



# IMPACT REPORT 2020

# A LETTER FROM JULIE FLYGARE

## PRESIDENT & CEO

Dear Project Sleep Community,

2020 was quite a year. While COVID-19 brought challenges, our community rallied together to support each other and further our shared mission.

With innovation more important than ever, Project Sleep continued to expand and develop initiatives to elevate underrepresented voices and facilitate connection and empowerment for sleep advocates.

Highlights include:

- Awarding 27 scholarships to students with narcolepsy and IH
- The Rising Voices of Narcolepsy program launched a new online Story Sharing series
- In the wake of the social justice movement, Project Sleep established new Sleep Health Disparities Policy Recommendations
- In response to COVID-19, Project Sleep created a video series on healthcare providers with narcolepsy and hosted an educational event with Dr. Emmanuel Mignot
- The inaugural Sleep Advocacy Forum took place in October with over 80 community leaders and stakeholders attending online.

This year proved that, even in the darkest of times, Project Sleep's strong community remains committed to building a brighter future together. We are forever grateful for your support.



Julie Flygare, JD  
President & CEO



# Project Sleep's 2020 Board of Directors



Julie Glazer Scher – Chair



Tracy Christensen – Secretary



Ed Sweet – Treasurer



Kylee Keskerian– Director



Anne Taylor - Director



Kamali (Kami) Barron - Director



Cienna Ditri - Director

# Project Sleep Hires New Programs Mgr.

We were thrilled to welcome Lauren Oglesby, MPH, as the new Programs Manager with Project Sleep. A public health educator and advocate with a focus on healthcare and resource accessibility for vulnerable and underserved populations, Lauren has personal and family experience with invisible disabilities and chronic conditions.

Joining the team in August 2020, Lauren coordinates Project Sleep's advocacy and awareness initiatives with the sleep community. She lives in Central Virginia with her family and loves cooking, reading, and hiking in the beautiful Blue Ridge Mountains.



# 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 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!*

# 2020 Programs at a Glance

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1. Sleep In 2020
2. Jack & Julie Narcolepsy Scholarship
3. Rising Voices of Narcolepsy
4. Narcolepsy Awareness Program
5. Sleep Advocacy Program



