



Impact Report 2017

A LETTER FROM JULIE FLYGARE FOUNDER AND PRESIDENT



Dear Friends,

There's a saying "Raise your voice, even if your voice shakes." For Project Sleep, 2017 was a year of incredible firsts, stepping forward into new spaces and places and encouraging new voices to join the conversation.

We officially launched Rising Voices of Narcolepsy – enrolling our first class of speakers and writers into the program. This was also a ground-breaking year for our advocacy work – piloting a new collaboration to educate and accelerate sleep education and research.

All this and so much more was made possible by generous individuals coming together to support Project Sleep's mission and vision for a brighter future. I hope you will enjoy reading this report knowing that you play a role in this work.

Gratefully yours,

A handwritten signature in black ink that reads 'Julie'.

Julie Flygare, JD
President & Founder
Project Sleep
www.project-sleep.com

2017 BOARD OF DIRECTORS

- Julie Flygare, JD - President
- Tracy Christensen - Vice-President
- Julie Glazer Scher - Treasurer
- Emilee Pressman, MPH - Secretary
- Melissa Buron - Director

ABOUT PROJECT SLEEP

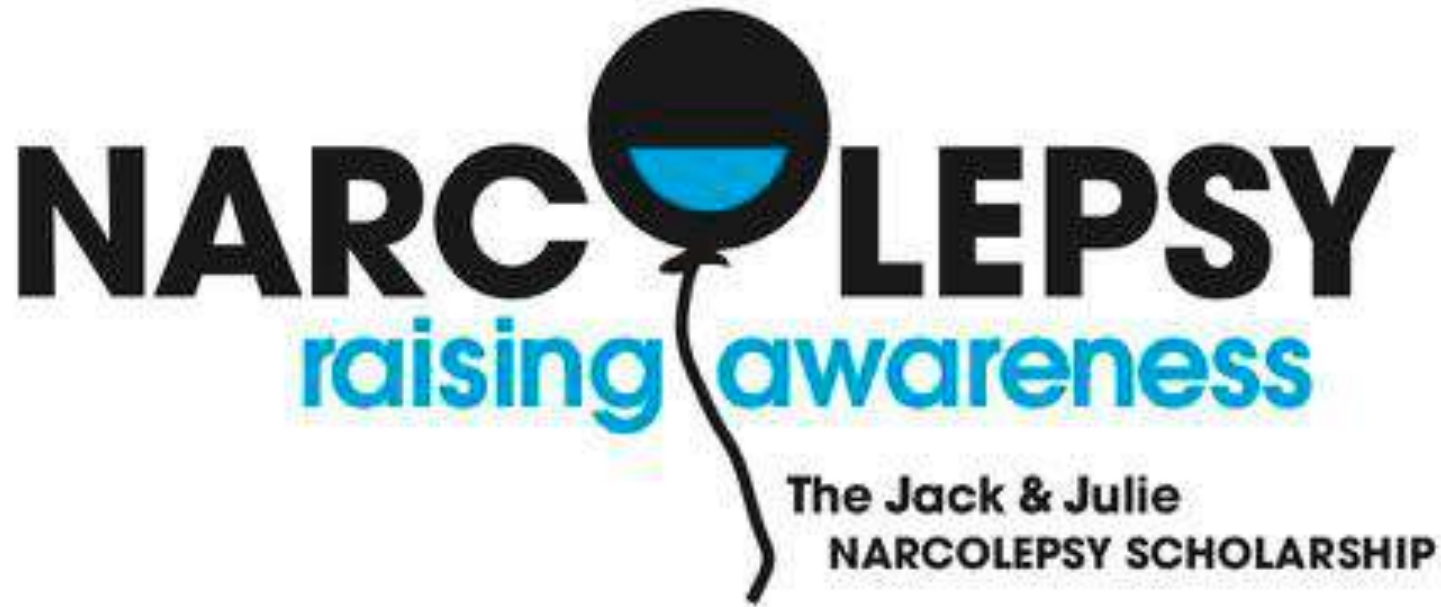
1. Incorporated in California in 2013
2. Received 501(c)(3) tax-exempt status in 2014
3. Mission:

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

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 (New!)



