



# IMPACT REPORT 2022

# A LETTER FROM JULIE FLYGARE

## PRESIDENT & CEO

Dear Project Sleep Community,

2022 was an exciting year, most notably with the establishment of our new Expert Advisory Board which includes clinicians, researchers, and patient advocates together. We also grew our leadership team with two fantastic new board members and our Digital Media Specialist joining the team!

Additional 2022 highlights include:

- Establishing the Project Sleep Podcast and publishing 16 podcast episodes
- Awarding 30 scholarships to students with narcolepsy and IH
- Representing Project Sleep at World Sleep in Rome, Italy and the APSS SLEEP meeting in Charlotte, NC
- Training 31 Rising Voices patient advocate speakers
- Hosting the third annual Sleep Advocacy Forum as an in-person event for the first time in Washington, DC
- Hosting an in-person narcolepsy event in Nashville, TN

Thank you to all those who give back to this cause, you make our progress possible.

Gratefully,



Julie Flygare, JD  
President & CEO



# Project Sleep's 2022 Board of Directors



Julie Glazer Scher – Chair



Tracy Christensen – Vice Chair



Kamali (Kami) Barron - Treasurer



Emma Cooksey - Secretary



Kristyn Beecher - Director



Kenya Gradnigo - Director



Cienna Ditri - Director



Ana Lara - Director



Anne Taylor - Director

# Meet New Board Member: Kenya Gradnigo

In January 2022, Kenya Gradnigo joined the Board of Directors of Project Sleep. She currently resides in Lafayette, LA.

Kenya was diagnosed with type 1 narcolepsy with cataplexy at age 9. In 2015, Kenya was awarded a Jack & Julie Narcolepsy Scholarship as she began her college education. She completed her Bachelor's in Psychology at Northwestern State University of Louisiana.

Receiving the scholarship marked the beginning of Kenya's journey with Project Sleep. Since then, she has been an active member of the Project Sleep community. In 2020, Kenya was featured in Project Sleep's "Health Care Providers with Narcolepsy" video series. In 2021, she shared her experience navigating school with narcolepsy on a "Narcolepsy Nerd Alert" broadcast. She has been a guest speaker for various other webinars focusing on sleep disorders.



# Meet New Board Member: Emma Cooksey

In January 2022, Emma Cooksey joined the Board of Directors of Project Sleep. She currently resides in Florida.

Emma Cooksey is a podcast host and writer. She was diagnosed with obstructive sleep apnea at the age of 30, after more than a decade of unexplained health problems. Once diagnosed, she felt alone while navigating life with sleep apnea and adjusting to CPAP therapy. In 2020, Emma began hosting a weekly podcast, "Sleep Apnea Stories." By sharing her journey and encouraging others to tell their stories, Emma has been breaking down stereotypes of sleep apnea while also raising awareness of symptoms and treatment options.

Emma first got involved with Project Sleep by participating in the Sleep In campaign and was inspired to learn more about the organization's programs. In summer 2021, Emma became the first person with sleep apnea to complete the Rising Voices speaker's training. It was a great experience and Emma realized how neatly Project Sleep's mission to raise awareness of sleep disorders aligned with her own.



# Meet New Staff: Rachel Aubrey

Rachel joined us as **Digital Media Specialist** in 2022. She is a content creator and digital communicator, with a passion for working in the non-profit sector. She has worked with a private nonprofit community arts organization in her hometown of Wausau, WI and with an animal rescue and transport organization based in Thailand.

Rachel is excited to continue learning about sleep health, sleep equity, and sleep disorders.

In her role, Rachel plans and implements multi-channel communications strategies, creates and publishes content for emails, web, and social media, reports on the effectiveness and performance of Project Sleep's initiatives, and engages with the sleep community to provide resources, information, and support.





# Project Sleep Overview

1. Incorporated in California in 2013
2. Received 501(c)(3) tax-exempt status in 2014
3. Mission:  
*Believing in the value of sleep, Project Sleep aims to improve public health by educating individuals about the importance of sleep health, sleep equity, and sleep disorders. Project Sleep will educate and empower individuals using events, campaigns, and programs to bring people together and talk about sleep as a pillar of health.*
4. Vision: *Let's make sleep cool!*

# 2022 At A Glance

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1. Sleep In 2022
2. Jack & Julie Narcolepsy Scholarship
3. Rising Voices of Narcolepsy
4. Narcolepsy Awareness Program
5. Sleep Advocacy Program
6. Expert Advisory Board
7. Sleep Health Disparities Initiative
8. Philanthropy





**Let's make peace with sleep!**

# 8th Annual Sleep In

Project Sleep's Sleep In 2022 (#SleepIn2022) brought the sleep community together online to honor our needs for rest and recovery. The eighth annual Sleep In event took place from March 18-20, 2022. Participants were encouraged to prioritize sleep, rest, and self care while fundraising for Project Sleep.

