



# 2024 ANNUAL REPORT

4514 Chamblee Dunwoody Road, #229, Atlanta, GA 39338  
[info@HypersomniaFoundation.org](mailto:info@HypersomniaFoundation.org)

## 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, drug developers, 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.

# CELEBRATING A DECADE OF ADVOCACY AND PROGRESS

2024 marked the tenth anniversary of the Hypersomnia Foundation, established in 2014 by three individuals personally affected by Idiopathic Hypersomnia (IH). Since its founding, the Foundation has worked to improve the lives of people with IH and related sleep disorders through advocacy, education, awareness, research funding, and community engagement.

Over the past decade, HF has grown from a start-up nonprofit to a respected leader in the sleep-health community. Early milestones included the launch of the patient-powered registry through the Coordination of Rare Diseases at Sanford (CoRDS), which now includes thousands of participants and provides valuable real-world data for researchers. The Foundation has also expanded its educational outreach, digital resources, and partnerships, ensuring better understanding and recognition of IH among clinicians and the public alike.

In recent years, HF has strengthened its strategic partnerships and leadership, including collaboration with the American Academy of Sleep Medicine Foundation (AASMF) to co-fund hypersomnia research. This partnership alone generated over \$663,000 in new research funding and increased the number of IH-related grants. Under the strong leadership of the Board of Directors, the organization continues to expand its impact through advocacy, data-driven insights, and community collaboration.

As HF looks to the future, it remains deeply committed to advancing research and improving both diagnostic tools and treatment options. A decade ago, there were no approved medications for idiopathic hypersomnia (IH). Today, one is available, with several more expected in the coming year. The Foundation continues to work tirelessly to ensure that people with IH receive the recognition, accommodations, and care they deserve. The first decade marks a period of steady progress and its next promises even greater impact.

# LEADERSHIP HIGHLIGHTS 2024

## WELCOMING EDWARD STEPANSKI, PHD, TO THE HYPERSOMNIA FOUNDATION BOARD



In 2024, the Hypersomnia Foundation proudly welcomed **Edward Stepanski, PhD**, to its Board of Directors. Dr. Stepanski brings a distinguished career in sleep medicine, with groundbreaking research demonstrating the impact of sleep fragmentation on daytime alertness, the role of hyperarousal in insomnia, and treatment outcomes for chronic insomnia. He has served on the Boards of the American Board of Sleep Medicine and the American Academy of Sleep Medicine (AASM), including chairing the AASM committee that established the subspecialty of Behavioral Sleep Medicine. He joins the Hypersomnia Foundation eager to leverage his deep expertise in sleep medicine and research innovation to advance the Foundation's mission of improving awareness, education, and outcomes for individuals living with Idiopathic Hypersomnia and related sleep disorders.

## AMPLIFYING VOICES: "SCIENCE FRIDAY" ELEVATES IH AWARENESS WITH DIANA KIMMEL



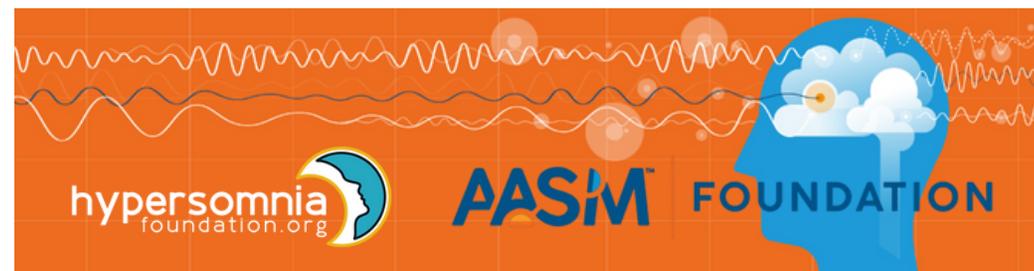
In March 2024, the *Science Friday* program featured an in-depth conversation with **Diana Kimmel**, co-founder of the Hypersomnia Alliance and board member of the Hypersomnia Foundation. Diane was joined by Quinn Eastman, author of *The Woman Who Couldn't Wake Up: Hypersomnia and the Science of Sleepiness*. Together they brought awareness of idiopathic hypersomnia (IH) to a national audience, describing the profound daily impairment faced by people with IH and advocating for broader research and awareness. Diana shared personal insights from her own multi-year diagnostic journey and emphasized the critical role of patient advocacy in moving science forward. With this high-visibility media engagement, the Hypersomnia Foundation strengthened its position as a leading voice for the IH community and helped further the goal of making the condition more visible, better understood, and better treated.

