



Annual Report 2016

A LETTER FROM JULIE FLYGARE FOUNDER AND PRESIDENT

Dear friends,

Thank you for making 2016 such a fantastic year in advancing Project Sleep's mission to raise awareness about sleep health and sleep conditions. From the White House to Stanford; from Ireland to Italy – 2016 was a transformative year of growth and community leadership for Project Sleep.

Perhaps the greatest lesson I learned this year was the power of **storytelling**. While at the Precision Medicine Initiative event at the White House, I gave a four-minute pitch about “How might we make research delightful?” but unlike others who had gone before me, I framed my pitch in the context of a story. Afterward, a few very important individuals approached me to thank me for my contribution.

This gives me great hope for our organization's future, as we advance the Rising Voices of Narcolepsy program with a strong emphasis on storytelling, among other things. Thank you for your support and generous contributions – together we are building a brighter future!

Gratefully yours,



Julie Flygare, JD
President & Founder



2016 BOARD OF DIRECTORS

- Julie Flygare, JD - President
- Tracy Christensen - Vice-President
- Sharon O'Shaughnessy - 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

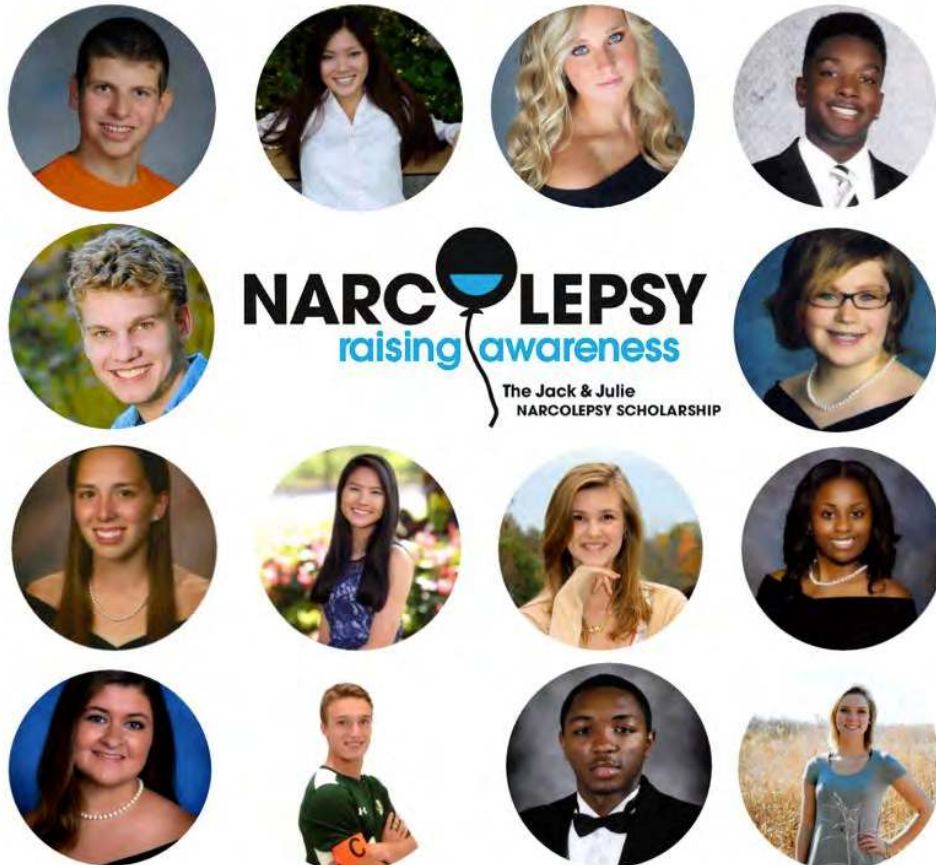
1. Jack & Julie Narcoplepsy Scholarship
2. Sleep In Campaign
3. Narcoplepsy: Not Alone Campaign
4. SLEEP-2 Award *(New!)*
5. Rising Voices of Narcoplepsy *(New!)*