- Over **200 posts** using the hashtag #SleepIn2022
- **96 individuals** and **17 teams** raised **more than \$10,000** to support Project Sleep
- Spanned **9 countries on 5 continents** including Australia, Argentina, Canada, South Africa, Germany, Spain, Great Britain, Scotland, and the United States.



# 8th Annual Sleep In

- Sleep In 2022 kicked off with an interview with Dr. Afolabi-Brown! Dr. Afolabi-Brown (@restfulsleepmd) is a board-certified pediatric pulmonologist and sleep medicine physician. Dr. Afolabi-Brown discussed the impact of caffeine, alcohol, CBD, and smartphones on the sleep of teens and ways we can encourage young people to prioritize their sleep. Watch the video [here](#).



  
How do we  
Make Sleep Cool?

LIVE INTERVIEW WITH DR. FUNKE AFOLABI-BROWN



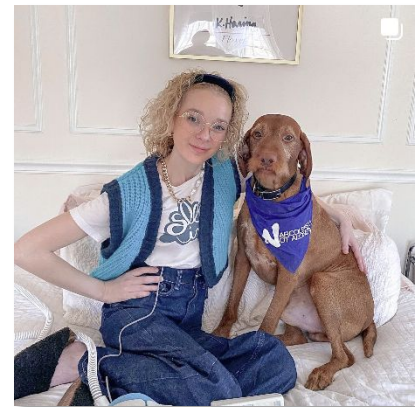
Friday, March 18 at 8pm ET via Project Sleep's Facebook Page