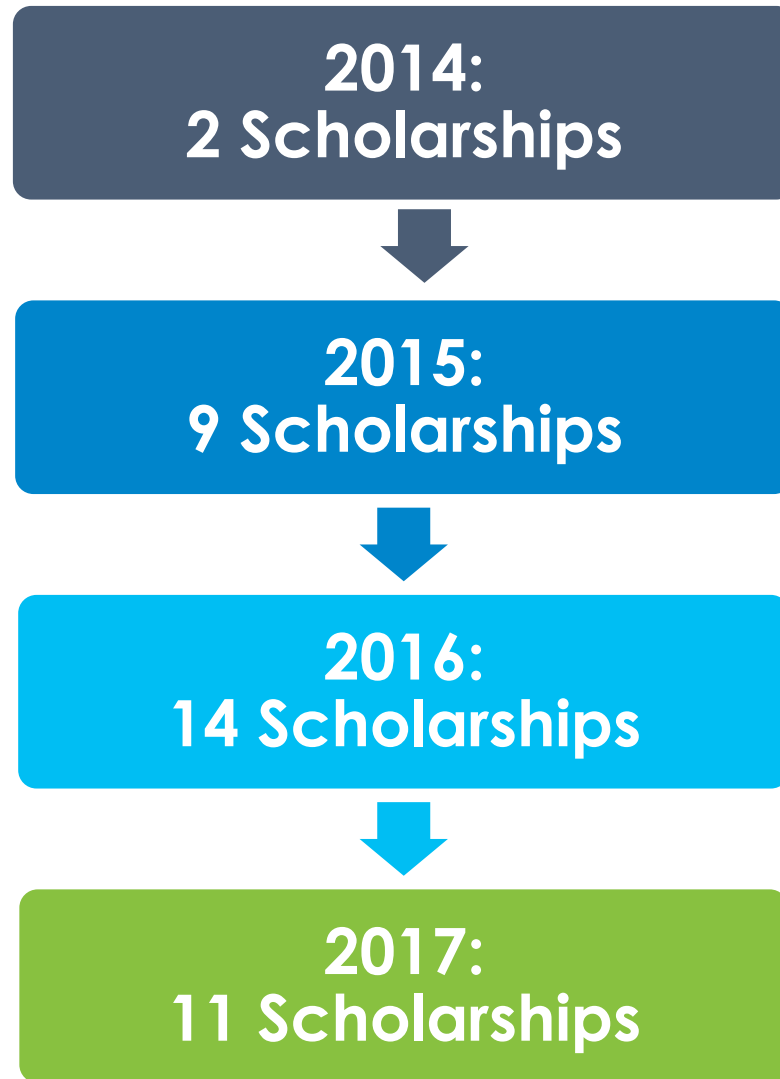
First-ever national scholarship program supporting students with narcolepsy while fostering awareness of this misunderstood condition within high school and college settings

Jack & Julie NARCOLEPSY SCHOLARSHIP

- Received applications from 45 students
- Distributed **11 scholarships** of \$1,000 each on 8/1/17
- Published “thank you from college” on 11/24/17



Jack & Julie NARCOLEPSY SCHOLARSHIP





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

Sleep In 2017 Review

- On March 10-12, 2017, this third annual event rallied individuals from around the world to make peace with sleep.
- Participants stayed in bed for 12-48 hours over the weekend while raising awareness via social media (#SleepIn2017) and raising vital funds for Project Sleep.

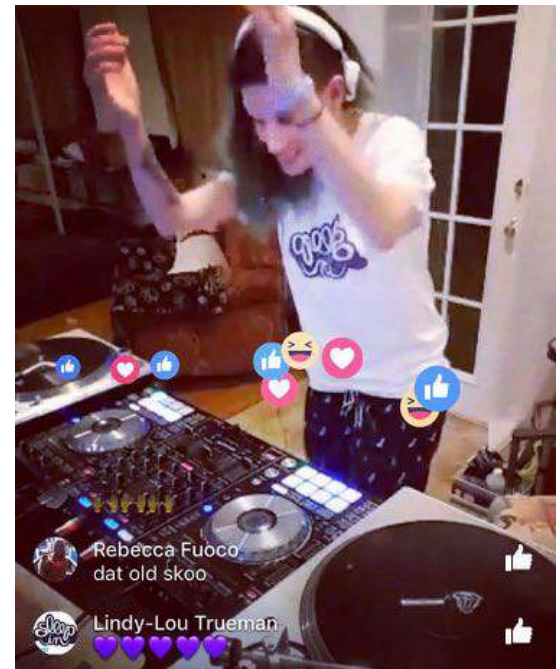
Sleep In 2017 - Schedule of Events:

