



# IMPACT REPORT 2019

# A LETTER FROM JULIE FLYGARE

## PRESIDENT & CEO

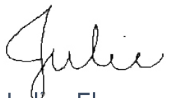
Dear friends,

2019 continued Project Sleep's growth trajectory, with the expansion of existing programs and the development of exciting new initiatives:

- Project Sleep's Jack & Julie Narcolepsy Scholarship awarded 18 scholarships out of a record-breaking pool of more than 80 applicants
- The Rising Voices of Narcolepsy program launched a powerful new video series
- Project Sleep led the narcolepsy community in the creation of World Narcolepsy Day on September 22

My personal passions are turning toward encouraging the federal government to more actively support sleep research. In collaboration with the Sleep Research Society, Project Sleep held an advocacy day in Washington, D.C. in February, which resulted in a recommendation from 31 congresspeople and one of the House appropriations committees to increase funding for sleep and circadian research.

This building year went by very quickly, and I'm proud to say that we laid a strong foundation for sustained growth in support of our community. Thank you for your contributions to this effort!



Julie Flygare, JD  
President & CEO



# Board of Directors 2019



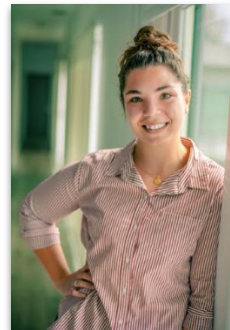
Julie Glazer Scher – Chair



Tracy Christensen – Secretary



Ed Sweet – Treasurer



Kylee Keskerian – Director



Anne Taylor – Director



Julie Flygare – Non-Voting Member

# 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!**

# 2019 Programs at a Glance

---

1. Rising Voices of Narcolepsy
2. Narcolepsy Awareness Program
  - World Narcolepsy Day
  - Ode to Joy Response
  - Central Texas Narcolepsy Forum
3. Jack & Julie Narcolepsy Scholarship
4. Sleep Advocacy Program
5. Annual Sleep In Campaign



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

# Rising Voices of Narcolepsy: 2019 Review

- 31 narcolepsy advocates graduated from the RVN training program from across the United States, and internationally in Canada and Australia
- Included a diverse set of participants:
  - 24 diagnosed with type 1 narcolepsy with cataplexy
  - 5 diagnosed with type 2 narcolepsy without cataplexy
  - 1 diagnosed with idiopathic hypersomnia
  - 1 diagnosed with Kleine-Levin syndrome
- Average age of participants: 34 years old



Rising Voices of Narcolepsy advocates met up in-person at the Narcolepsy Network's annual patient conference in Albuquerque, NM, in Oct. 2019.



# RVN 2019 Deliverables

- 17 live speaking presentations
- Continued sharing from past RVN graduates



RVN trained speakers, Keta and Shannon meeting at an event in Atlanta, GA



RVN trained speaker, Ellis, speaking at Rush Medical School in Chicago, IL



RVN trained speaker, Matt, speaking to pharmacy students in Nashville, TN



# RVN 2019 Participant Evaluations

Overall Participant Satisfaction Rating: 4.9/5



RVN graduates provided feedback about the program:

*"This training has given me the confidence to raise awareness and help others by sharing my story again."*

*"Hearing stories from other people with narcolepsy helped me develop confidence in my own ability."*

# RVN 2019 Video Project

- Five RVN speakers met in 2018 to record videos
- The videos were published in **January 2019**
- **26.4K views** on YouTube and Facebook