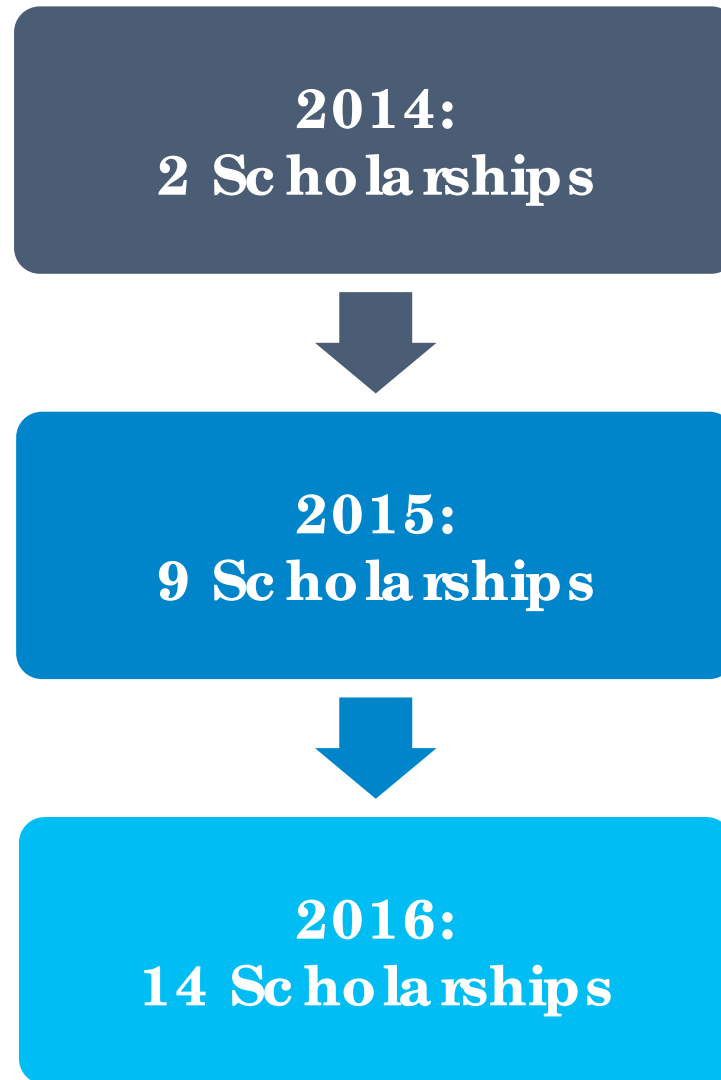
First-ever national scholarship program supporting students with narcolepsy while fostering awareness of this misunderstood condition within high school and college settings

Jack & Julie NARCOLEPSY SCHOLARSHIP

- Received a record number of applicants – 53 students representing 30 states across the country
- Distributed 14 scholarships of \$1,000 each on 8/1/16
- Published “thank you from college” on 11/24/16



Jack & Julie NARC OLEPSY SCHOLARSHIP

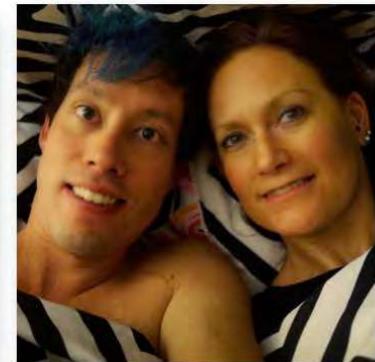




**Raising awareness about sleep health &
sleep disorders during National Sleep Awareness Week**

Sleep In 2016 Review

- March 11-13, 2016
- 92 participants from 10 countries (Australia, Antigua and Barbuda, Canada, France, Germany, Ireland, the Philippines, South Africa, Sweden and US) and 31 US states.
- Activities:
 - Friday – Insta Sleep In on Instagram
 - Saturday – Sleep In Twitter Chat
 - Sunday – Live Broadcast



NARCOLEPSY: NOT ALONE

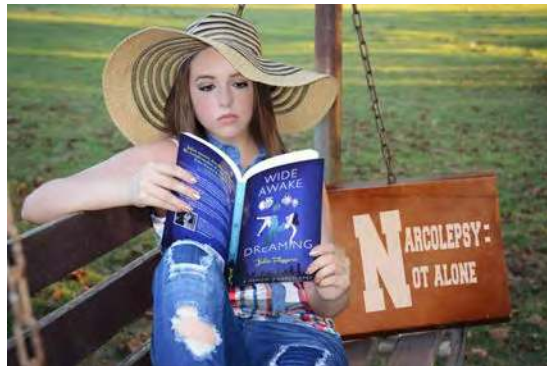
International narcolepsy awareness campaign

