

Project Sleep's World Narcolepsy Day Ambassadors Toolkit

About World Narcolepsy Day Ambassadors

Thank you for stepping up to be a leader in raising awareness for **World Narcolepsy Day** (Sept. 22nd) with Project Sleep. Project Sleep's World Narcolepsy Day Ambassadors promote awareness of narcolepsy by participating in activities, raising funds, and spreading the word about narcolepsy in their schools, workplaces, or communities.

Why become an Ambassador?

Public understanding of narcolepsy is limited and often inaccurate, with media portrayals associating narcolepsy with humorous sleepiness rather than with a serious condition requiring medical attention. Misperceptions and low awareness of narcolepsy perpetuate stigma and delays in diagnosis, with an average of **8 to 15 years** between narcolepsy symptom onset and accurate diagnosis. Further, **the majority** of people living with narcolepsy are currently undiagnosed.

By raising our voices together, we are fostering community, fighting stigma and helping people find accurate diagnoses faster!

Who are World Narcolepsy Day Ambassadors?

We encourage a variety of individuals and stakeholders to become Ambassadors. World Narcolepsy Day is a day for our entire community, including:

- People living with narcolepsy or idiopathic hypersomnia (IH)
- Supporters and loved ones of people with narcolepsy or IH
- Sleep clinicians and researchers
- Other narcolepsy community members

What do Ambassadors do?

We believe that *global awareness* begins with *local awareness*! This is why *you* play a key role in elevating narcolepsy awareness. During the month of September, leading up to World Narcolepsy Day on Sept. 22nd, World Narcolepsy Day Ambassadors will be leaders in spreading the word. No two people's contributions will be the same, but activities may include:

- Raising awareness in your school, workplace, or communities
- Sharing your story via your customizable Ambassador Page
- Challenging friends to raise awareness or donate
- Contacting local media and sleep centers
- Participating in events and activities
- Joining a community of fellow narcolepsy advocates

Why raise funds?

One great way for family and friends to show support and encouragement is by making a donation to a non-profit organization like Project Sleep. **See sample fundraising message on page 7.** Funds raised provide critical support for Project Sleep's current programming (including the Jack & Julie Narcolepsy Scholarship, Rising Voices of Narcolepsy and sleep advocacy efforts) and help us to expand our efforts to reach even more sleepy people. Project Sleep is a small 501(c)(3) non-profit, so your support makes a huge impact. Thank you!

How do I login to customize my Ambassador Page?

Once you've signed up as an Ambassador, you can log-in to your Ambassador page by going to the <u>World Narcolepsy Day Ambassadors 2023 Page</u>. Scroll all the way to the bottom, there's a button to log-in to manage your Ambassador page. From here, you can customize your page with your photo, share your story, track your goal, post updates, and thank your donors! If you have any issues, contact us at <u>info@project-sleep.com</u>.

About World Narcolepsy Day

World Narcolepsy Day (Wednesday, Sept. 22) is a day dedicated to raising global awareness of narcolepsy. Co-led by patient advocacy organizations across six continents, World Narcolepsy Day unites the international narcolepsy community to inspire action, increase public knowledge, and elevate the voices of the three million people living with narcolepsy worldwide. Together, we can raise awareness and reduce stigma!

About Project Sleep

Project Sleep is a 501(c)(3) non-profit organization dedicated to raising awareness about sleep health and sleep disorders. 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 educates and empowers individuals using events, campaigns, and programs to bring people together and talk about sleep as a pillar of health.

Graphics to Share

Images are available to download from the <u>WND Infographics Page</u>.

Facts to Share

Share narcolepsy facts using our Narcolepsy Quick Facts.

Hashtag

Important: Use the hashtag **#WorldNarcolepsyDay** and tag **@project_sleep** on all related social media posts. Feel free to tag colleagues and friends to help spread the word.

First Things First!

- Customize your Ambassador Page! Now that you've signed up to be a WND Ambassador, you can start using your own Ambassador's Page as a place to share your story, raise funds and post updates for your donors and supporters.
- To log-in to your Ambassador Page, go to the <u>World Narcolepsy Day Ambassadors Page</u> and scroll to the bottom, there's a black button to log in to manage your Ambassador page.

Ambassador Login

From here, you can customize your page with your photo, your story, make edits, track your goal progress, share your page with friends and family, post updates, and thank your donors! If you have any issues logging in or using your Ambassador's page, contact us at <u>info@project-sleep.com</u>.

What's Next?