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





# WORLD NARCOLEPSY DAY

SEPT 22, 2019



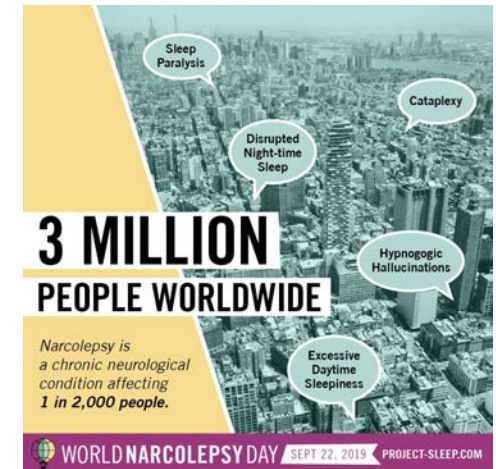
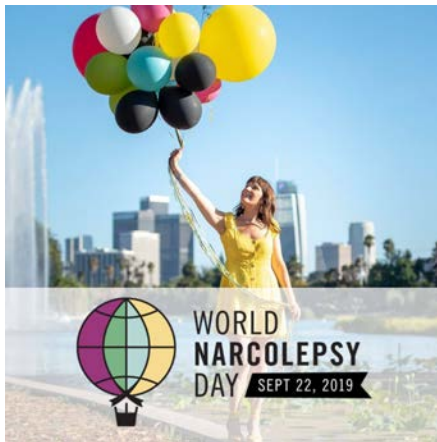
# World Narcolepsy Day 2019

---

1. Project Sleep led the creation of World Narcolepsy Day (WND)—September 22—to bring the community together and generate awareness on a global scale
2. In-person activities took place in Vancouver at the World Sleep Congress 2019
3. Online activities and social media engagement occurred worldwide
4. 24 participating organizations co-led the inaugural World Narcolepsy Day and conducted widespread media outreach

# Project Sleep's WND Online Activities

- Sign/photo submissions
- Infographics & tools
- Facebook frame
- T-shirt fundraiser
- Congressional recognition





# Project Sleep's WND In-Person Activities

In-person activities took place at the World Sleep Congress in Vancouver, Canada. Project Sleep led:

- A pronouncement featuring interviews with world-leading narcolepsy specialists streamed live via Facebook Live
- An event featuring various narcolepsy non-profit orgs
- A WND photo booth



# World Narcolepsy Day: Media

- Media outreach from participating organizations generated 20 articles in the U.S., Ireland, Australia, Canada, and the UK
- Two Spanish language stories were published, including a feature article on [CNN Español](#)



# Ode to Joy: Project Sleep Response

In August 2019, IFC released the film *Ode to Joy*, featuring a main character portrayal of narcolepsy with cataplexy. While Project Sleep was not involved in the development or filming, we worked both with the film team and independently to help viewers learn more about narcolepsy with cataplexy.

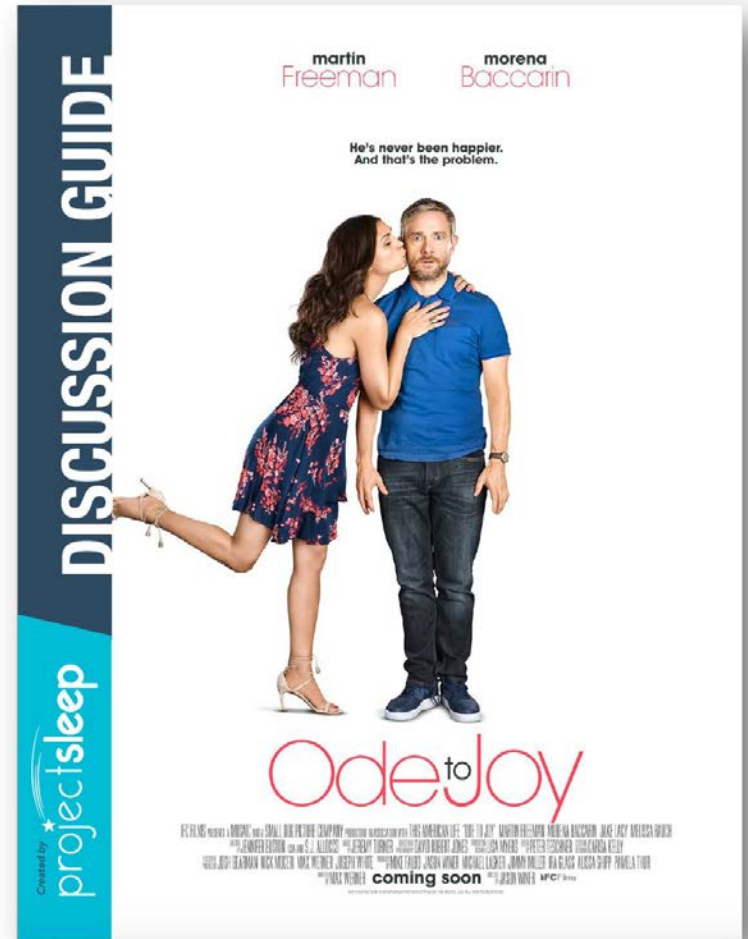


Julie Flygare and Project Sleep Board Member Ed Sweet saw the film at the Phoenix Film Festival.