Friday 3/10/17 @ Your Bedtime – InstaSleepIn

Saturday 3/11/17 @ 12noon ET – Live Broadcast w/ Julie Flygare

Saturday 3/11/17 @ 5pm ET – Twitter Chat

Sunday 3/12/17 @ 7pm ET – REM Dance Party w/ DJ Fe

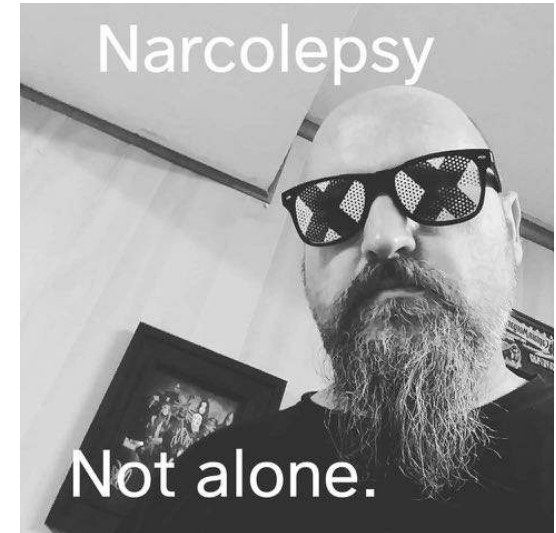




International narcolepsy awareness campaign

NARCOLEPSY: NOT ALONE 2017 Review

- Over 1,400 photos representing over 45 countries





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

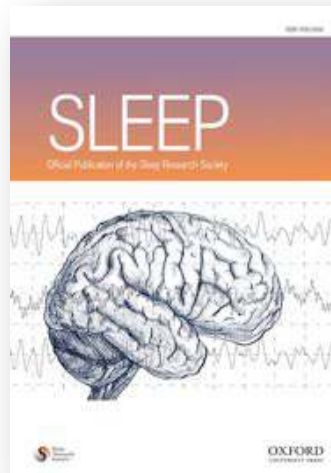
SLEEP-2 2017 Review

- Second SLEEP-2 Meeting held in Boston, MA on 6/3/17 (focused on narcolepsy)
 - Developed the SLEEP-2 Narcolepsy Survey and collected over 1,239 responses
 - Coordinated a narcolepsy patient panel
- Third SLEEP-2 Meeting held in Bethesda, MD (focused on insomnia)



SLEEP-2 2017 Review

- PS consultant, Rebecca Fuoco, MPH's scholarship from 2016 SLEEP-2 meeting led to two paper publications in the academic journal, SLEEP and resulted in the journal updating their author guidelines in accordance with Ms. Fuoco's recommendations.
 - Rebecca E. Fuoco, MPH. "People-Centered Language Recommendations for Sleep Research Communication". Sleep, Volume 40, Issue 4, 1 April 2017, <https://doi.org/10.1093/sleep/zsx039>
 - Daniel J. Buysse, MD; Sairam Parthasarathy, MD; Julie Flygare, JD. "Introducing People-Centered Language to SLEEP" Sleep, Volume 40, Issue 4, 1 April 2017, <https://doi.org/10.1093/sleep/zsx038>