# RESEARCH HIGHLIGHTS 2024

## LEVERAGING RESEARCH PARTNERSHIPS: OUR COLLABORATION WITH THE AASM FOUNDATION

The Hypersomnia Foundation strengthened its commitment to advancing the understanding and treatment of central disorders of hypersomnolence through a **strategic research partnership with the AASM Foundation**. This collaboration supports the Strategic Research Grant program, focusing on investigator-initiated projects that address critical gaps in **diagnosis and treatment of conditions** such as Idiopathic Hypersomnia. According to the AASM Foundation’s research update, our partnership has **helped to direct more than \$1.7 million toward hypersomnolence research** since 2022. The standout feature of these co-funded grant opportunities is that every dollar contributed by the Hypersomnia Foundation is leveraged by partner funding, effectively transforming each \$1 from HF into \$4 for research.

This arrangement **amplifies the impact of our donors’ support**: a contribution from the Foundation not only advances our mission directly but also triggers expanded research investment by leveraging partner funds. By positioning ourselves as a pivotal collaborator in high-impact sleep research, we help ensure that **patient-driven priorities**—such as improved diagnostics, novel therapies, and better treatment pathways—are elevated and resourced.



# RESEARCH HIGHLIGHTS 2024

## 2024 STRATEGIC RESEARCH GRANTS: ADVANCING IH THROUGH PARTNERSHIP & INNOVATION

In 2024, the Hypersomnia Foundation (HF) **partnered with the AASM Foundation to co-fund two landmark Strategic Research Grants** focused specifically on central disorders of hypersomnolence (CDH), including idiopathic hypersomnia (IH). The first award supports **Margaret Blattner, MD, PhD** (Beth Israel Deaconess Medical Center / Harvard Medical School) in researching a circadian mechanism of long sleep duration in IH, using an extended inpatient monitoring protocol to measure circadian biomarkers and extended sleep in relation to waking signals. The second award supports **Oliver Sum-Ping, MD** (Stanford University), who is applying machine learning analysis of awake EEG to pinpoint electrodiagnostic correlates of hypersomnolence—an innovative approach to identify objective biomarkers for disorders like IH.

The Hypersomnia Foundation supported the establishment of the **NICHY Consortium**—an international collaboration dedicated to studying the neuroimaging correlates of central disorders of hypersomnolence—and funded a **NICHY MRI Brain Imaging Grant**. Throughout 2024, the consortium was prominently represented at leading international conferences, sharing its findings through posters, talks, and award-winning presentations. As the consortium continues to expand in both membership and scientific momentum, the Hypersomnia Foundation is proud to **foster this growing body of research and to advance the search for treatable mechanisms** underlying hypersomnolence disorders.

These grants reflect HF's **strategic emphasis on collaboration and high-impact research**: by joining forces with the AASM Foundation, the Foundation helps ensure that **each dollar invested is leveraged** for maximum scientific return and aligned with **patient-centered priorities**.



# CONFERENCES 2024

## BEYONDSLEEPY SATELLITE: EXPANDING KNOWLEDGE AND COMMUNITY IMPACT IN ATLANTA



The Hypersomnia Foundation hosted the **BeyondSleepy Satellite Conference in Atlanta**, bringing together **361 attendees** to explore the latest research, patient perspectives, and clinical insights on Idiopathic Hypersomnia (IH). The conference featured an impressive lineup of speakers: **Devon Price, PhD**, presented “Laziness Does Not Exist”; **Alyssa Cairns, PhD**, shared “Turning Diagnosis into Discovery: Perspectives from an IH Patient-Turned-Researcher”; **Lindsay Jesteadt** discussed the Results of the Illuminate

Hypersomnia Voice of the Patient Report and the DREAM Portal, a patient- and caregiver-reported data collection initiative; and **Lynn Marie Trotti, MD, MSc**, addressed “Misconceptions Surrounding IH.”