# Ode to Joy: Project Sleep Response

## Project Sleep created resources including:

- A PSA with the film's director, Jason Winer
- A resource page on the movie website
- A Media Guide for the film's stars and director, with suggested language and accurate talking points
- A Project Sleep web page with a movie discussion guide
- A Cheat Sheet for narcolepsy experts and sleep clinicians
- An *Ode to Joy* movie review on the Project Sleep blog
- An AASM blog post on what sleep doctors should know





# Ode to Joy: Project Sleep Response

Project Sleep's Julie Flygare proudly partnered with IFC Films and *Ode to Joy* Director, Jason Winer, to create this PSA about narcolepsy with cataplexy. **[Watch now!](#)**



# Central Texas Narcolepsy Forum

On Saturday, June 15, 2019, more than 90 people gathered in Austin, TX for the **Central Texas Narcolepsy Forum**, an event co-hosted by Project Sleep and the Austin Narcolepsy Support Group.





# Central Texas Narcolepsy Forum

---

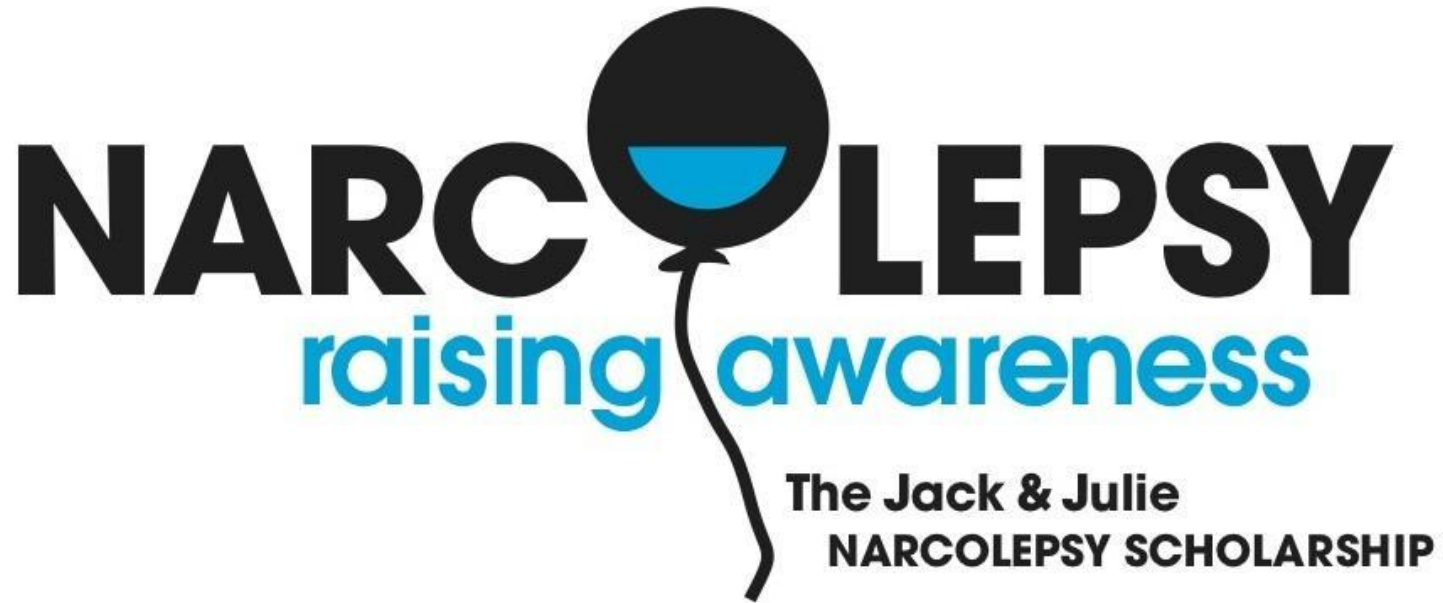
## Participant Reflections

*“This was a phenomenal experience. ...I’m so grateful that my husband could attend with me. His perspective on what I go through changed dramatically.”*

