



# IMPACT REPORT 2018

# A LETTER FROM JULIE FLYGARE

## PRESIDENT & CEO

Dear friends,

2018 was a banner year for Project Sleep. By unanimous approval, the board of directors officially appointed me as our organization's first President & CEO. I'm honored to serve the organization in a full-time capacity, and am committed to accelerating Project Sleep's efforts to empower advocates, increase our impact and improve many more lives.

In 2018, Project Sleep's Jack & Julie Narcolepsy Scholarship awarded 14 scholarships of \$1,000 each, accelerating the scholarship to a major milestone – awarding a total of 50 scholarships to 50 students in five years.

Over the course of 2018, we also trained our second class of Rising Voices of Narcolepsy advocates, launched the Narcolepsy Awareness Program and advocated for federally-funded research on sleep and sleep disorders.

Likewise, I personally took our message to various key audiences at schools, hospitals and conferences, delivering 15 speaking engagements in seven U.S. states, and abroad in Australia and Sweden.

I'm thrilled to report that we are poised for continued growth, and I'm grateful for your interest and support.



Julie Flygare, JD  
President & CEO



# 2018 BOARD OF DIRECTORS



Julie Glazer Scher – Chair



Tracy Christensen – Secretary



Ed Sweet – Treasurer



Julie Flygare – President & CEO



Melissa Buron – Director

# ABOUT PROJECT SLEEP

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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!*

# PROGRAMS AT A GLANCE

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1. Jack & Julie Narcolepsy Scholarship
2. Sleep In Campaign
3. Narcolepsy: Not Alone Campaign
4. SLEEP-2 Award
5. Rising Voices of Narcolepsy
6. Sleep Advocacy
7. Narcolepsy Awareness Program (New!)



**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

- Received 51 applicants from 28 states
- Awarded 14 scholarships of \$1,000 each
- Collaborated with Hypersomnia Foundation to give out our **first scholarship** to a student with idiopathic hypersomnia



# Jack & Julie NARCOLEPSY SCHOLARSHIP

2014:  
2 Scholarships



2015:  
9 Scholarships



2016:  
14 Scholarships



2017:  
11 Scholarships



2018:  
14 Scholarships

## TO DATE:

50 scholarships of \$1,000 each (totaling \$50,000) distributed to 50 students in our first five years.



**Raising awareness about sleep health &  
sleep disorders during National Sleep Awareness Week**

# Sleep In 2018

- March 9-11, 2018
- 77 individuals and 16 teams from 8 countries and 37 U.S. states
- A total of 1,538 hours in bed pledged
- 370 #SleepIn2018 Instagram posts
- Raised more than \$6,000 to support Project Sleep programming





International narcolepsy awareness campaign

# Narcolepsy: Not Alone in 2018

- The campaign now has more than 1,400 photos from 49 countries



Taiwan



Connecticut



Sweden



Australia



Sweden

# Narcolepsy: Not Alone in 2018

- Watson joined the Narcolepsy: Not Alone campaign!
- Watson is Dr. Emmanuel Mignot's dog living with canine narcolepsy with cataplexy





PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE



THE UNIVERSITY OF ARIZONA

College of Medicine

Tucson



To engage patients, scientists and other stakeholders  
as partners across the entire span of sleep research

# SLEEP-2 2018 Review

- Final meeting held in Baltimore, MD on 6/1/18
- Meeting recap:
  - Laura Forsythe, PhD, MPH, Director of Evaluation & Analysis at PCORI, kicked off the event with a fantastic keynote on “Engaging Patients in Sleep Research: How to Measure Success?”
  - Project Sleep’s President & CEO, Julie Flygare, JD, along with consultant Rebecca Fuoco, MPH, followed up with “Patient Reported Outcomes (PROs) & Narcolepsy Research Priorities.” The presentation highlighted the group’s progress in advancing:
    - People-centered language recommendations in sleep research
    - The SLEEP2 Narcolepsy Survey data set
    - The exploration of “brain fog” as a possible PRO for narcolepsy
  - Lisa Meltzer, PhD, gave a lively talk on “School Start Times and Adolescent Health”