By combining scientific expertise, patient experiences, and innovative data collection, the BeyondSleepy Satellite Conference fostered education, advocacy, and community-building, **empowering attendees with knowledge and tools** to advance awareness and improve the lives of those living with hypersomnia.

## BEYONDSLEEPY 2024 HOUSTON: ADVANCING KNOWLEDGE, ADVOCACY, AND COMMUNITY



The Hypersomnia Foundation hosted the **BeyondSleepy Conference in Houston**, welcoming **750 attendees** eager to engage with leading experts and patient advocates on Idiopathic Hypersomnia and related sleep disorders. The conference featured a rich mix of presentations, including **Heather Lill and Matthew Horsnell** on healthy relationships, **Alicia Roth, PhD, DBSM** on mental health in hypersomnia, **Jo Ghormley, LCSW** on effective communication with healthcare providers, and **Michael Grandner, PhD** on using sleep technology to understand and manage the condition. Attendees also learned from researchers like **Christopher Drake, PhD, FASM** and **Yves Dauvilliers, MD, PhD** about innovative treatments, precision medicine, and patient-centered approaches in drug development.

By blending patient perspectives, clinical insights, and cutting-edge research, BeyondSleepy Houston **empowered participants with practical knowledge, advocacy strategies, and stronger connections** within the hypersomnia community, highlighting the Foundation’s ongoing commitment to education, awareness, and advancing care for those living with IH.

# PROGRAM HIGHLIGHTS 2024

## UNIGHT: BUILDING COMMUNITY AND KNOWLEDGE THROUGH MONTHLY VIRTUAL GATHERINGS



The Hypersomnia Foundation **continues to expand** its highly successful community outreach program, **UNIGHT**, a monthly virtual gathering dedicated to topics that matter most to individuals living with sleep disorders. Each session brings together patients, caregivers, researchers, and clinicians for **meaningful discussions and shared learning**. Throughout the year, UNIGHT has featured a distinguished lineup of guest speakers, including **Dr. Kiran Maski, Kimberly McCleary, Ellen Wermter, Dr. Alicia Roth, Maggie Lavendar, Josh Andrews, Dr. Michael Grandner, Dr. Jesse Cook, Shelly Gonzales**, and Hypersomnia Foundation Board Member **Diana Kimmel**.

Topics have spanned a **wide range of issues** central to the hypersomnia community, such as Treatment Options for Idiopathic Hypersomnia; Illuminate Hypersomnia: Shining Light on the Lived Experience of IH; Nutritional Considerations for Central Disorders of Hypersomnolence; Mental Health in Central Disorders of Hypersomnolence; Communication with Your Healthcare Provider; Using Your Voice for Change; Sleep Health Disparities; Actigraphy and Sleep Tracking; and a Clinical Trials Discussion Panel.

Through UNIGHT, the Foundation continues to **foster connection, education, and empowerment** among those affected by hypersomnia and related sleep disorders.

## UNIGHT: SUPPORT4SUPPORTERS — EXPANDING SUPPORT FOR THE HYPERSOMNIA COMMUNITY



Building on the success of its monthly UNIGHT series and in response to community feedback, the Hypersomnia Foundation **launched a new initiative, UNIGHT: Support4Supporters**. This **outreach program** is designed specifically for the families, friends, and caregivers of people living with hypersomnia and related sleep disorders.

UNIGHT: Support4Supporters offers a welcoming and informal space where participants can share experiences, express concerns, exchange resources, and learn from one another. By creating this dedicated forum, the Hypersomnia Foundation **continues its commitment** to fostering understanding, connection, and **mutual support** across all who are touched by hypersomnia.

# PROGRAM HIGHLIGHTS 2024

## INTRODUCING “THE SIT DOWN” — A NEW CONVERSATION SERIES FROM THE HYPERSOMNIA FOUNDATION

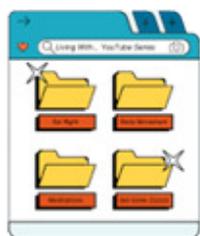


The Hypersomnia Foundation launched “**The Sit Down**,” a new video interview series featured on the Foundation’s social media platforms, including Facebook and YouTube. Designed to foster open, authentic dialogue, the series features **real-life conversations** with people living with hypersomnia, caregivers, advocates, researchers, and partner organizations.