—Sharon

*“It was literally the first time in eight years that I’ve had an opportunity to be present and get familiar with my own narcolepsy.”*

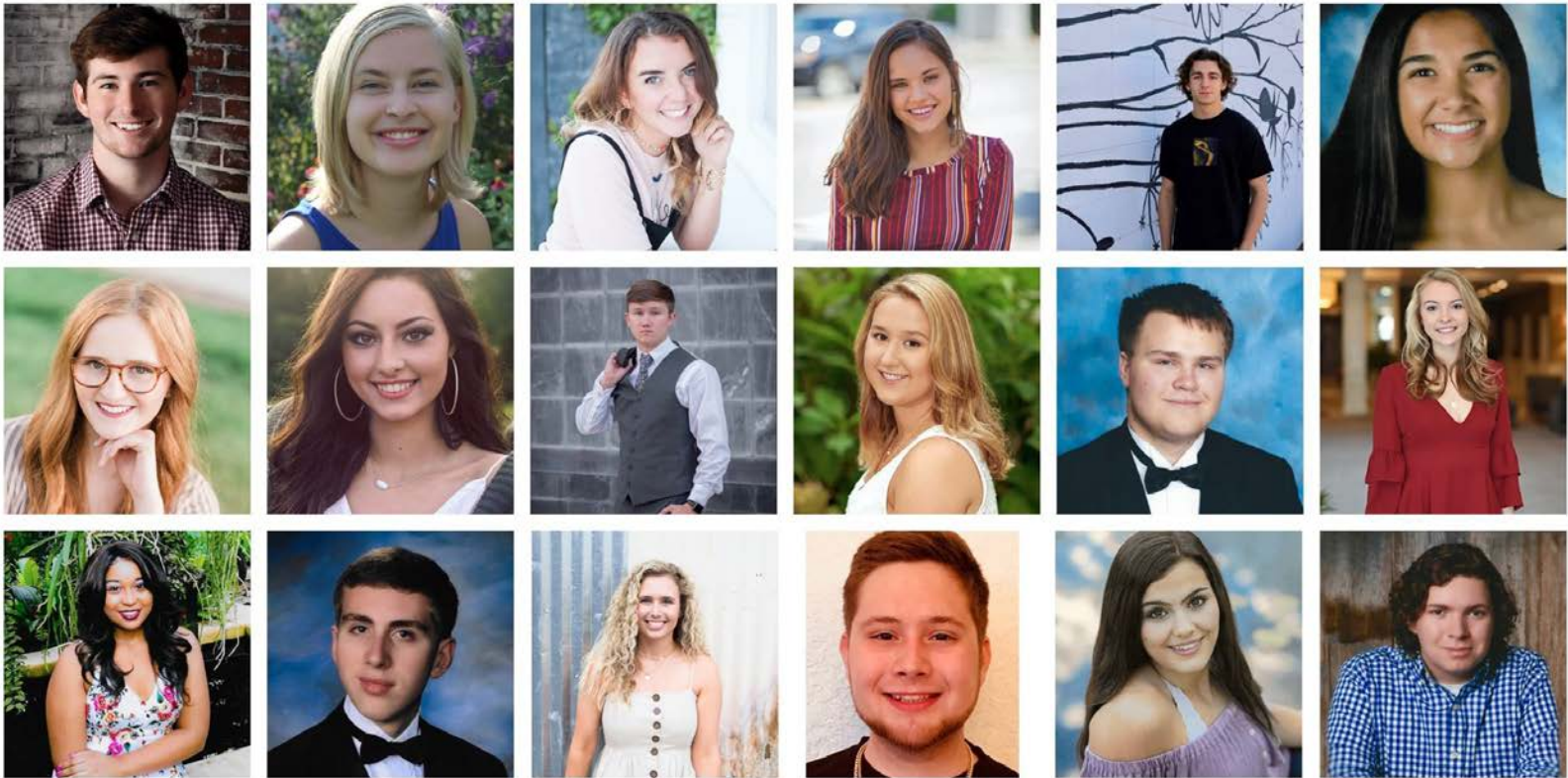
—Vanessa



**National scholarship program supporting  
students with narcolepsy while fostering awareness**

# Jack & Julie Narcolepsy Scholarship

1. 18 Recipients were awarded scholarships
2. More than 80 applicants applied
3. Collaboration with the Hypersomnia Foundation
4. College updates published in November 2019