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

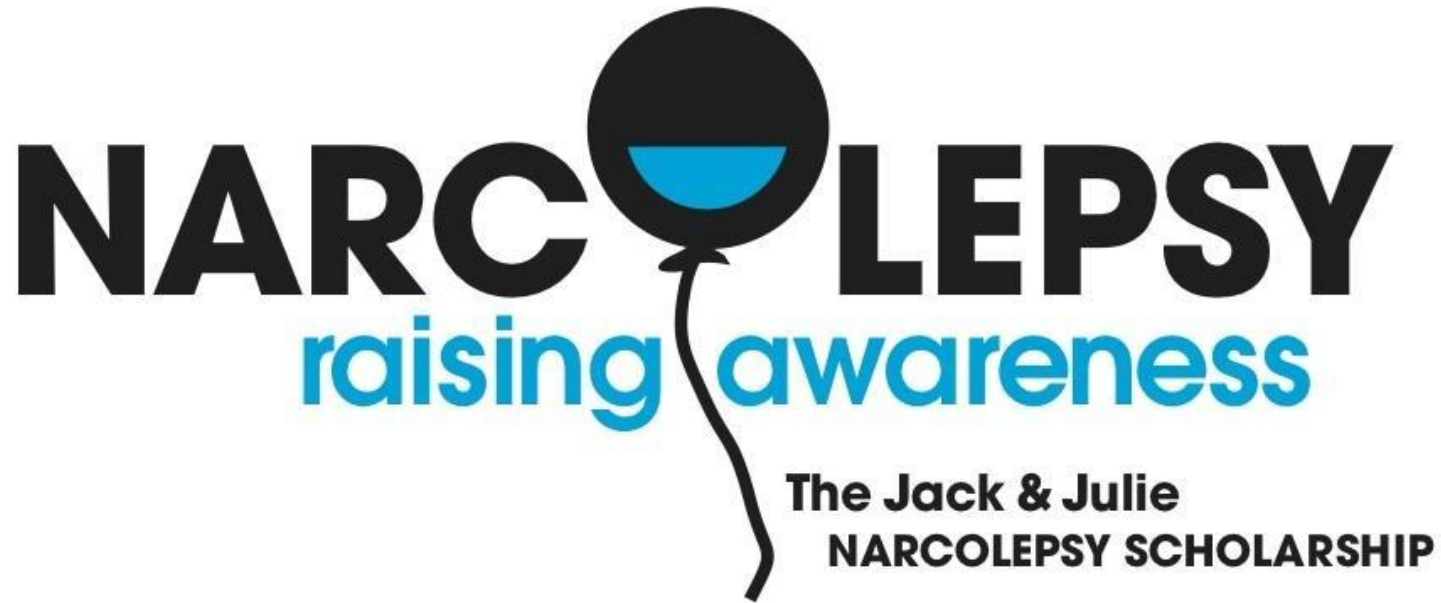
# Sixth Annual Sleep In

For the sixth year in a row, Project Sleep challenged individuals to stay in bed for 12-48 hours to raise awareness about sleep health and sleep disorders—and funds for Project Sleep—during the National Sleep Foundation's Sleep Awareness Week and Suddenly Sleepy Saturday in March. Sleep In 2020 participants:

- Posted **over 400 times** using the hashtag #SleepIn2020 on Instagram
- Pledged **1,795 hours** in bed
- Raised **over \$5,000** to support Project Sleep
- Spanned **5 countries**







**First-ever national scholarship program supporting students with narcolepsy while fostering awareness of this misunderstood condition within high school and college settings**

# Jack & Julie Narcolepsy Scholarship

In June 2020, **27 college-bound students** received scholarships through the Jack & Julie Narcolepsy Scholarship program. This was by far our largest class of recipients to date, with each recipient receiving \$1,000 toward their college education. Recipients included students diagnosed with narcolepsy or idiopathic hypersomnia.



# Scholarship Recipients Stay Involved

Kenya Gradnigo  
Opelousas, LA



2015

- Kenya received a Jack & Julie Narcolepsy Scholarship in 2015. She was diagnosed with narcolepsy with cataplexy at age 8.
- Kenya recently graduated from college and started her Master of Social Work (MSW) degree at Louisiana College.
- Her story is featured in our 2020 video [Healthcare Providers with Narcolepsy](#)

Kenya was diagnosed with narcolepsy with cataplexy when she was eight years old. She competes in pageants with narcolepsy awareness as her platform. She completed four years at her high school's magnet academy for biomedical sciences. She also has a black belt in Tae Kwon Do. She will be majoring in nursing at Northwestern State University this fall with the ultimate goal of becoming a nurse anesthetist.



2020





# Scholarship Recipients Stay Involved



Cassandra Stewart  
Nitro, WV

Cassandra was diagnosed with narcolepsy with cataplexy at age 5. Since then, her family and teachers have strived to provide a positive and efficient atmosphere for a great learning environment. Cassandra graduated in the top 25 of her class and will be attending **West Virginia University** in the fall, majoring in Fashion, Dress and Merchandising.

2017

- Cassandra received a Jack & Julie Narcolepsy Scholarship in 2017. She was diagnosed with narcolepsy with cataplexy at age 5.
- She advocated on Capitol Hill with Project Sleep in Nov. 2019.
- Cassandra recently graduated from WVU in Dec. 2020 with a passion for designing “adaptive fashion” for people with disabilities.
- She became an official Rising Voices of Narcolepsy speaker in 2020.