Unlike traditional educational webinars, “The Sit Down” takes a more personal and conversational approach, offering viewers insight into the **lived experiences and diverse perspectives** within the hypersomnia community. Episodes such as the conversation with **Michelle Chadwick** of Hypersomnolence Australia, representatives from **Project Sleep, Wake Up Narcolepsy, Hypersomnia Alliance, NAPS4LIFE, PWN4PWN**, and **ABRAHNI** highlight shared challenges, successes, and the power of community connection.

Through “The Sit Down,” the Hypersomnia Foundation continues its mission to **raise awareness, build understanding, and strengthen ties** across the global sleep disorder community.

## “LIVING WITH...”: SHARING STORIES AND INSIGHTS ON HYPERSOMNIA



**LIVING WITH...**

The Hypersomnia Foundation continued producing its popular **YouTube series**, “**Living With...**,” hosted by HF CEO Claire Wylds-Wright. Each episode features **engaging conversations** with sleep experts, researchers, clinicians, and individuals living with Idiopathic Hypersomnia, providing an intimate look at the daily realities of managing this complex condition.

The series aims to **raise awareness** of IH, promote healthy sleep practices, and **highlight emerging research** in sleep medicine. In 2024, topics explored included Treatment Innovations for IH, Sleep Health Disparities, Mental Health and Hypersomnia, Navigating Clinical Trials, and Caregiver Perspectives, with guest speakers such as **Dr. Kiran Maski, Dr. Michael Grandner, Shelby Gonzales, Josh Andrews**, and Hypersomnia Foundation Board member **Diana Kimmel**.

Through “Living With...,” the Foundation continues to **amplify patient voices, educate the public**, and foster a deeper understanding of life with hypersomnia.

# OUTREACH HIGHLIGHTS 2024

## ADVANCING RESEARCH THROUGH THE CORDS PATIENT REGISTRY



Since 2015, the Hypersomnia Foundation has **partnered with the Coordination of Rare Diseases at Sanford (CoRDS)** to maintain a disease-specific patient registry for central disorders of hypersomnolence (CDH), including Idiopathic Hypersomnia (IH). Hosted at Sanford Research, the registry provides a secure and comprehensive platform for individuals with IH and related sleep disorders to contribute their health data. The IH-specific registry had grown to over 3,500 participants, with numbers continuing to rise annually. By sharing their experiences—including symptom profiles, treatment outcomes, and the diagnostic journey—**patients play a direct role in advancing research and improving understanding of these rare sleep disorders.**

The Hypersomnia Foundation / CoRDS partnership is a cornerstone of the Foundation's research strategy, offering a robust, longitudinal dataset that **strengthens the evidence base** for both IH and related hypersomnolence disorders. CoRDS representatives attended the 2024 Houston BeyondSleepy Conference highlighting the ongoing integration of the registry into HF's broader community and research initiatives. This collaboration ensures that **patient voices continue to inform research, clinical trials, and the development of new therapies.**

## ENHANCED DIGITAL PRESENCE AND INNOVATIVE FUNDRAISING

The Hypersomnia Foundation made significant strides in its **digital and fundraising capabilities**. The Foundation **revamped its website**, creating a more intuitive, user-friendly experience for patients, caregivers, and the public, making it **easier to access** educational resources, event information, and community programs.

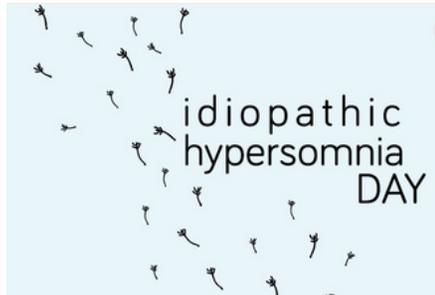
Simultaneously, the Foundation implemented a new fundraising platform, FunRaise, which played a pivotal role in driving the **most successful end-of-year fundraising campaign** to date. Demonstrating strong leadership and commitment, **100% of the Board of Directors contributed**, underscoring their dedication to the mission.

Together, these advancements have **strengthened the Foundation's ability** to engage the community, support research, and expand programs that improve the lives of those affected by Idiopathic Hypersomnia and related sleep disorders.