# Meeting Our Scholarship Recipients

It is wonderful to see our scholarship recipients get involved in our other programs and activities!



Mary, 2019 scholarship recipient, attended our Central Texas Narcolepsy Forum in Austin, TX.



Jessica, 2017 scholarship recipient, took a Narcolepsy: Not Alone photo with Julie Flygare at Narcolepsy Network's Annual Patient Conference.



Cassandra, 2017 scholarship recipient, attended our Advocacy Day on Capitol Hill in Nov. 2019, and met with her Senator, Joe Manchin of West Virginia.





Give  
Sleep  
a Voice!

## Sleep Advocacy Program

# Advocacy Day: February 2019

Patient advocates and sleep researchers went to Capitol Hill to educate policy makers about the importance of sleep health and sleep disorders. This Hill Day was co-led by the Sleep Research Society and Project Sleep.

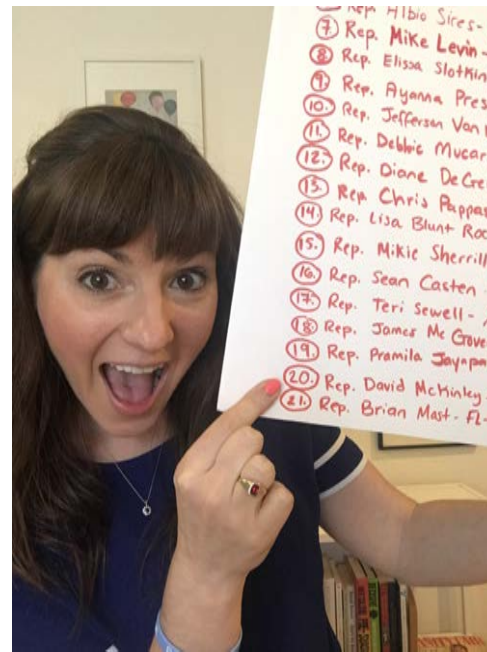
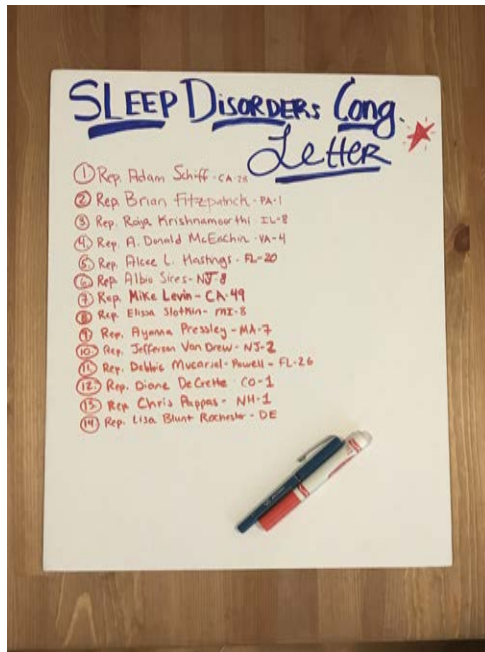




# Congressional Letter: March 2019

Sleep advocates across the country urged their members of the U.S. House of Representatives to sign a letter supporting sleep community priorities, including:

- NIH funding for sleep disorders research
- DoD funding for sleep disorders research
- CDC funding for sleep awareness



# Congressional Letter: March 2019

31 members of the House of Representatives signed the letter in a bi-partisan effort.



# Advocacy Gets Results!

Thanks to the efforts of Project Sleep and the Sleep Research Society, the House Appropriations Committee on Labor, Health and Human Services, and Education published a show of support for increased funding in FY2020.