2019



2020

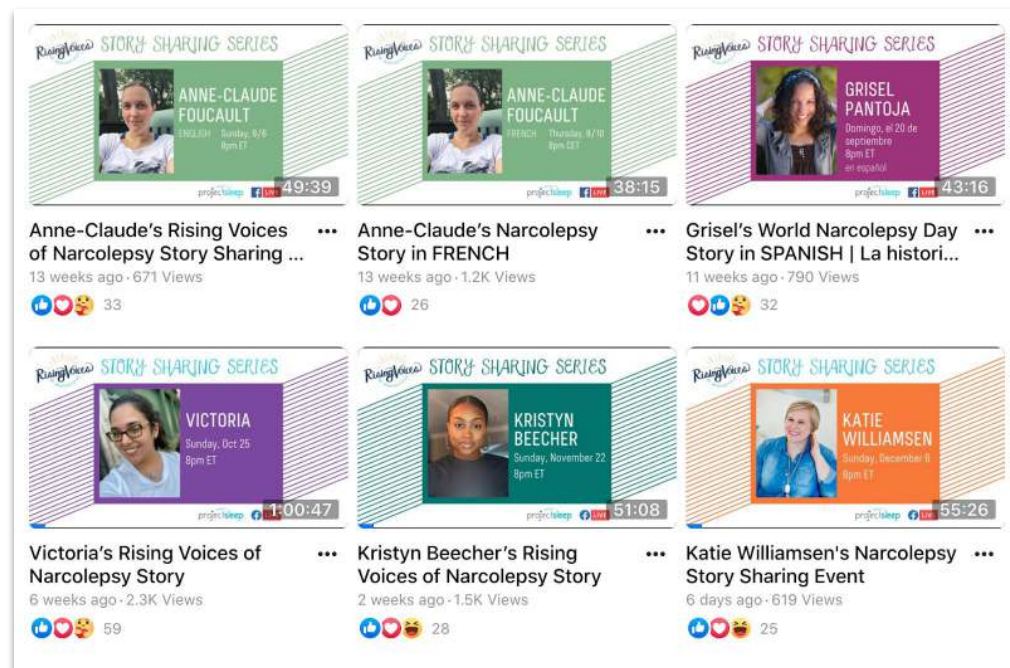




**Training people with narcolepsy to effectively share their stories through public speaking and writing**

# New Story Sharing Series

- In January 2020, Project Sleep launched the **Rising Voices of Narcolepsy Story Sharing Series**.
- These broadcasts aired twice monthly via Facebook Live, hosted by Julie Flygare, and featuring an RVN advocate's story followed by audience Q&A.
- In 2020, **24 trained advocates** shared their powerful stories live, including one in French and one in Spanish.
- Videos are available on Facebook and YouTube.



# Rising Voices of Narcolepsy Training

- Project Sleep held our 4th annual **Rising Voices of Narcolepsy training** in Summer 2020.
- 24 participants from the U.S., Mexico, England, and Portugal graduated from this year's training, including 14 diagnosed with narcolepsy with cataplexy, 8 diagnosed with narcolepsy without cataplexy, and 2 diagnosed with idiopathic hypersomnia.



# RVN 2020 Participant Evaluations

## Overall Participant Satisfaction Rating



**100%**

*All post-training survey respondents agreed that RVN gave them the skills and confidence needed to write about their experience with narcolepsy.*

*"I feel connected to a purpose that is bigger than just me...and I've gained the courage to speak to anyone about narcolepsy."*



# RVN 2020 Outcomes

- Despite the challenges of 2020, our trained speakers delivered an incredible **13 presentations** reaching about 5,210 audience members, including:
  - Medical students
  - Nursing students
  - Neurology residents
  - Neuroscience researchers
  - Universities
  - Medical assisting students
  - Polysomnography students
  - Pulmonologists and sleep specialists at the CHEST conference
- Additionally, RVN advocates conducted six media interviews and published two articles in 2020!



# Powerful Audience Responses

"The personal point of view of the patient is invaluable."

"I found myself eagerly awaiting more of her story."

"I loved the presenter's honesty and determination to succeed."

"Authentic."

"Very inspirational."

"A **voice** for her cause."

"Widened our perspective."

"She is still fighting for her dreams."

"The presenter was amazing."

"Informative and captivating."



"Genuine."

"Takes vulnerability and courage to present it."

"It taught me a lot about narcolepsy."

"Enlightening and educational."

"I now know there is something like this out there."

"I enjoyed the vivid explanations of discovery."

"I love how real, brave, and open you are."



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 2020

# New Narcolepsy Resources

In the wake of COVID-19, Project Sleep produced a Vice-style, three-part video series on Healthcare Providers with Narcolepsy. We promoted the videos via our blog, e-blasts, and social media platforms. This series includes:

- [Doctors with Narcolepsy](#)
- [Nurses with Narcolepsy](#)
- [Healthcare Providers with Narcolepsy](#)



- On Facebook, the three videos have over 31,000 views to date.
- On Instagram, the three videos have over 4,500 views to date.

# Fresh News Content

Project Sleep addressed community concerns regarding COVID-19 with a timely interview with Dr. Emmanuel Mignot on April 23, 2020. The [original Facebook video](#) has over **10,000 views and 355 comments**.