# OUTREACH HIGHLIGHTS 2024

## RAISING AWARENESS: IH DAY AND IH AWARENESS WEEK 2024



The Hypersomnia Foundation proudly **hosted Idiopathic Hypersomnia Day and IH Awareness Week**, events dedicated to increasing public understanding of IH and supporting the global hypersomnia community. As part of these efforts, the Foundation created a **public service announcement titled “Hey Sleepyhead,”** designed to engage a wide audience and bring attention to the daily challenges faced by those living with IH.

Through virtual gatherings, social media campaigns, educational resources, and patient stories, the **events highlighted both the resilience of the hypersomnia community** and the urgent need for greater awareness, improved diagnosis, and expanded treatment options. These initiatives offered patients, caregivers, and clinicians the chance to connect, share experiences, and **advocate for progress** in the understanding and management of central disorders of hypersomnolence.

## “CAUGHT IN THIS RIPTIDE”: A POWERFUL MINI-DOCUMENTARY ON LIVING WITH IH

The Hypersomnia Foundation released the **short documentary *Caught In This Riptide***, which follows **Beth Boyce**—a person living with Idiopathic Hypersomnia (IH) in Hood River, Oregon—and offers viewers an intimate **look at her daily experience** with this rare and often misunderstood sleep disorder.

The mini-documentary captures Beth in her everyday environment—her home, her community, her work—revealing not only the struggles of living with IH but also the **resilience, coping strategies, and personal strength** that accompany it. Crafted with care in collaboration with filmmaking partner **Podhead Studios**, the film was shot with the goal of authentically portraying the lived experience of IH and **raising awareness** among a wider audience.

By sharing Beth’s story in *Caught In This Riptide*, the Foundation deepens its **commitment to patient-centered storytelling** and multimedia outreach—bringing visibility to idiopathic hypersomnia and helping bridge the gap between clinical research and real-world lives.



## EMPOWERING STUDENTS WITH HYPERSOMNIA: PROJECT SLEEP'S JACK & JULIE NARCOLEPSY SCHOLARSHIP



The Hypersomnia Foundation was proud to see **five students living with Idiopathic Hypersomnia** recognized through **Project Sleep's Jack & Julie Narcolepsy Scholarship** program this year.

Established to support students with narcolepsy and related sleep disorders, this national scholarship **honors young people** who demonstrate resilience, leadership, and commitment to their education while managing the challenges of their condition.

Through this partnership, the Hypersomnia Foundation **celebrates the achievements of students with IH** and applauds Project Sleep's continued dedication to **raising awareness and empowering the next generation of advocates** within the sleep disorder community.

## DR. DAVID RYE RECEIVES THE HYPERSOMNIA FOUNDATION'S 10TH ANNIVERSARY PIONEER IMPACT AWARD



In **celebration of its 10th anniversary**, the Hypersomnia Foundation proudly presented **Dr. David Rye** with the **Pioneer Impact Award** in recognition of his **groundbreaking research and lasting contributions** to the understanding and treatment of hypersomnia.

Dr. Rye's pioneering work has fundamentally advanced scientific knowledge of Idiopathic Hypersomnia and related central disorders of hypersomnolence, leading to improved diagnosis and patient care. His **dedication, innovation, and mentorship** have inspired both clinicians and patients alike, embodying the spirit of progress and collaboration that defines the Hypersomnia Foundation's mission.

