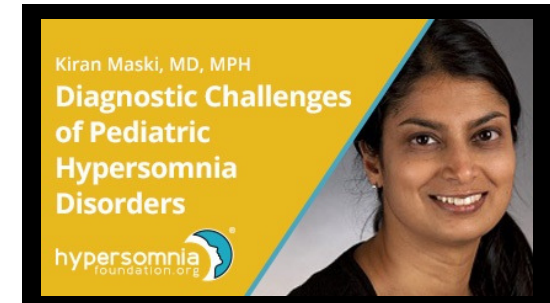
## EDUCATION, OUTREACH, AND AWARENESS

We released multiple new videos into our free educational resource library:



“IH and GABA”—Dr. Andrew Jenkins, Associate Professor of Pharmacology & Anesthesiology at Emory University School of Medicine, describes the current understanding of how GABA<sup>A</sup> receptors are activated and modulated and discusses how this is different in people with IH and how these differences can be corrected by therapeutics. (February 2020)

“Diagnostic Challenges of Pediatric Hypersomnia Disorders”—Dr. Kiran Maski, assistant professor at Harvard Medical School and a child neurologist and sleep medicine specialist at Boston Children’s Hospital, discusses the challenges in diagnosing narcolepsy and idiopathic hypersomnia, particularly in pediatric populations, and the novel diagnostic procedures and biomarkers that could improve diagnostic accuracy for these conditions. (May 2020)



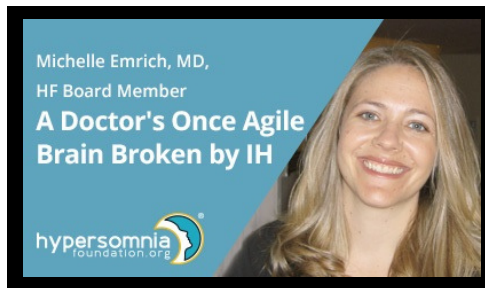
“Structural and Functional Brain Alterations in Idiopathic Hypersomnia”—Dr. Thanh Dang-Vu, Associate Professor at Concordia University in Montreal and currently the University Research Chair in Sleep, Neuroimaging and Cognitive Health, explains the results of his groundbreaking research into brain imaging studies of people with IH and answers the question, “Do people with IH have different brains than people without IH?” (April 2020)

## EDUCATION, OUTREACH, AND AWARENESS



“Participating in a Clinical Trial”—Ms. Veronica Moore, MA, Patient Advocate and Insights Lead at IQVIA, a leading global organizer of clinical trials, discusses how patient data influence the design and endpoints of clinical trials and how patients can best engage with the clinical trial process. (August 2020)

“IH and Disability: What You Need to Know”—Ms. Anjel Burgess, a disability attorney specializing in the areas of Social Security Disability Law for adults and children, Veterans Disability and Guardianships, discusses her work advising clients, including idiopathic hypersomnia patients, on their rights and obligations with respect to long-term disability. (August 2020)



“A Doctor’s Once Agile Brain Broken by IH”—Hypersomnia Foundation Board member Dr. Michelle Emrich, is an internal medicine physician whose beloved career was cut short when she was 32 years old by the onset of severe, treatment-refractory idiopathic hypersomnia. Michelle describes the huge impact of IH on every aspect of her life and the great importance of therapy and supportive healthcare providers. She hopes that sharing her story will help foster better understanding of this invisible disease. (November 2020)

“Sleeping My Life Away”—Hypersomnia Foundation volunteer, Meghan Mallare describes the profound impact idiopathic hypersomnia has had on her life. She shares the long journey to diagnosis and the misconceptions surrounding this condition. She also describes the emotional, physical, social, and professional difficulties of being a young adult living with IH. (November 2020)



# MESSAGE FROM THE TREASURER

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, 2020.

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. From 2015-2019, these programs were held in-person, allowing members of the sleep community to come together and share their experiences, while also learning about the latest in IH research. In early 2020, however, the COVID-19 pandemic forced the Foundation to pivot from in-person events to virtual events. Despite this, the Foundation continued to offer support and resources to those in the sleep community through a series of virtual events, while also revising our website to make it more accessible, and granting our second-ever research award to Todd M. Bishop, PhD of the Veterans Health System.

Although the ongoing COVID-19 pandemic has adversely affected the activities and finances of all nonprofit organizations, including the HF, the Foundation remains financially stable, due to the strong support of our individual donors and our corporate partners. I am confident that, with this continuing financial support and careful stewardship of our finances, the Hypersomnia Foundation will remain fiscally strong as we navigate the future.



**Elizabeth "Betsy" Ashcraft**

# 2020 FINANCIALS

## REVENUE

Unrestricted Revenue --	
Contributions and Grants	149,891
Interest Income	242
Net Assets Released from Restrictions	58,238
<b>TOTAL UNRESTRICTED REVENUE</b>	<b>208,371</b>

Restricted Revenue --	
Contributions and Grants	154,195
Satisfaction of Program Restriction Expenditures	(58,238)
<b>TOTAL RESTRICTED REVENUE</b>	<b>95,957</b>

**TOTAL REVENUE** **\$ 304,328**

## STATEMENT OF ACTIVITIES FOR FISCAL YEAR ENDING DECEMBER 31, 2020

<b>EXPENSES</b>	<b>PROGRAM SERVICES</b>	<b>GENERAL &amp; ADMINISTRATIVE</b>	<b>FUNDRAISING</b>	<b>TOTAL</b>
Conferences/Education & Awareness	6,307	0	0	6,307
Scholarships and Grants	14,000	0	0	14,000
Website	16,200	0	2,314	18,514
Marketing and Outreach	527	0	0	527
Registration, Professional, & Other Fees	9,122	24	0	9,146
Employee Compensation, Payroll Tax	42,002	2,283	1,369	45,655
Office & Administrative	2,901	977	361	4,239
Professional Services (Accounting & Insurance)	0	8,806	0	8,806
<b>TOTAL EXPENSES</b>	<b>\$ 92,445</b>	<b>\$ 12,090</b>	<b>\$ 4,045</b>	<b>\$ 108,579</b>

<b>TOTAL REVENUE</b>	<b>\$304,328</b>
<b>TOTAL EXPENSES</b>	<b>\$108,579</b>
<b>INCREASE IN NET ASSETS</b>	<b>\$195,749</b>
<b>NET ASSETS AT BEGINNING OF YEAR (01/01/2020)</b>	<b>\$410,021</b>
<b>NET ASSETS AT END OF YEAR (12/31/20)</b>	<b>\$605,770</b>

## BOARD OF DIRECTORS 2020



**Diane Powell**  
CEO/Chair



**Elizabeth Ashcraft, JD**  
Treasurer



**Sarah Beazley, RN**  
Secretary



**Anjel Burgess, JD**



**David Burley**



**Michelle A. Emrich, MD**



**Rebecca King**

## CORPORATE OFFICERS 2020



**Evan Desmarais**



**Andrew Powell, JD**



## **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.





**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.



## **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.



**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

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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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**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.