## Coronavirus, Infections, Immunology & Neurology



Part I of Julie Flygare's Interview  
with Narcolepsy Expert  
**Dr. Emmanuel Mignot**



# 2nd Annual World Narcolepsy Day

- The worldwide group of nonprofit organizations co-leading World Narcolepsy Day increased from 24 to **26 patient advocacy organizations**.
- A **16-member volunteer committee** developed and implemented Project Sleep's WND 2020 communications plan.
- Project Sleep's powerful new social media **"cloud campaign"** invited participants to write a message on a cloud and snap a photo to share online.



projectsleep



# Project Sleep's WND 2020 Events

Project Sleep hosted seven events during Sept. 2020 in preparation for and in honor of World Narcolepsy Day 2020:

- Three RVN presentations (including 1 in French and 1 in Spanish)
- World Narcolepsy Day Media Training
- Friends and Family Sharing Session
- World Narcolepsy Day Advocacy Training
- International Research Panel featuring six experts across five continents



# Celebrities & Influencers Raising Awareness

- Lawrence Gilliard Jr. (Actor)
- Ted Lieu (U.S. Rep. for California's 33rd district)
- Alex McKenna (Actor)
- Jeremy Palko (Actor)
- Rob Paulsen (Voice Actor)
- Aaron Schwartz (Actor)
- Isiah Thomas (NBA All-Star and Coach)
  - [Watch](#) Isiah Thomas raise critical awareness on TNT's The Arena on World Narcolepsy Day





# WND 2020 In the News

Rising Voices of Narcolepsy advocates Amanda Myers of Gainesville, FL and Lindsey Kizer from Charlotte, NC were featured in the news for World Narcolepsy Day.

## UF student lifts narcolepsy message

By Danielle Ivanov Correspondent

Published 11:05 a.m. ET Sept. 22, 2020 | Updated 11:09 a.m. ET Sept. 22, 2020

[View Comments](#)



Amanda Myers competes in the clean and jerk event at National University & Under 25 Championships in Las Vegas, Nevada, in March 2019. Myers has been diagnosed with narcolepsy. Andy Blaida



HEALTH

## Project Sleep Shows What Narcolepsy Really Looks Like

BY CHRISTIAN NOGUERA | CHARLOTTE  
PUBLISHED 2:45 PM ET SEP. 22, 2020



CHARLOTTE, N.C. — Narcolepsy is a chronic neurological condition that impairs the brain's ability to regulate the sleep-wake cycle.

According to Project Sleep, symptoms include:

- Excessive daytime sleepiness: Periods of extreme sleepiness during the day that feel comparable to how someone without narcolepsy would feel after staying awake for 48-72 hours. Often resulting in difficulty concentrating and staying alert.

# Josh Andrews: My Cause My Cleats

In 2020, NFL player Josh Andrews (#68) of the New York Jets chose Project Sleep as his #MyCauseMyCleats organization. On Dec. 6, Andrews wore his custom Project Sleep cleats in the Jets game against the Las Vegas Raiders.







## Sleep Advocacy Program 2020

# 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.

# Advocacy Day: February 2020

Patient advocates and sleep researchers met on Capitol Hill to educate policy makers about the importance of sleep health and sleep disorders.





# Tremendous Support from Congress

- In March 2020, a bipartisan group of **41 Representatives** signed onto an important letter prioritizing sleep health and sleep disorders in the Federal appropriations/budget process.
- This huge success is due to **sleep advocates** taking action across the country, with almost 10% of the House of Representatives supporting sleep community priorities.



# Project Sleep's Statement Against Racism and Commitments to Our Community

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- In June 2020, Project Sleep published a statement unequivocally condemning institutionalized racism, police brutality, and discrimination.
- Further, Project Sleep made commitments to:
  - Listen and learn, and then act intentionally to help reduce racism, bias, and barriers to healthcare access.
  - Highlight sleep research focused on race, racism, and sleep and health disparities, as well as advocate for more research in this area.
  - Deliberately work toward increasing the racial and ethnic diversity of our leadership community, including our board of directors and volunteer advocates.
  - Elevate powerful and important Black voices of the sleep community.

# New Sleep Health Disparities Policy Priorities

- In September 2020, Project Sleep published new sleep health disparities policy recommendations, in collaboration with leading sleep researchers.
- These new priorities were then incorporated into our ongoing national and grassroots advocacy efforts.