NNA 2016 Review & 2017 Goals

- Over 1,300 photos representing over 40 countries



Narcolepsy not alone





PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE



THE UNIVERSITY OF ARIZONA

College of Medicine

Tucson

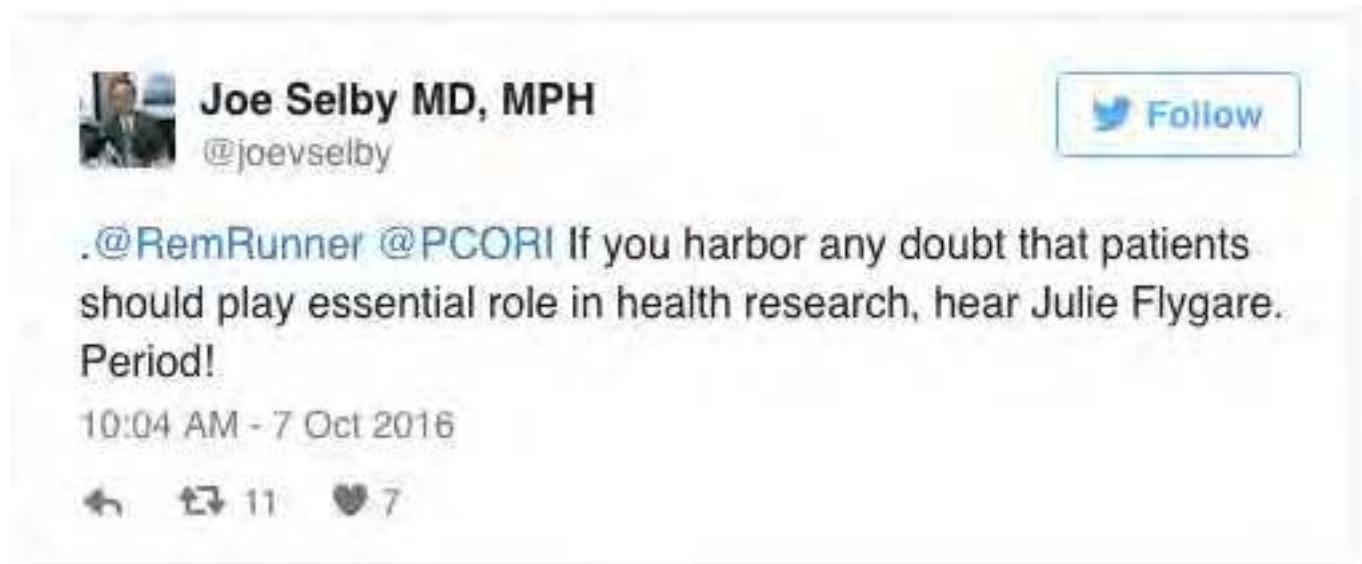


To engage patients, scientists and other stakeholders
as partners across the entire span of sleep research

SLEEP-2 2016 Review

- First of 4 meetings held in Bethesda, MD on 10/7/16
- Next meeting in Boston on 6/3/17 (focus on narcolepsy)
- Meeting recap:

<https://project-sleep.com/pcori-engagement-conference-unite-scientists-and-advocates-to-make-sleep-research-more-patient-centered/>



