

The Monthly Wake Up



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Dear Community Members,

One of the wonderful things about our community is how it isn't just made up of people living with Narcolepsy or IH, but their loved ones as well. It's touching to see parents asking questions at webinars, siblings attending conferences and friends donating to fundraisers.

There is a place for everyone here, whether it be extended family, friends, neighbors or coworkers. Inviting others to join the communities being built goes hand in hand with spreading awareness, which is one of

our core goals at Wake Up Narcolepsy (WUN). World Narcolepsy Day is a great time to start! By sharing your journey, you are contributing to accurate representation that goes a long way. It also allows the people you educate to share that knowledge with others in their own circles, creating a ripple effect.

Some of our recent events have been wonderful places to broaden that community. At our Alberta Night Walk WUN Town Hall, there was a heavy presence from the local area just looking to learn more. At Vincent Arthur's recent race in North Carolina, he was asked about his journey with Narcolepsy and racing as well as the WUN logo on his car. We also had our second annual event at a Boston Red Sox game where volunteers set up a table and answered questions. Getting into public spaces that might not initially seem connected to sleep disorders can be a wonderful tool for starting important conversations.

People are often more than happy to support others in their life in ways you might not expect. By taking that step to talk to them about your experiences, you never know where it could lead. In light of that, this month's mission moment comes from a dedicated parent of someone living with Narcolepsy: ***"I can't fix this, but I can honor him and get involved."***

Tammy Anderson



Tammy Anderson
WUN Executive Director



WORLDWIDE STEP UP FOR SLEEP 2025

If you haven't already registered, there's still time!

Check out our progress so far:

\$2,235 raised, **56** participants registered, **4** teams formed and **18,749** active minutes tracked!

Week Four Challenge (OPEN NOW): The individual who raises the most money in a 24-hour period this week will receive a WUN apparel item of their choice.

Learn more and register: p2p.onecause.com/worldwidestepup

NEW TRANSLATED RESOURCES

Last year, we released two translated resources for World Narcolepsy Day! This year, we are launching a dedicated webpage and releasing more resources in the 11 languages.

"The Student with Narcolepsy and the Education System" and "Advancing the Knowledge of Narcolepsy to Find a Cure" brochures are now available in Brazilian Portuguese, Chinese (Simplified), English, French, German, Italian, Japanese, Sinhala, Spanish, Swahili and Tamil!

Check them out now: wakeupnarcolepsy.org/translated-resources/

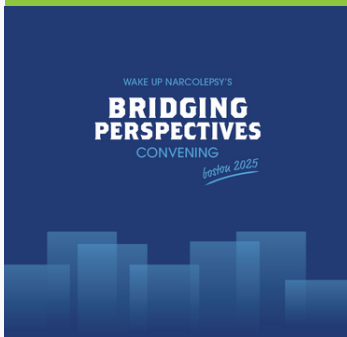
SUPPORT GROUP UPDATES

We are excited to celebrate our dedicated online support group facilitators as they travel to Boston for Bridging Perspectives!

To give them adequate time to prepare, support groups will be paused for the week starting today, Monday, September 22nd. Meetings will resume Monday, September 29th and continue as scheduled from there. We appreciate your understanding!

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WUN TOWN HALLS

Thank you to everyone who helped with our recent events!

Denver, Colorado had a lovely park gathering where attendees could share stories and enjoy the beautiful weather together.

Alberta, Canada hosted an educational session with a nighttime glow walk complete with signs featuring Narcolepsy facts.

Vincent Arthur, a driver living with Narcolepsy, had his final race of the season where he led 40 of 50 laps and finished second.

Volunteers attended a Boston Red Sox game where they spread awareness and education with game attendees.

Learn more: wakeupnarcolepsy.org/get-involved

UPCOMING BROWN BAG WEBINARS

There's still time to register for our September webinar happening TODAY, World Narcolepsy Day, at 10am ET!

Understanding & Managing Cataplexy

Michael Thorpy, MD | Montefiore Medical Center

Registration for October's webinar is also open!

October 23rd - 2pm ET

Advocating with Confidence in the Educational System

Kim Hindery | Child Neurology Foundation

Do you ever feel unsure about how to advocate for your child's educational needs? This webinar will walk through various components, sharing practical strategies to communicate with confidence, understand your child's rights and work effectively with the IEP and 504 teams to support their success.

Register today & bring your questions for Kim!

ONGOING:

Weekly **online support groups** for people with Narcolepsy, Idiopathic Hypersomnia and loved ones!

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Gold:  **HARMONY BIOSCIENCES**

Gold:  **Jazz Pharmaceuticals**

Silver:  **CENTESSA PHARMACEUTICALS**

**UPCOMING EVENTS**

September 22nd - 10am ET

World Narcolepsy Day

September BBW: Understanding & Managing Cataplexy

September 26th

Inaugural Bridging Perspectives Convening

October 18th - 10:30am - 2pm ET

Ottawa WUN Town Hall

THE KYRA STUDY

The KYRA Study is exploring options for those with narcolepsy without cataplexy (sudden loss of muscle tone) and is currently enrolling participants. Visit sleepdisorderstudies.com/WUN to learn more.

OSA RESEARCH FROM HOME

On behalf of Sanguine Biosciences, we're sharing a new at-home research opportunity for those diagnosed with Obstructive Sleep Apnea. You can help advance research from the comfort of your own home. To learn more or sign up, visit studies.sanguinebio.com/condition/osa/?campaign=WUN_osa or call 855-836-4759 to speak with a research coordinator and see if you qualify.

EFFICIENT CME SURVEY

Your perspective is needed! We are conducting a survey of patients with narcolepsy types 1 and 2 to learn about their experiences with the condition as well as their journey through the healthcare system. Your input will be used to create a nationally distributed continuing education program for healthcare providers about how to better support and care for their patients in the future.