## Social Justice and Sleep Health Disparities Policy Recommendations

- **Training and Career Development:** Ensure funding for early-career pipeline programs that help individuals of low socio-economic status and underrepresented racial/ethnic minority groups to thrive in the medical and research fields. This can include strengthening existing loan forgiveness programs, bolstering career development and training grants and fellowships (at NIH), and providing infrastructure at the institutional level for developing minority faculty.
- **Community-Led Interventions:** Ensure dedicated research funding to develop and implement people-centered, community-led interventions to improve community awareness and treatment of sleep disorders and sleep loss. This could include building and strengthening existing NIH and PCORI initiatives to support Community-Based Participatory Research, Community Engaged Research, Community-Derived Interventions. These would fund projects that include the community as a full partner in research.
- **Education for Healthcare Providers:** Provide funding to educate public health and healthcare providers on signs of sleep loss and sleep disorder issues impacting racial minorities and underrepresented groups. Care providers are increasingly aware of the importance of sleep health, but providers often lack training in how to assess and treat sleep disorders.
- **Research Funding:** Provide meaningful research funding to better understand and address health disparities for minorities.
- **School Start Times:** Ensure research funding to study how school start times impact low socio-economic and minority communities. Ample evidence shows that delaying high school start times is a public health priority, and this can disproportionately impact minority-serving schools, undercutting academic success, mental health, and other outcomes in these communities.