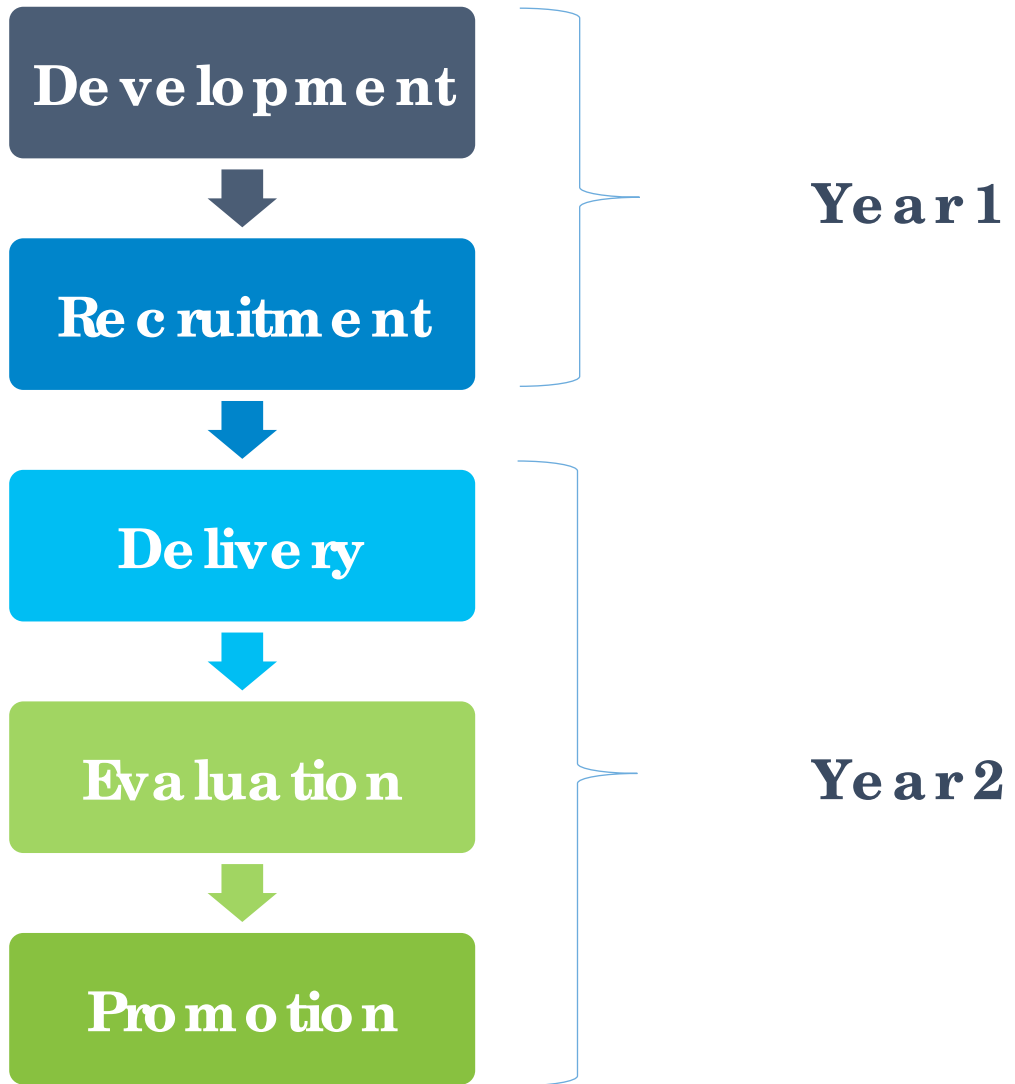


Training people with narcolepsy to effectively share their stories through public speaking and writing