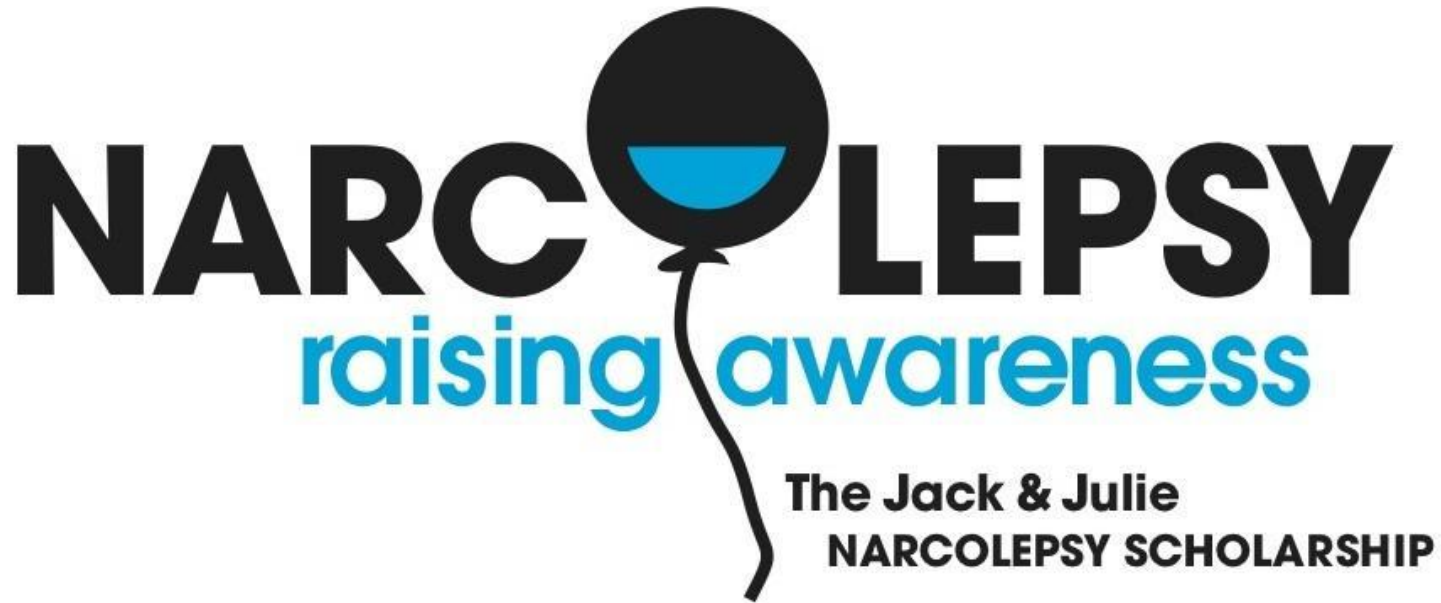
#SleepIn2022



# 8th Annual Sleep In

- Participants woke up on Saturday with breathwork exercises to support rest and relaxation led by Georgie Lawlor. Watch the stream on Facebook [here](#).
- On Saturday evening, Sleeping Under The Stars: Camping and Traveling with Sleep Disorders took place. From mountain climbing with narcolepsy to camping with sleep apnea, the guests shared their stories of traveling and camping with sleep disorders. Watch on [Instagram](#).
- During Sunday Brunch: Talking Nutrition and Sleep, board member Cienna Ditri and registered dietician Anita Dharwadkar explored questions such as does having chocolate before bed cause bad dreams? And is Sleepytime tea actually making you sleepy? Along with much more! Watch on [Instagram](#).





**Scholarship program supporting  
students with narcolepsy and idiopathic hypersomnia  
while fostering awareness**



# Jack & Julie Narcolepsy Scholarship

Project Sleep is honored to introduce the 30 recipients of the 2022 Jack & Julie Narcolepsy Scholarship, who each received \$1,000 towards their college education. In nine years, the scholarship program has now awarded a total of 156 scholarships to 156 students, totaling \$156,000. Learn [more](#).





**Training people with sleep disorders  
to effectively share their stories**



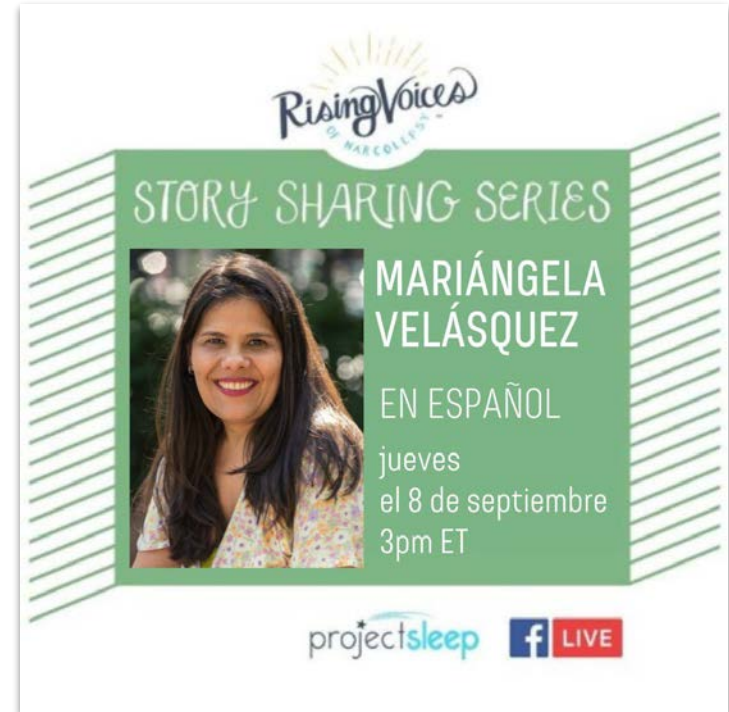
# Rising Voices Speakers 2022

- Over the summer, Project Sleep held our 6th annual Rising Voices speaker training course.
- 31 speakers from 6 countries completed the training.
- Over the course of 2022, 21 Rising Voices speakers secured speaking engagements, reaching over 1450 audience members!



# Rising Voices Story Sharing Series

The Rising Voices Story Sharing Series continued in 2022, with 6 advocates sharing their powerful stories via live video broadcast, including a Spanish-language broadcast. Videos are available on Facebook and YouTube.





Increase the percentage of general population who have heard of narcolepsy from 70% to 80% by 2025



Reduce delays to proper narcolepsy diagnosis from 8 – 15 years to an average of two years by 2030



Reduce stigma for those living with narcolepsy

*to improve outcomes for people with narcolepsy*

## Narcolepsy Awareness Program 2022

# New! Narcolepsy Podcast

Exciting news! Project Sleep has launched a podcast. The Project Sleep Podcast, hosted by Julie Flygare, aims to improve public health by educating individuals about the importance of sleep health, sleep equity, and sleep disorders.



Starting with the Narcolepsy Nerd Alert Series, adapted from our Narcolepsy Nerd Alert live broadcasts, this series invites listeners to dive deeper into specific topics relevant to living with narcolepsy. Please watch for these episodes released weekly and visit our Project Sleep Podcast page or your favorite podcast platform to listen!