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

# RVN Dual Purpose

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1. Empower participants and foster growth
2. Increase public awareness and correct misperceptions

# RVN 2018 Review

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- 36 participants from 18 U.S. states, Australia, Canada, and the UK
- 70% diagnosed with N+C, 30% diagnosed with N-C
- Average age: 35
- Represent a wide range of educational and professional backgrounds
- 17 participants completed all coursework

# RVN 2018 Articles & Presentations

- “Scared of the Dark: The Narcolepsy Symptoms that No One Talks About,” Kayla D., Medium, September 13, 2018
- Michelle Z. spoke at Project Sleep’s Innovations in Narcolepsy Awareness event, Boston, MA, September 15, 2018
- Katie W. spoke at Avadel Pharmaceuticals headquarters, St. Louis, MO, September 20, 2018
- Lisa L. spoke at SOMNEX, The Sleep Show, London, UK, October 13, 2018
- Sheila C. spoke to nurses at a Children’s Hospital in Nova Scotia, Canada, November 1, 2018
- Estefy F. spoke at University of Texas Southwestern, November 30, 2018



# RVN 2018 Video Project

- Five RVN speakers, Julie Flygare, and videographers met in San Jose, CA for a weekend in September, 2018
- Videos were made to raise narcolepsy awareness and promote the RVN program
- Videos scheduled to launch in January, 2019



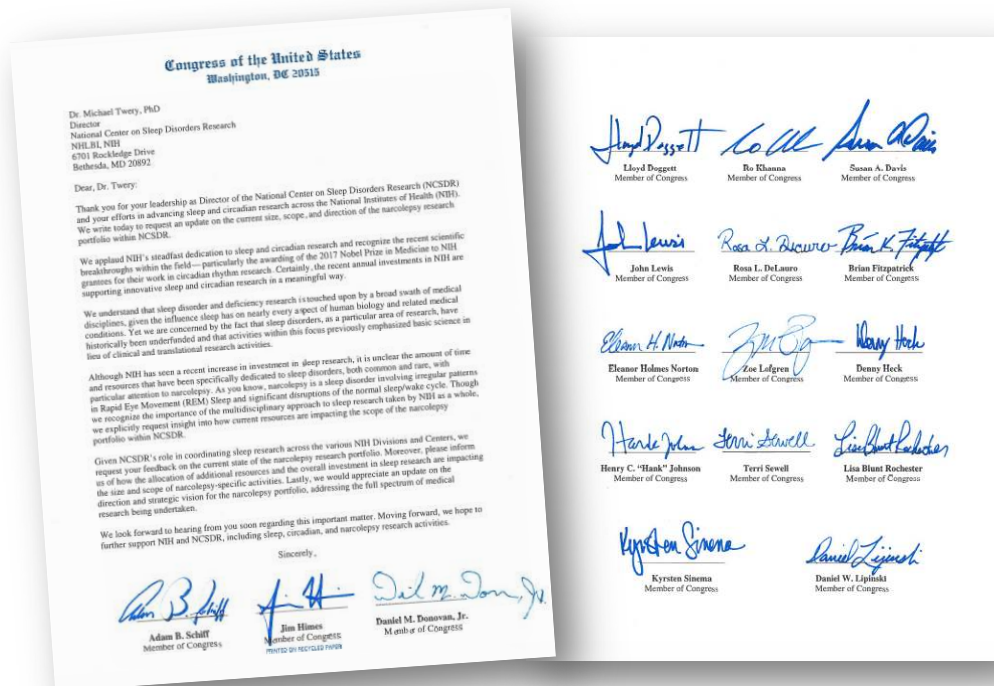


## Sleep Research Education and Advocacy Collaboration with Sleep Research Society

# Advocacy Program 2018

## Collaboration with Sleep Research Society:

- Led narcolepsy initiative, bipartisan letter from 17 members of Congress sent to NIH and NIH responded
- Created new opportunity to meet w/ legislators during summer recess – focus on CDC funding issues