RVN Dual Purpose

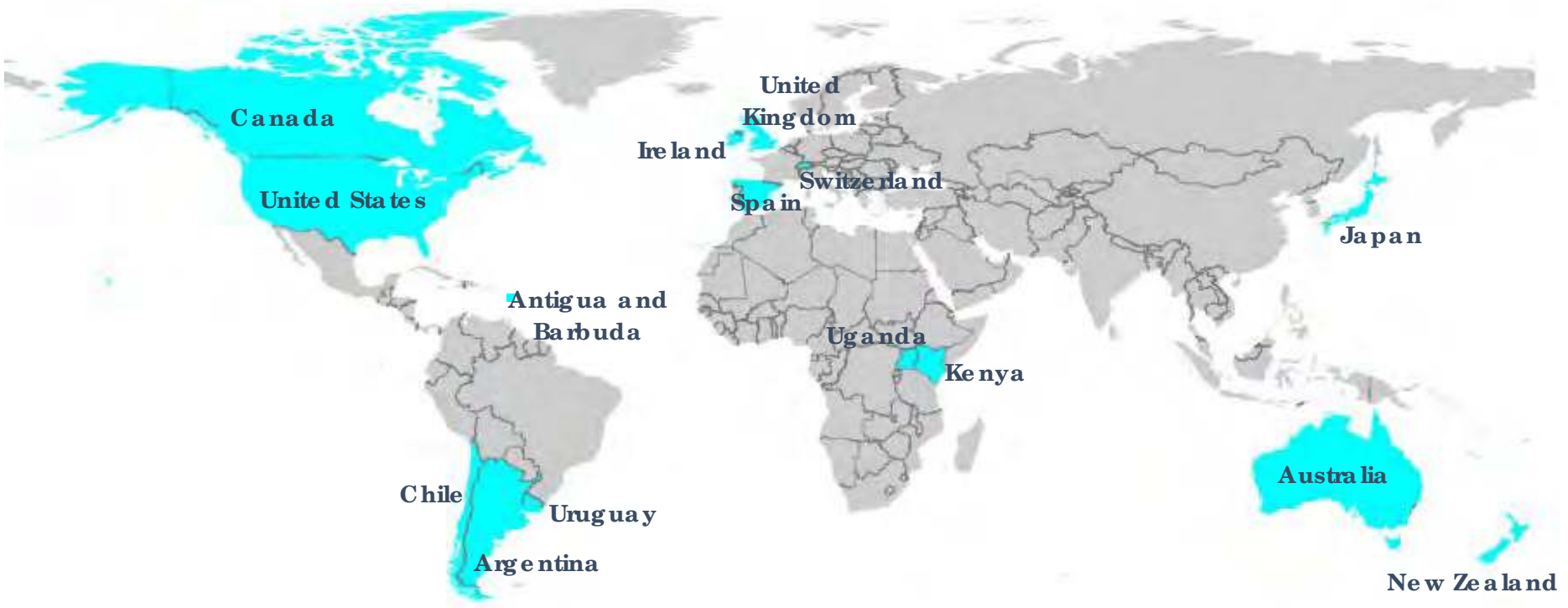
1. Participant empowerment and growth
2. Increasing public awareness and correcting misperceptions