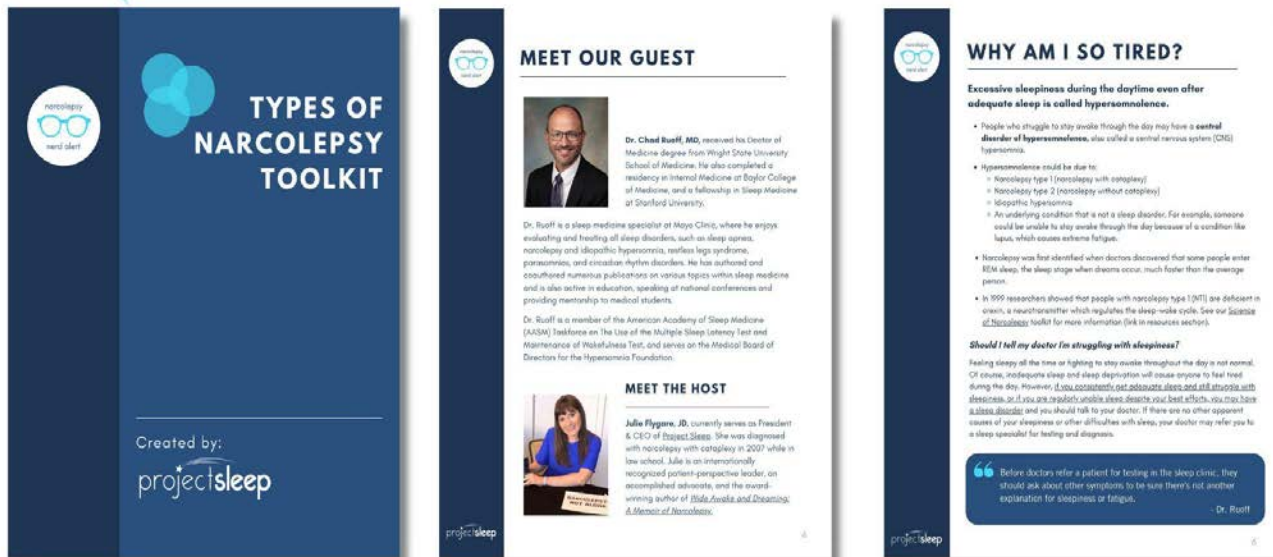
[LISTEN TO PODCAST](#)



# Narcolepsy Nerd Alert

In 2022, Project Sleep hosted 6 live Narcolepsy Nerd Alert broadcasts and created corresponding PDF toolkits with expanded resources and information. Topics included:

- Pregnancy + Narcolepsy
- Health Insurance 101
- Types of Narcolepsy
- Narcolepsy at Work
- Narrating Narcolepsy
- Sleep Paralysis + Hallucinations



# Josh Andrews Speaks at Conference

On Feb. 9, 2022, NFL player Josh Andrews was a featured speaker at the Black Men's Brain Health Conference, in Los Angeles, CA. This conference brought together a multidisciplinary group of scientists and community leaders to increase representation of Black men in brain science research and reduce brain health disparities among Black men. Project Sleep worked with Josh to prepare his story of living with narcolepsy to share at conference. Watch the [replay](#).



# TEDx Talk on Sleep and Sleep Disorders

On March 22, 2022, Project Sleep's President & CEO, Julie Flygare, JD, delivered a TEDx Talk at San Diego State University. Flygare's talk, "What Can You Learn from a Professional Dreamer?" shared her personal story and raised awareness about sleep health and sleep disorders.



[WATCH ON YOUTUBE](#)



# 2022 World Sleep Congress

On March 10, 2022, Project Sleep's President & CEO, Julie Flygare, JD, presented about Narcolepsy in Cinema at the World Sleep Congress in Rome, Italy. This presentation highlighted Project Sleep's new research findings from a recent systematic analysis of film and television portrayals of narcolepsy. The goal was to enable attendees to identify representations of narcolepsy in popular media and be prepared to discuss with patients how representations may differ from first-hand patient experience.



# Support from Congress

In April 2022, thanks to grassroots sleep advocates across the country, a bipartisan group of 36 Representatives signed onto an [important letter](#) prioritizing sleep health and sleep disorders in the Federal appropriations/budget process.



# Sleep 2022

In June 2022, Project Sleep hosted a booth and participated in sessions at SLEEP 2022 in Charlotte, North Carolina. Sessions included **Narcolepsy & Pregnancy: Elevating Patient and Clinician Voices to Explore Best Practices and Shared Decision-making**; and **Rise of the Patient Voice in Sleep Medicine: The Role of Patient Advocacy Groups in Enhancing Sleep Care**.