Sleep  
Research  
Society®



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 (NAP)

# NAP Tactics 2018

1. Media Efforts
2. Speaking Engagements
3. Evergreen Narcolepsy Resources
4. Fresh News Content
5. Event – Innovations in Narcolepsy Awareness, September 15, 2018 in Boston, MA



# Innovations in Narcolepsy Awareness

- One-day meeting in Boston with more than 40 attendees
- Nick Dawson, ED of Innovation at Kaiser Permanente, facilitated a “design thinking” interactive workshop



# “Ask Us Anything” FB Live with Dr. Mignot, Watson and Julie Flygare

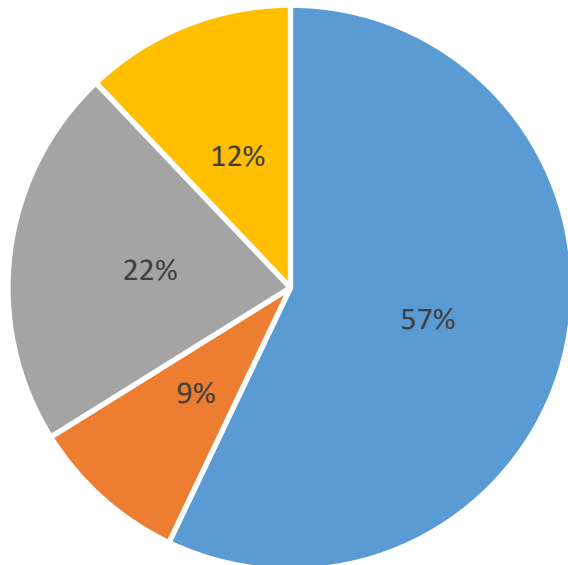


Watch Video:

<https://www.facebook.com/ProjectSleepAwareness/videos/532777383811403/>

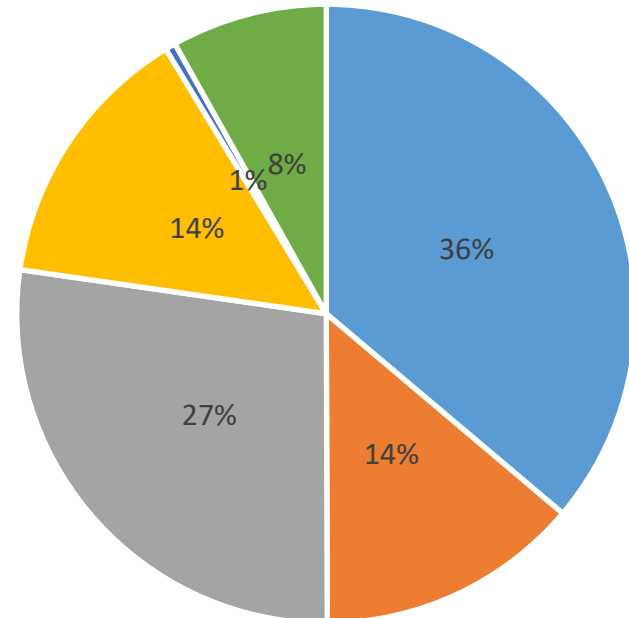
# 2018 FINANCIAL POSITION

**Total Revenue for 2018**  
**\$148,913**



- Corporate Giving
- Government Grants
- Individual Giving
- Foundation/Nonprofit Contributions

**Total Expenses for 2018**  
**\$138,873**



- Narcolepsy Awareness Program
- Rising Voices of Narcolepsy
- Fundraising
- Scholarships
- Education, Advocacy & Awareness
- General and Administrative



**Thank you for your incredible support!**