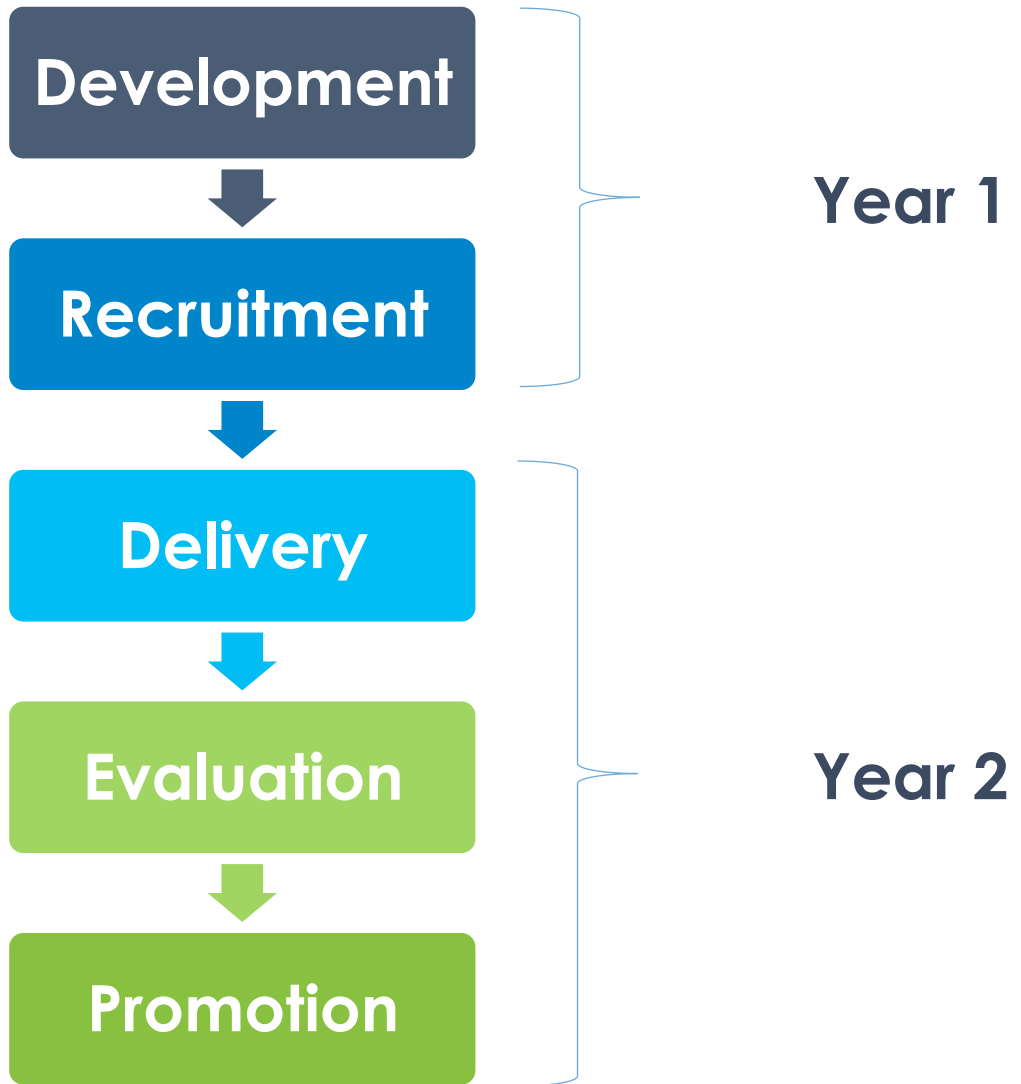


Training people with narcolepsy to effectively share their stories through public speaking and writing

RVN Dual Purpose

1. Participant empowerment and growth
2. Increasing public awareness and correcting misperceptions

RVN Pilot Timeline – Currently in Year 2



RVN 2017 Review

- Conducted our first RVN training sessions over the summer 2017
- 20 participants completed coursework to go on to become official RVN trained speakers and writers.



RVN Review through December 2017

- Two speeches delivered by two speakers
- Two articles published by one writer



"Grisel held the attention of her audience every single minute and was genuine, inspiring, and spoke with confidence."

– Diann Newman, FIU



Sleep Research Education and Advocacy Pilot Collaboration with Sleep Research Society

2017 Pilot Collaboration with SRS

1. Targeted Letter Writing Campaign (109 letters from 36 states)
2. Advocacy Day and Congressional Briefing on Nov. 17, 2017



SELECT SPEAKING ENGAGEMENTS

- Congressional Briefing on Sleep at the US Capitol
- PCORI-funded SLEEP-2 Conference
- Hoag Health Sleep Symposium



MEDIA HIGHLIGHTS

- CNN Health: [Having narcolepsy is harder than running a marathon, says runner](#)
- Up/Lifted Podcast: [Episode #9 Guest Julie Flygare](#)
- NBC Affiliate WSAZ Charleston 3: [Nitro graduate receives national narcolepsy scholarship](#)
- Daily Press: Greyer received prestigious scholarship
- KSL.com: [How sleep, zombies, duct tape and more can earn you money for college](#)





Thank you for your incredible support!