# Sleep 2022

On June 6, 2022, Project Sleep's President & CEO, Julie Flygare, JD, spoke on an expert panel at a CME event at SLEEP 2022. The symposium, "Achieving Optimal Outcomes in Patients with Narcolepsy: Aligning Treatment Goals with Patients" was one of the first CME symposiums to feature a person living with a sleep disorder alongside clinicians at a major sleep-related meeting. Watch the [replay](#).



*"Imagine going to medical school without knowing any other medical students, without knowing any doctors... What would that be like? Pretty isolating and challenging. That's what it's like to leave a doctor's office and know no one else who shares this part of your identity that will be with you for the rest of your life."*

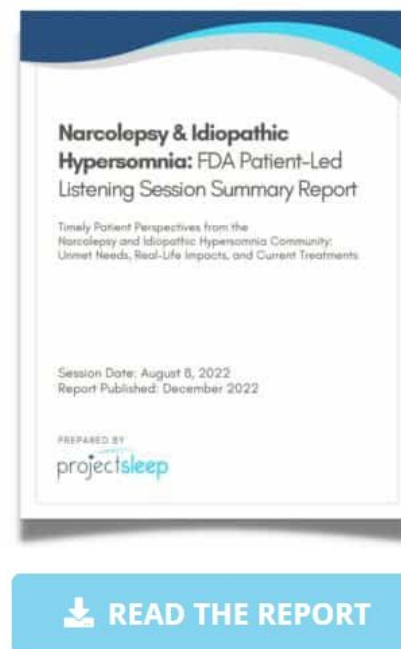
– Julie Flygare, JD

# FDA Listening Sessions

On August 8th, 2022, a patient-led Listening Session took place online between the Food and Drug Administration (FDA), Project Sleep, and patient advocates in the narcolepsy and idiopathic hypersomnia community. This 90-minute meeting featured seven patient or caregiver advocate speakers, along with a Project Sleep representative and a clinician.

## Topics Discussed

- Impacts of symptoms on daily functioning and quality of life
- Underrecognized and invisible aspects of living with narcolepsy or idiopathic hypersomnia
- Challenges with current therapies
- Patient and caregiver concerns including symptom severity, quality of life, disruption of daily activities, impacts on employment and parenting, and related considerations that are self-reported and often difficult to track clinically



# Nashville Advocacy Event

On August 13, 2022, Project Sleep held **Innovations in Narcolepsy Awareness & Advocacy**, a unique one-day meeting to empower the community with updates from the forefront of narcolepsy advocacy and awareness in Nashville, Tennessee.



# World Narcolepsy Day 2022 Events

Project Sleep hosted events in Sept 2022 leading up to World Narcolepsy Day on Sept. 22nd, 2022 including:

- Sept. 8: Mariángela Velásquez Story Sharing in Spanish. Watch [replay](#).
- Sept. 13: Mariángela Velásquez Story Sharing from Madrid. Watch [replay](#).
- Sept. 18: Adriana Andreeva Story Sharing in Bulgaria. Watch [replay](#).
- Sept. 22: Championing Awareness with Lauren & Isiah Thomas. Watch [replay](#).



In our featured World Narcolepsy Day event, we spoke with Lauren Thomas and her father, Isiah Thomas about all things narcolepsy, family support, and awareness.



# 4th Annual World Narcolepsy Day

In 2022, Project Sleep's Virtual Photo Booth generated over 620 photos and 20 videos by participants from six continents.

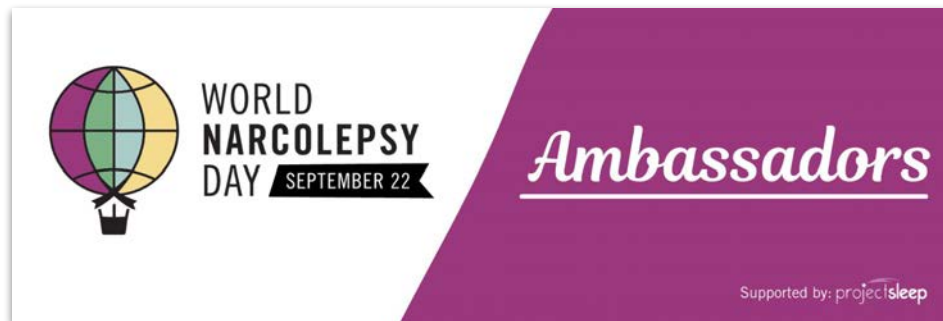


# World Narcolepsy Day Awareness

In 2022, almost 600 World Narcolepsy Day t-shirts were sold to advocates raising awareness around the world.