RVN Pilot Timeline – Currently in Year 1



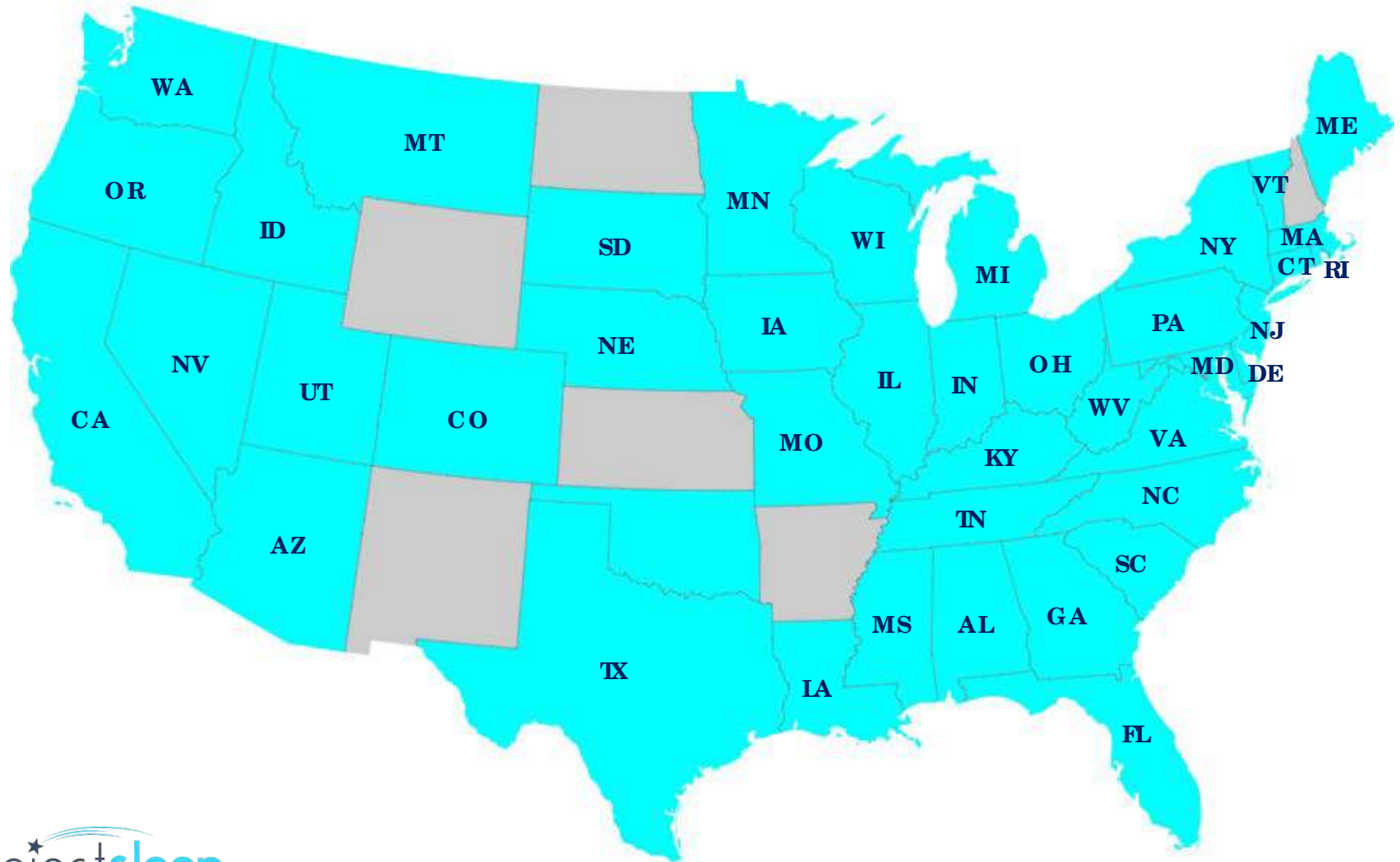
RVN Interest Form Responses

200 PWN from 15 countries



RVN Interest Form Responses

160 PWN from 42 US states



RVN Interest Form Responses

“This is an amazing opportunity!!!! I am looking forward to sharing my experience over the past six years of living, working, and coping with narcolepsy!”

“This is a very exciting opportunity, and I am extremely interested in where this could take the narcolepsy community!”

“Can’t wait to play a part in narcolepsy advocacy! Count me in.”

“This is so incredible, thanks for making this happen! I’ve been looking for a way to write about narcolepsy for over two years now”

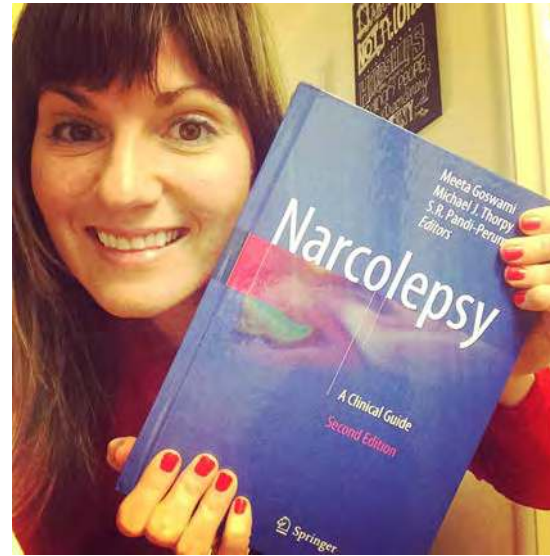
SELECT SPEAKING ENGAGEMENTS

- UCLA Medical School
- Ireland's Narcolepsy Conference Keynote
- Sleep Success Summit
- Health: Further Keynote to over 1,000 Health Professionals
- Stanford Medicine X
- Italian Narcolepsy Association Keynote
- California Sleep Society
- PCORI-funded SLEEP-2 Conference