# 2024 FINANCIALS



## HYPERSONMIA FOUNDATION, INC.

### STATEMENTS OF ACTIVITIES

	Year Ended December 31, 2024			Year Ended December 31, 2023		
	Without Donor Restrictions	With Donor Restrictions	2024 Totals	Without Donor Restrictions	With Donor Restrictions	2023 Totals
	<b>SUPPORT AND REVENUES</b>					
Contributions and Grants	\$ 752,175	\$ -	\$ 752,175	\$ 813,644	\$ -	\$ 813,644
Program Income	56,482	-	56,482	75,679	-	75,679
Interest Income on investments	51,133	-	51,133	20,096	-	20,096
Unrealized gain on investments	7,483	-	7,483	7,987	-	7,987
Net Assets Released from Restrictions						
Satisfaction of Program Restriction Expenditures	51,167	(51,167)	-	323,772	(323,772)	-
<b>TOTAL SUPPORT AND REVENUES</b>	<b>918,440</b>	<b>(51,167)</b>	<b>867,273</b>	<b>1,241,178</b>	<b>(323,772)</b>	<b>917,406</b>
<b>EXPENSES</b>						
Programs	772,316	-	772,316	658,178	-	658,178
Supporting Services:						
General and Administrative	92,443	-	92,443	70,288	-	70,288
Fundraising	6,140	-	6,140	6,018	-	6,018
Total Supporting Services	98,583	-	98,583	76,306	-	76,306
<b>TOTAL EXPENSES</b>	<b>870,899</b>	<b>-</b>	<b>870,899</b>	<b>734,484</b>	<b>-</b>	<b>734,484</b>
<b>INCREASE (DECREASE) IN NET ASSETS</b>	<b>47,541</b>	<b>(51,167)</b>	<b>(3,626)</b>	<b>506,694</b>	<b>(323,772)</b>	<b>182,922</b>
<b>NET ASSETS AT BEGINNING OF YEAR</b>	<b>990,407</b>	<b>159,777</b>	<b>1,150,184</b>	<b>483,713</b>	<b>483,549</b>	<b>967,262</b>
<b>NET ASSETS AT END OF YEAR</b>	<b>\$ 1,037,948</b>	<b>\$ 108,610</b>	<b>\$ 1,146,558</b>	<b>\$ 990,407</b>	<b>\$ 159,777</b>	<b>\$ 1,150,184</b>

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.

# 2024 FINANCIALS



## HYPERSONMIA FOUNDATION, INC. SCHEDULES OF FUNCTIONAL EXPENSES

	Year Ended December 31, 2024				Year Ended December 31, 2023			
	Program Services	General and Administrative	Fundraising	Total 2024	Program Services	General and Administrative	Fundraising	Total 2023
Conferences space	\$ 285,722	\$ -	\$ -	\$ 285,722	\$ 137,002	\$ -	\$ -	\$ 137,002
Consulting	36,784	8,423	-	45,207	82,087	-	-	82,087
Insurance	-	3,883	-	3,883	-	3,727	-	3,727
Legal, accounting and auditing	-	24,882	-	24,882	-	12,400	-	12,400
Marketing and outreach	15,858	-	-	15,858	36,403	-	-	36,403
Office expenses	18,344	4,127	459	22,930	8,284	1,864	207	10,355
Other fees	342	-	-	342	810	-	-	810
Personnel Costs:								
Salaries and wages	210,906	47,454	5,273	263,633	217,521	48,942	5,438	271,901
Payroll taxes	16,329	3,674	408	20,411	14,913	3,355	373	18,641
Postage and delivery	1,442	-	-	1,442	583	-	-	583
Scholarship and grants	129,993	-	-	129,993	55,000	-	-	55,000
Travel	44,951	-	-	44,951	74,680	-	-	74,680
Website	11,645	-	-	11,645	30,895	-	-	30,895
	<u>\$ 772,316</u>	<u>\$ 92,443</u>	<u>\$ 6,140</u>	<u>\$ 870,899</u>	<u>\$ 658,178</u>	<u>\$ 70,288</u>	<u>\$ 6,018</u>	<u>\$ 734,484</u>

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.

# LOOKING FORWARD

## Building on a Decade of Progress to Advance the Future of Hypersomnia Care

As the Hypersomnia Foundation celebrates its first decade (2014–2024), it reflects on significant strides in **patient advocacy, research, education, and clinical collaboration**. While challenges remain—Idiopathic Hypersomnia (IH) and related sleep disorders are still under-recognized, diagnostic tools continue to evolve, and treatment options are limited—the Foundation’s growth over the past ten years has created a strong platform for future impact.

Looking ahead, the Foundation’s priorities include:

- **Funding groundbreaking research** to better understand IH and related disorders.
- **Providing tools and resources** to help individuals manage daily life with hypersomnia.
- **Hosting community events** that empower participants, helping them feel seen, supported, and confident in self-advocacy.
- **Expanding information on clinical trial opportunities and outcomes**, ensuring patients and families are fully informed.
- **Collaborating with drug development companies** to share insights on patient needs, effective treatments, and real-world experiences—guiding the creation of therapies that make a meaningful difference.

With enhanced infrastructure, strategic partnerships, and a committed leadership team, the Hypersomnia Foundation is poised to accelerate progress and improve the lives of people living with hypersomnia in the years ahead.