Project Sleep's 82 World Narcolepsy Day Ambassadors participated in activities, raised funds, and spread the word about narcolepsy in their local communities.





# World Narcolepsy Day Awareness

Thanks to amazing international volunteers, infographics and fact sheets are now available in French, Portuguese, Spanish, Polish, Dutch, and Danish.

parálisis del sueño

sueño nocturno interrumpido

cataplejía

alucinaciones hipnagógicas

somnolencia diurna excesiva

## 3 MILLONES DE PERSONAS MUNDIALMENTE

La narcolepsia es una condición neurológica crónica que afecta a 1 de cada 2,000 personas.

WORLD NARCOLEPSY DAY SEPTEMBER 22 PROJECT-SLEEP.COM

## BEHANDLING ER EN INDIVIDUALISERET PROCES

Der findes pt ingen kur mod narkolepsi. Forløbet for behandling af symptomer varierer fra person til person og kan inkludere medicinering, skemalagte lure, livsstilssændringer og social støtte.

WORLD NARCOLEPSY DAY SEPTEMBER 22 PROJECT-SLEEP.COM

## A NARCOLEPSIA É UMA CONDIÇÃO NEUROLÓGICA

A narcolepsia é uma condição neurológica crónica que prejudica a capacidade do cérebro regular o ciclo do sono.

WORLD NARCOLEPSY DAY SEPTEMBER 22 PROJECT-SLEEP.COM



## Sleep Advocacy Program 2022

# Our Advocacy Guiding Principles

- Advance Sleep Research
- Accelerate Treatment Options
- Ensure Access to Healthcare
- Further Education, Awareness, and Training
- Address Sleep Health Disparities

## Project Sleep's Advocacy Program Growth

- In 2017, Project Sleep began an advocacy partnership with the Sleep Research Society.
- In 2020, Project Sleep established the **Sleep Advocacy Forum** to increase federal awareness of sleep, ensure sleep's place in the federal advocacy process, and increase the effective coordination of sleep-related advocacy priorities to improve health outcomes for people with sleep disorders and the public at large.

# 3rd Annual Sleep Advocacy Forum

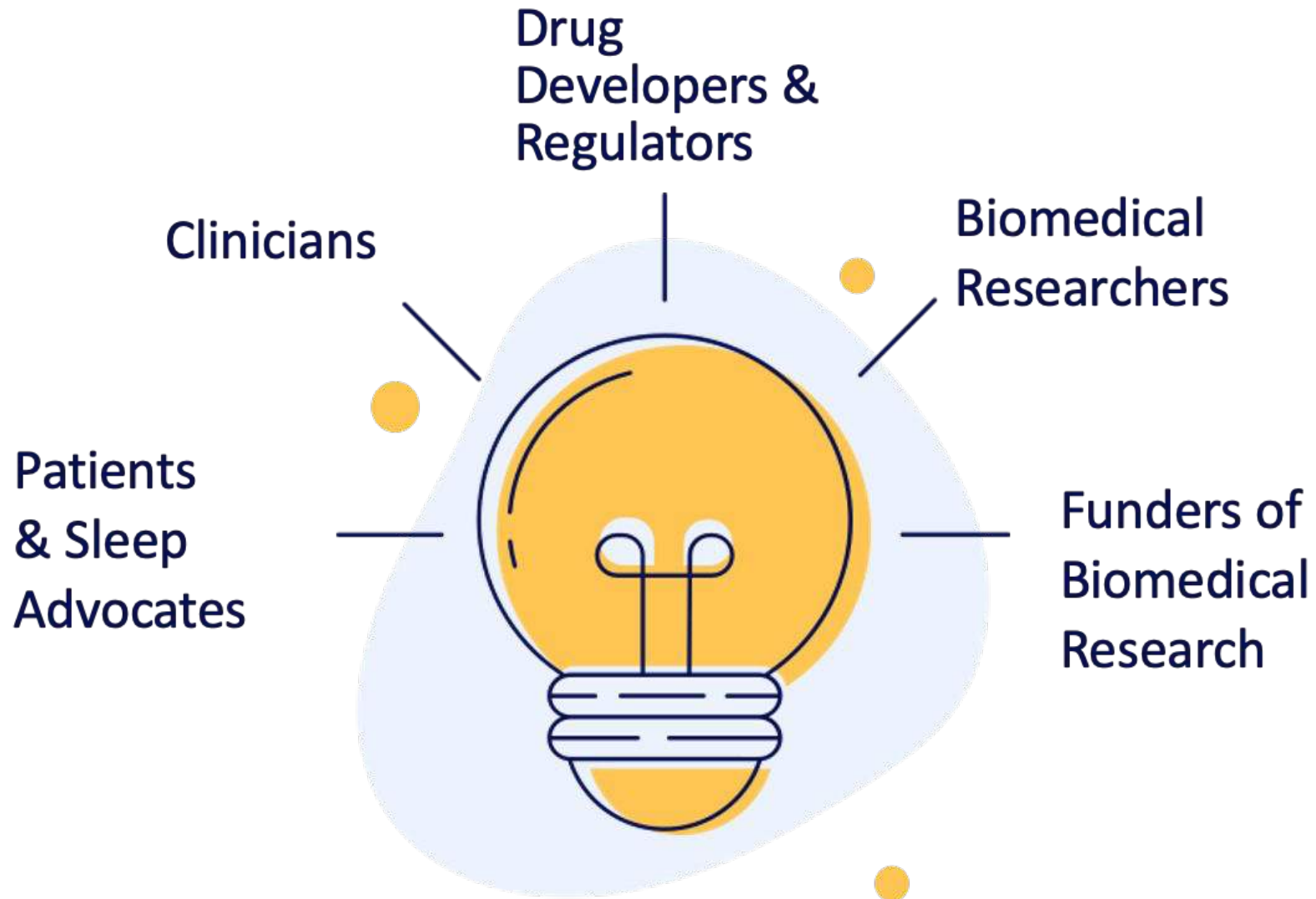
- Monday Oct 24, 2022, Project Sleep facilitated the third annual Sleep Advocacy Forum in Washington, DC. This in-person event brought together a diverse group of policy makers and sleep advocates to share updates and discuss areas of common interest. [Learn more.](#)
- Rising Voices of Narcolepsy speaker Matthew Horsnell kicked off the event, sharing his journey from feeling alone with narcolepsy toward becoming an empowered sleep advocate and community leader.