*“The Committee commends the recent expansion and advancement of the sleep and circadian research portfolio under the coordination of the National Center on Sleep Disorders Research. The Committee encourages dedicated research activities on **specific sleep disorders**, such as narcolepsy and restless legs syndrome, to ensure scientific progress benefits **patients** impacted by debilitating conditions disordering their sleep and biological rhythms.”*



# Advocacy Day #2: November 2019

In the fall of 2019, Project Sleep and the Sleep Research Society co-hosted a second Advocacy Day, including a Congressional briefing. Leaders from other major patient advocacy organizations and professional societies participated in the day's activities, including:

- American Academy of Sleep Medicine
- Circadian Sleep Disorders Network
- Hypersomnia Foundation
- Narcolepsy Network
- Society for Research on Biological Rhythms
- Start School Later
- Wake Up Narcolepsy



# Advocacy Day 2: November 19

During the briefing, **Ebony Lay**, a telecommunications engineer and Rising Voices of Narcolepsy speaker from Kansas, shared her story of going 28 years with symptoms before finding an accurate narcolepsy diagnosis.



*“I’m sharing my story because representation matters.”*

— Ebony Lay



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



# Sleep In 2019: Record-Setting Slumber Party!

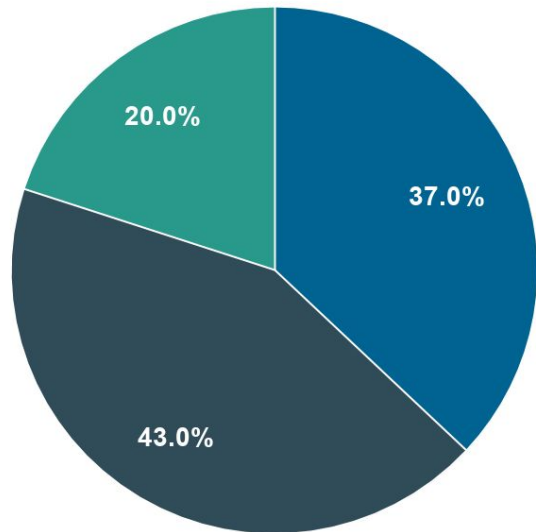
Over the weekend of March 8-10, Project Sleep challenged individuals to stay in bed for 12-48 hours to raise awareness about sleep health and sleep disorders—and funds for Project Sleep. In conjunction with the National Sleep Foundation's Sleep Awareness Week and Suddenly Sleepy Saturday, Sleep In 2019 participants:

- Pledged **1,420 hours** in bed
- Raised **\$10,000** to support Project Sleep
- Spanned **8 countries**: Australia, Canada, Germany, Myanmar, New Zealand, Tunisia, Turkey, and the U.S.



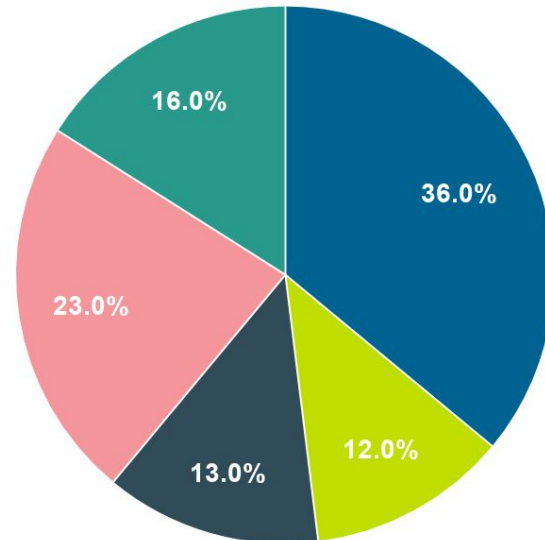
# 2019 Financial Position

## Total Revenue for 2019 \$167,503



● Individual Giving ● Corporate Giving  
● Foundations & Non-Profit Contributions

## Total Expenses for 2019 \$152,654



● Narcolepsy Awareness Program ● Education, Advocacy & Awareness  
● General & Admin ● Rising Voices of Narcolepsy ● Scholarship Program



***Thank you for your incredible support!***