October 2024



CELEBRATING 15 YEARS

The Monthly Wake Up

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Message from WUN Executive Director

Greetings,

I want to take a moment to reflect on the incredible achievements our community has made over the past month. September was truly a month of milestones for Wake Up Narcolepsy (WUN).

Our inaugural Shadows to Light Gala on September 20th highlighted Narcolepsy like never before. I am thrilled to share that we raised nearly half a million dollars. The

funds raised will be instrumental in WUN's mission of furthering education, awareness, research and support for those living with Narcolepsy.

World Narcolepsy Day 2024 was celebrated around the globe. Individuals got creative with participating whether signing up for Worldwide Step Up For Sleep, sharing their Narcolepsy story, organizing or attending local events, spreading awareness or just allowing themselves to rest. It's always wonderful to see the community come together to support one another.

On top of this, four WUN community events took place last month. Without our volunteers who go above and beyond, these wouldn't have been possible. The successes of this year's WUN Town Halls and Step Up For Sleep events showcase the passion of these individuals.

There is still plenty of excitement in store for the year. Our annual Narcolepsy Family Weekend will take place in Kentucky this weekend and WUN representatives will attend the Sleep Advocacy Forum in Washington D.C. later this month. Two more WUN Town Halls are scheduled for November in Syracuse and Cincinnati, along with our final Brown Bag Webinar of 2024.

I'd like to extend my heartfelt gratitude to each and every one of you reading this. Your support is the backbone of our organization. We are committed to building on our recent successes and continuing to push the boundaries of what we can achieve together.

Thank you for believing in our mission!

- Monica Gow



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Shadows to Light Gala 2024



Visit WakeUpNarcolepsy.org or connect with us on Instagram, Facebook, Twitter, LinkedIn, Tik Tok, Threads or YouTube.

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Worldwide Step Up For Sleep

Thank you to everyone who celebrated World Narcolepsy Day with us! If you haven't already heard, here are the results from our month-long campaign:

86 participants registered across 3 countries and 26 states, tracking over 9,075 active minutes and raising \$2,015!

Congratulations to our challenge winners:

Week One Winner: Megan Kelly for sharing how she's #SteppingUpForSleep Week Two Winner: Kristin Gagnon for recruiting 4 new participants that week Week Three Winner: Sarah Wolf for tracking 252 active minutes, with runner-up Fiona Mobbs at 236.4 minutes that week

Week Four Winner: **Sarah Wilton** for raising **\$100** that week Ultimate Challenge Winner: **Sophia Miller** for raising **\$310** in September Special Recognition: Monique Myers for raising \$575 after starting in August

Thank you to our 2024 awareness sponsors:

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Updated WUN Impact Statement

Another way WUN celebrated World Narcolepsy Day 2024 was through the release of our updated Full Impact Statement, as well as an additional Highlights and Publications document. Both can be found on the Featured Research page of our website.

Since inception in 2008, WUN has donated \$1.39 million to Narcolepsy research. Check out the documents and short video to learn more about the impact of our funding!

Visit WakeUpNarcolepsy.org or connect with us on Instagram, Facebook, Twitter, LinkedIn, Tik Tok, Threads or YouTube.



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Recent Community Events



Alberta Night Walk WUN Town Hall Olds, Alberta, Canada - September 21st Sponsored by: Deladin



Boston Red Sox WUN Town Hall

Boston, MA - September 22nd



Colorado Step Up For Sleep Golden, CO - September 28th

Thank you to volunteers who made these events possible!

Upcoming Community Events

Syracuse WUN Town Hall Baldwinsville, NY - November 9th - 11:00am ET

Cincinnati WUN Town Hall

Cincinnati, OH - November 16th - 10:00am ET

Thank you to our sponsors:



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Brown Bag Webinar Updates



Thank you, Dr. Stultz & Miranda, for wonderful webinars!

Full recordings can be found on the Wake Up Narcolepsy YouTube channel.

Register now for our final Brown Bag Webinar of 2024 on November 14th: "Unraveling the Mysteries of Dreams & Nightmares in Narcolepsy" with Dr. Ingram & Dr. Mundt! This is a great opportunity to ask the experts, so make sure you bring your questions for the live Q&A session.

Thank you to our BBW sponsors:



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National Summit Information

Keep an eye out for registration opening soon for our 2025 National Summit on April 26th near Raleigh, NC!



In the meantime, check out the highlights from the 2024 National Summit available now on our YouTube channel!

Craving Good Sleep? So's Your Heart

People with common sleeping disorders such as obstructive sleep apnea or insomnia also are far more likely to have heart arrhythmias, plaque buildup, heart failure and coronary artery disease.

Visit heart.org/sleepdisorders to learn more about your potential risks and how we're partnering with the American Heart Association to highlight this important link.

Visit WakeUpNarcolepsy.org or connect with us on Instagram, Facebook, Twitter, LinkedIn, Tik Tok, Threads or YouTube.



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Upcoming Events

October 18th-20th WUN Family Weekend 2024

October 28th-29th

WUN attending 2024 Sleep Advocacy Forum

November 9th Syracuse WUN Town Hall

November 14th Unraveling the Mysteries of Dreams & Nightmares in Narcolepsy Webinar

November 16th Cincinnati WUN Town Hall

ONGOING

Weekly support groups for people with Narcolepsy & Idiopathic Hypersomnia (IH)

Diamond:

Clinical Trials

Narcolepsy Type 1: Orexin Agonist Restoration

Because partial or complete Orexin receptor deficiency plays an important role in the development of EDS, orexin replacement therapy may improve EDS through a pathophysiology-directed mechanism of action. We are currently investigating a new novel drug that acts to help address the deficiency of orexin-2 receptor agonists that may address the spectrum of narcolepsy symptoms and have greater efficacy than currently approved drugs for EDS and cataplexy.

Learn more below

Thank you to our Sponsors:

Jazz Pharmaceuticals. Gold: Avadel.