*"Sharing my journey with fellow sleep advocates makes the struggles of living with sleep disorders worthwhile. There is no greater honor than representing the sleep community with legislative advocacy."*

– Matt Horsnell

# Sleep Advocacy Forum Participants





# Sleep Advocates return to Capital Hill

After 2.5 years of virtual advocacy, Project Sleep and the Sleep Research Society returned to Washington DC for an in-person Hill Day on Tuesday, October 25th, 2022. Over 30 advocates from 11 states visited over 20 Congressional offices on Capitol Hill to educate and advocate for sleep research and awareness.

*"Being in Washington DC with Project Sleep to share my story of living with obstructive sleep apnea meant the world to me. It was a wonderful opportunity to discuss the 10 years I went without a diagnosis to push for more research and public awareness to make things better in the future."*

– Emma Cooksey, Project Sleep Board Member, Rising Voices Speaker & Sleep Apnea Stories Podcast Host



# Sleep Advocates return to Capital Hill



# New! Expert Advisory Board

In 2022, Project Sleep established an Expert Advisory Board. Project Sleep's Expert Advisory Board includes clinicians, researchers, patients, and advocates who are thought leaders and trailblazers in their respective fields. This powerful group will work together to accelerate our mission of improving public health by educating individuals and communities about sleep health, sleep equity, and sleep disorders. [Learn more.](#)





# Sleep Health Disparities Initiative

In 2022, Project Sleep celebrated diversity and intersectionality via features by month including:

- Black History Month, Women's History Month, National Poetry Month, LGBTQ+ Pride Month





## Philanthropy 2022



# Snowmobiling for Narcolepsy

In honor of all those living with narcolepsy, Rising Voices speaker Emily Kreuziger conducted a fundraiser to support Project Sleep while taking on the Park Rapids 250-mile Snowmobile Race on Jan 29-30, 2022. As both a person living with narcolepsy and a woman in a male-dominated sport, Emily certainly pushes the envelope as a high-level competitive snowmobile racer!

- Watch Emily's fundraising video
- Create your own fundraiser to celebrate a birthday, an athletic challenge, or in tribute or honor of a loved one



# Thank You from our Scholarship Recipients!

Huge thanks to our generous donors for providing critical support to college-bound students living with narcolepsy or idiopathic hypersomnia. In the fall, we caught up with the recipients to hear how college life is going and what the scholarship meant to them. Read [more](#) to discover the profound impact your support makes!