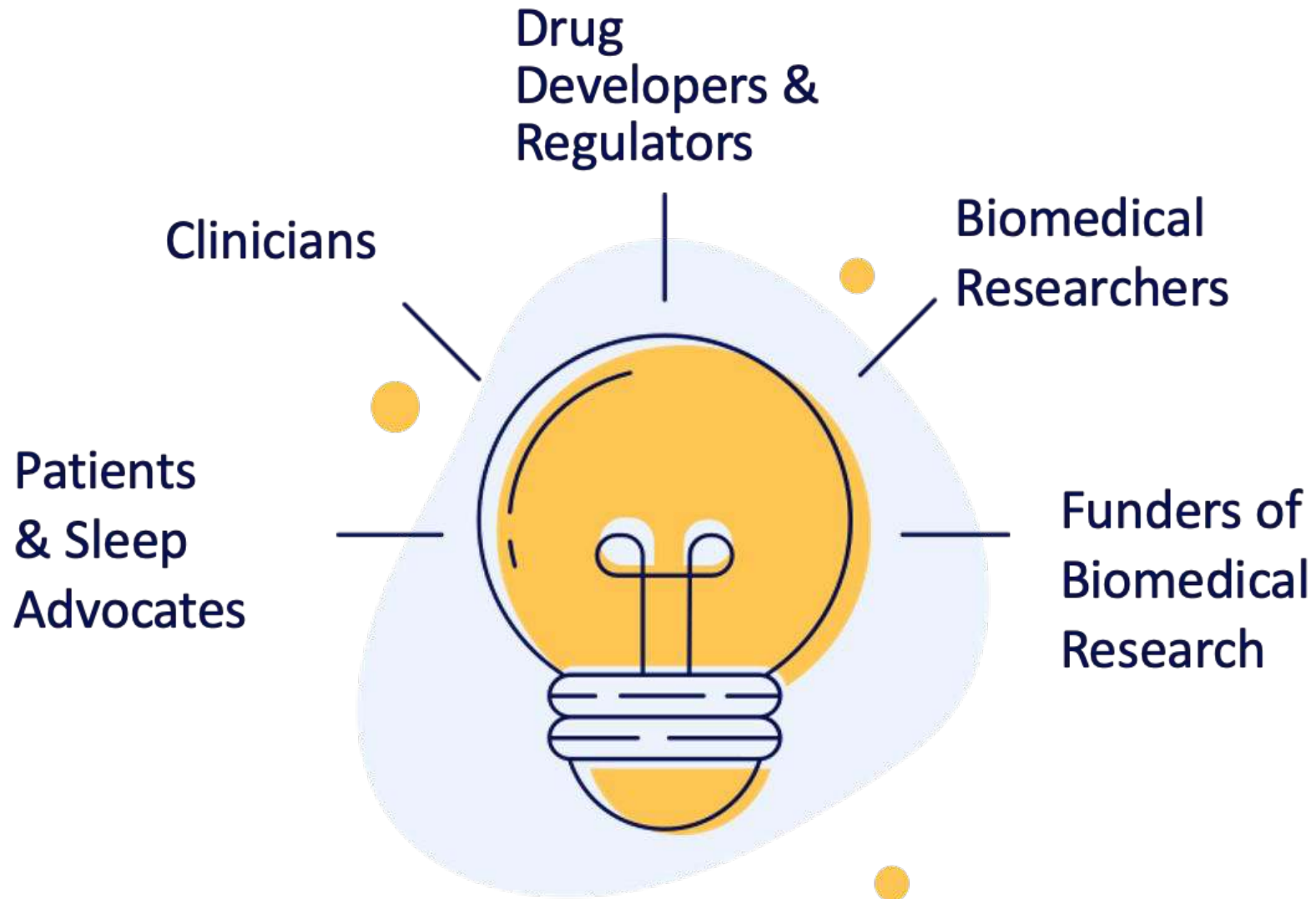


# Inaugural Sleep Advocacy Forum

- On Oct. 5, the inaugural **Sleep Advocacy Forum** featured educational sessions on a variety of topics important to the sleep community, including a featured panel on sleep health disparities.
- Over 80 advocates and panelists attended online, including Congressional staff, federal agency representatives, professional and advocacy leaders, drug developers, and sleep advocates.
- On Oct. 6, an Executive Session brought together organization leaders to talk about shared priorities and collaboration opportunities.



# Sleep Advocacy Forum Participants



# Participating Patient & Professional Orgs, Federal Institutes, Policy Makers & Sponsors

- Circadian Sleep Disorders - Network
- Hypersomnia Foundation
- KLS Foundation
- Narcolepsy Network
- Project Sleep
- RLS Foundation
- Start School Later
- Wake Up Narcolepsy
- FDA, NINDS, NHLBI, PCORI
- American Academy of Sleep Medicine
- American Lung Association
- American Thoracic Society
- Sleep Research Society
- Society for Research on Biological Rhythms
- Congressman Adam Schiff
- Avadel, Harmony, Jazz, and Takeda

# Highlight Videos on Website & YouTube

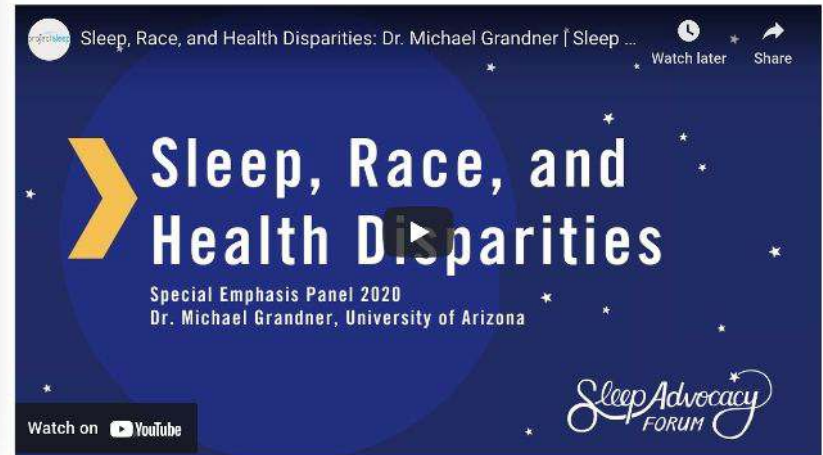
## Congressional Update: Congressman Adam Schiff



“You know the power of your voice, the power of your voices together, and the power of your community to make the change we all demand.”

— Congressman Adam Schiff

## Sleep, Race, and Health Disparities: Dr. Michael Grandner, University of Arizona



“If we’re going to make an impact on sleep in the real world and in public health, we have to understand what’s upstream.”

— Dr. Michael Grandner

# Huge Advocacy Win!

- In December 2020, Project Sleep had a definitive advocacy win when Congress established the new CDC **Chronic Disease Awareness Program** in the final FY21 Omnibus Bill!
- Our community's hard work advocating over several years for the establishment of this program paid off.

Vision and Eye Health.....	35,600,000
Alzheimer's Disease.....	4,000,000
Inflammatory Bowel Disease.....	1,000,000
Interstitial Cystitis.....	20,500,000
Excessive Alcohol Use.....	1,000,000
Chronic Kidney Disease.....	1,100,000
Chronic Disease Education and Awareness....	4,000,000
Prevention Research Centers.....	2,500,000
Heart Disease and Stroke.....	1,500,000
	26,961,000
	143,105,000
	148,129,0
	29,300

DIVISION II—DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGREEMENTS  
APPROPRIATIONS ACT, 2021

The explanatory statement accompanying this division is approved and indicates Congressional intent. Unless otherwise noted, the language set forth in House Report 116-450 carries the same weight as language included in this explanatory statement and should be complied with unless specifically addressed to the contrary in this explanatory statement. While some language is repeated for emphasis, it is not intended to negate the language referred to above unless expressly provided herein.