- ◆ Get your gear! Order your World Narcolepsy Day t-shirts.
 - New shirts will be available to order by late-August, link via Project Sleep's World Narcolepsy Day webpage.
 - Must order early to arrive by Sept. 22nd. International arrival by Sept 22 cannot be guaranteed.
- Visit our Virtual Photobooth Opens on Sept. 1st! Snap a photo and share on social media. Don't forget to use the hashtag #worldnarcolepsyday and to tag @project_sleep. Available from Sept. 1st - 23rd.
 - Click the link to visit the Virtual Photobooth from <u>Project Sleep's World</u> <u>Narcolepsy Day webpage.</u>

Suggested Social Media Post #1

To post on Sept. 1 (three weeks away)

Suggested caption:

21 days until #WorldNarcolepsyDay and I'm excited to raise #narcolepsy awareness from [your location]. [Optional: add about your connection to the cause.] Get involved: https://project-sleep.com/worldnarcolepsyday/

Tag: @project_sleep

Suggested image:

[Share a photo from the Virtual Photobooth, with a Cloud Sign or wearing your World Narcolepsy Day t-shirt.]





Take Action Throughout September

- Calendar of Activities: Lots of exciting activities are planned for the weeks leading to World Narcolepsy Day, including media training! Stay up-to-date by checking the calendar of activities on: <u>www.project-sleep.com/worldnarcolepsyday</u>.
- Look for local opportunities: Are there any clubs, groups or communities that you're a part of that might be interested in celebrating World Narcolepsy Day with a local or virtual event? Ask your friends and family to help you brainstorm ideas!
- Fundraising: Use your Ambassador's Page as a wonderful place to share your story and raise funds for Project Sleep.
- Got Gifs? Use the new World Narcolepsy Day gifs in your IG & FB stories.



Suggested Social Media Post #2:

To post on Sept. 15th (one week away)

Suggested Caption:

#WorldNarcolepsyDay is ONE week away on 9/22! Did you know? #Narcolepsy is a chronic neurological condition that impairs the brain's ability to regulate the sleep-wake cycle. Learn more: <u>https://project-sleep.com/worldnarcolepsyday/</u>

Tag: @project_sleep

Choose one or a few infographics, see all graphic options via

www.project-sleep.com/world-narcolepsy-day-infographics/



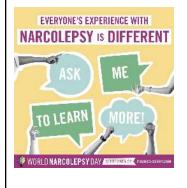
Suggested Social Media Post #3: To post on Sept. 21st or any other time!

Suggested Caption:

Tomorrow is #WorldNarcolepsyDay! Ask me about #narcolepsy. [Optional: Add more about your experience like: *I was diagnosed/my son was diagnosed last year at age X after going X* years with mysterious symptoms.] Learn more: <u>https://project-sleep.com/worldnarcolepsyday/</u>

Tag: @project_sleep

Suggested image is here: <u>www.project-sleep.com/world-narcolepsy-day-infographics/</u>.



Suggested Social Media Post #4:

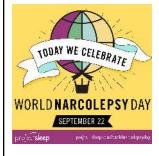
To post on Sept. 22nd - World Narcolepsy Day!

Suggested Caption:

Today is #WorldNarcolepsyDay, a day for raising global awareness of #narcolepsy! With the majority of people living with #narcolepsy currently undiagnosed, I'm raising my voice for others. Learn more: <u>https://project-sleep.com/worldnarcolepsyday/</u>

Tag: @project_sleep

Suggested image is here: <u>www.project-sleep.com/world-narcolepsy-day-infographics/</u>.



Important Links & Resources:

- Project Sleep's World Narcolepsy Day Webpage: <u>https://project-sleep.com/worldnarcolepsyday/</u>
- Project Sleep's WND Ambassador's Sign-Up & Log-in: <u>https://projectsleep.salsalabs.org/worldnarcolepsydayambassadors2023</u>

Connect with Us

Instagram: @project_sleep Twitter: @project_sleep Facebook: facebook.com/ProjectSleepAwareness LinkedIn: linkedin.com/company/project-sleep/ YouTube: youtube.com/c/Project-sleep

Sample Fundraising Message:

Dear Mom,

This September, I'm participating in Project Sleep's World Narcolepsy Day Ambassadors program to raise awareness and funds leading up to World Narcolepsy Day on Sept. 22nd! Learn more: https://project-sleep.com/worldnarcolepsyday/

This is so important to me because _____ (insert a bit about your connection to this cause).

Did you know? Narcolepsy is a neurological condition impacting 1 in every 2,000 people, that's 3 million people worldwide. However, narcolepsy is extremely under-diagnosed, with the majority of people living with narcolepsy currently undiagnosed.

I challenge you to join me in raising awareness or sponsoring my efforts! Donations are tax-deductible, benefitting Project Sleep, a 501(c)(3) non-profit organization.

Thank you for supporting my efforts!