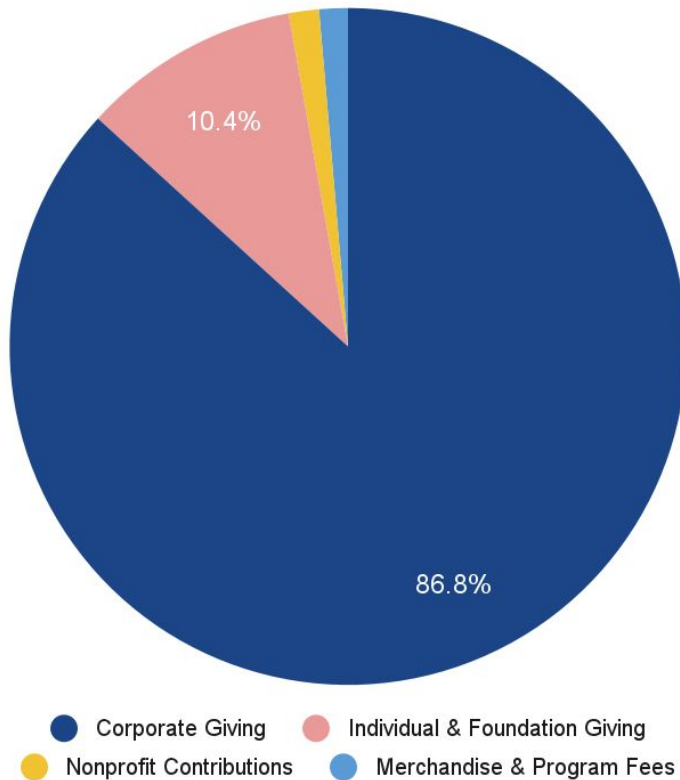


“Receiving the Jack & Julie Narcolepsy Scholarship made me feel heard and supported. Seeing the community of students who relate to me more than anyone pushed me even more to pursue my goals. This scholarship showed me that I am not alone.”

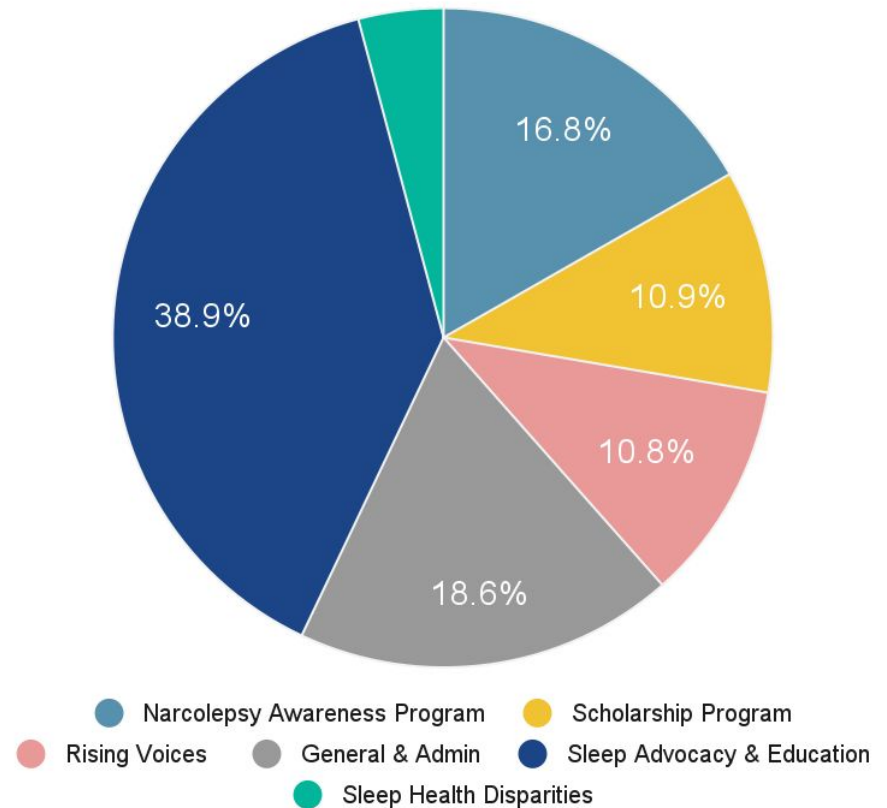
— **Fernanda, studying Kinesiology (Pre-PA) at Texas Tech University**

# 2022 Financial Position

## Total Revenue for 2022 \$695,549



## Total Expenses for 2022 \$423,644





**Thank you for your incredible support!**