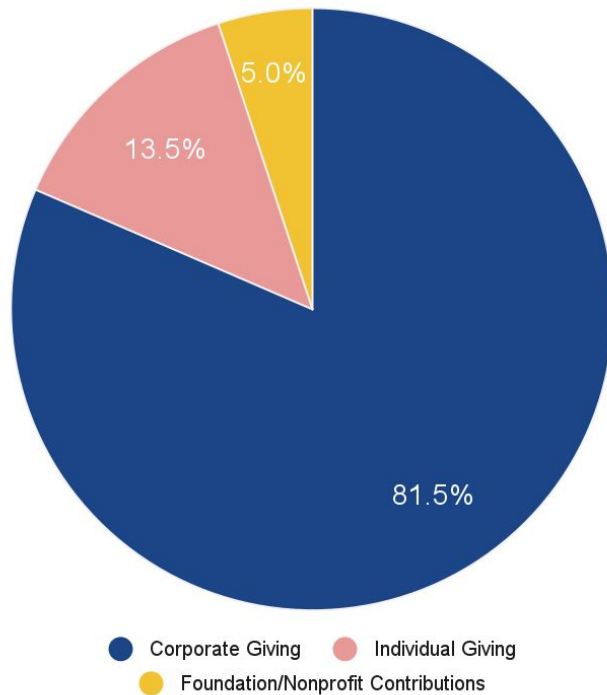
In providing the operating plan required by section 516 of this Act, the departments and agencies funded in this Act are directed to include all programs, projects, and activities, including those in House Report 116-450 and this explanatory statement accompanying this Act. All such programs, projects, and activities are subject to the provisions of this Act.

In cases where House Report 116-450 or this explanatory statement directs the submission of a report, that report is to be submitted to the Committees on Appropriations of the House of Representatives and the Senate. When an explanatory statement refers to the Committees on Appropriations, unless otherwise stated, it refers to the Committees on Appropriations of the House of Representatives and the Senate.

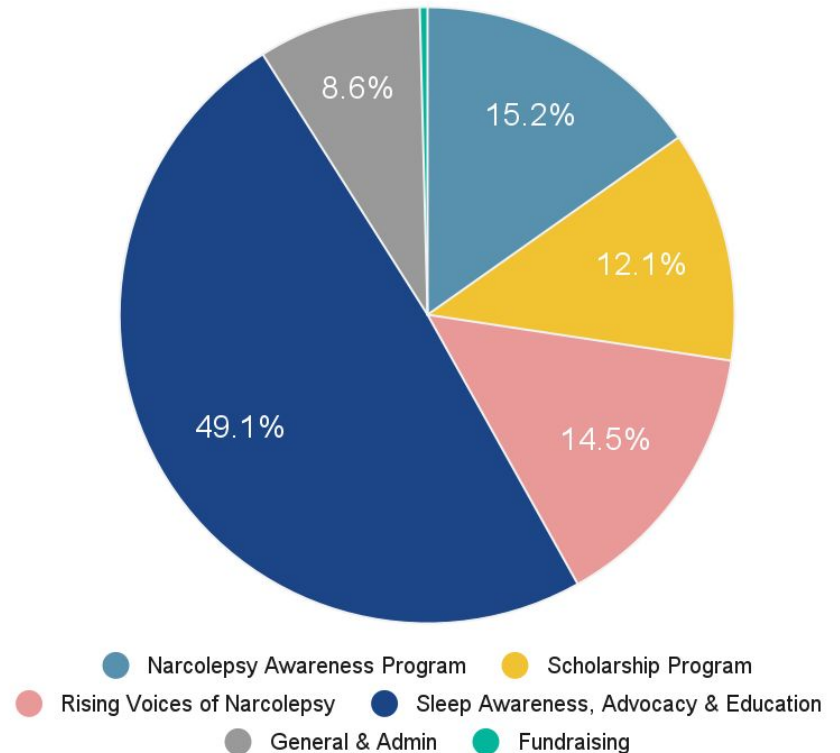


# 2020 Financial Position

## Total Revenue for 2020 \$376,890



## Total Expenses for 2020 \$243,863





**Thank you for your incredible support!**