COMMUNITY LEADERSHIP

- Participant, White House/Stanford Medicine X Workshop, “Engaging Participants as Partners in Research” as part of the Precision Medicine Initiative (June 2016)
- E-patient Scholar, Stanford University’s Medicine X (Sept 2016)
- Published book chapter: Flygare, J. (2016) “Succeeding in School and in the Workplace with Narcolepsy.” Edited by M. Goswami, M. Thorpy and S.R. Pandi-Perumal (Eds), *Narcolepsy: A Clinical Guide*, 2nd ed. (pp. 395 - 405). Springer
- Taught the Engage & EmpowerMe class at Stanford Medical School (Dec 2016)



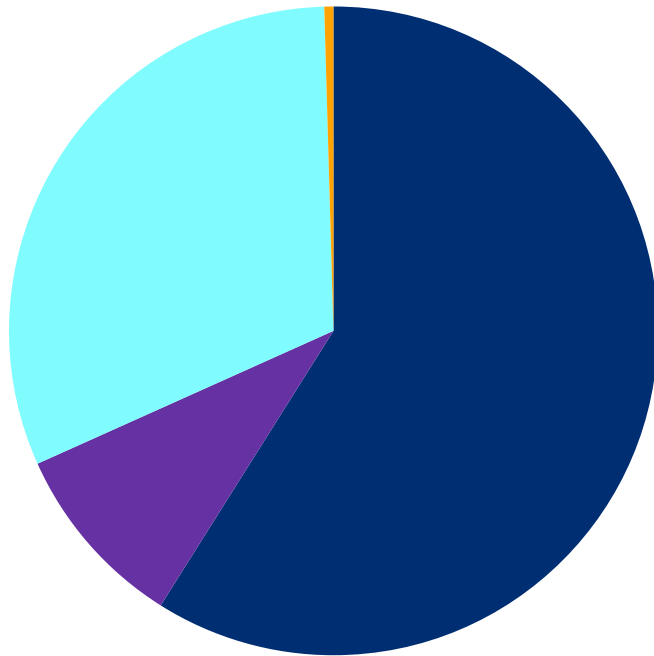
MEDIA HIGHLIGHTS

- Neurology Now: [Self Diagnose Successfully](#)
- New York Times writer and editor, Phyllis Korkki features my story in:
[The Big Thing: How to Complete Your Creative Project Even If You're a Lazy, Self-Doubting Procrastinator Like Me](#) (Harper, 2016)
- CBS News Los Angeles: LA Woman Describes Serious Sleep Disorder: [‘It Feels Like Being Awake Inside A Corpse’](#)



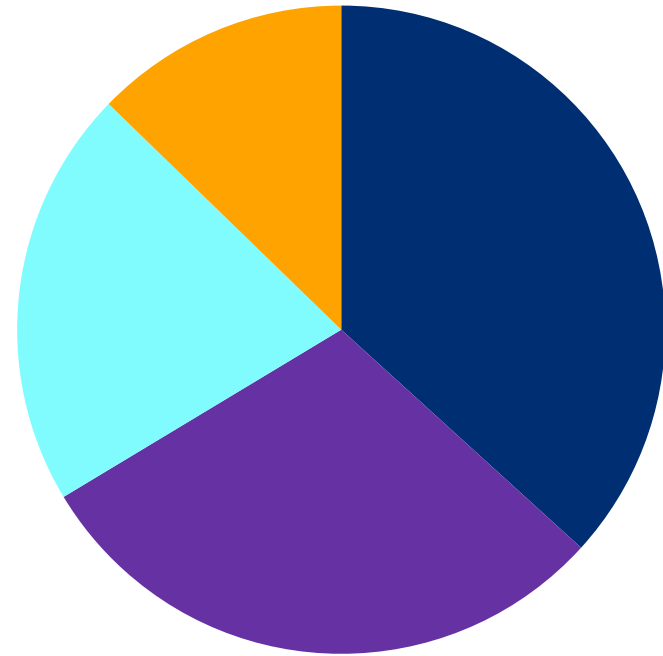
2016 FINANCIAL POSITION

Total Revenue for 2016
\$50,672



■ Corporate Giving ■ Government Grants
■ Individual Giving ■ Merchandise Income

Total Expenses for 2016
\$38,406



■ Scholarships ■ Rising Voices of Narcolepsy
■ Sleep-2 Grant ■ General and Administrative



Thank you for your incredible support!