

The Monthly Wake Up



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Dear Community Members,

As summer comes to an end, I find myself reflecting on the progress we've made so far this year and looking to our future plans. Wake Up Narcolepsy (WUN) has a busy fall approaching with many ways to get involved.

Awareness is a key part of WUN's mission, but is something people often overlook. There is true power in spreading accurate information about a disorder that has been misunderstood for so long. It's also a

wonderful driving force to bring a community together. When we all work toward a unified goal, we become part of something larger than ourselves and realize the impact we can make.

Last year for World Narcolepsy Day, we launched Worldwide Step Up For Sleep, allowing participants from all over the world to come together in a beautiful way to get active, fundraise, share their stories and motivate each other. Whether they were on a team together or having some friendly competition, seeing each other's progress throughout the month drove more and more participants toward their goals. I am happy to share that the campaign will be returning for the month of September again this year! Let's see if we can reach even further as we all come together to advocate for Narcolepsy.

If you're looking for in-person opportunities, I encourage you to check out our upcoming community events to see if we'll be in your area. Today's mission moment comes from a WUN volunteer who highlights the importance of these, expressing how ***"We need to stay connected and communicate with each other. Walking this journey alone is isolating, but together we can offer each other the support we all need."***

Tammy Anderson



Tammy Anderson
WUN Executive Director

WAKE UP NARCOLEPSY'S
**BRIDGING
 PERSPECTIVES**
 CONVENING
Boston 2025

BRIDGING PERSPECTIVES SPONSORS:

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STEP UP FOR SLEEP
Worldwide

09 25
 MONTH YEAR



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BRIDGING PERSPECTIVES SPEAKERS

There's still time to secure your spot for Bridging Perspectives in Boston! Hear from:

Featured panelists including Emmanuel Mignot, MD, PhD, Thomas Scammell, MD, David Ingram, MD, MHPE, Kiran Maski, MD, MPH, Anne Marie Morse, DO, Tessa Appleman, David Gow and Todd Grisco

WUN support group leaders including Madie Behrends, Kelsey Biddle, MD, Kelsey Bingham, Emily Clegg Barker, PhD, Tatiana Maria Corbitt, Taylor Dillon, Dom Jillings, Shelly Gonzalez, Elaine Gregory, Brina-Hope, Casey McGarry, Meryl R, Lisa Rose, Anne Samarawickrama, Rorey Smith, Heather Trueman, Tracy Veit, Audelia and Sara Wolf, MPH

WORLDWIDE STEP UP FOR SLEEP 2025

Are you looking for ways to celebrate World Narcolepsy Day? Join us for the second year of Worldwide Step Up For Sleep! The entire month of September, participants all over the globe can raise Narcolepsy awareness and critical funds. They'll have the opportunity to track physical activity, participate in challenges and compete with friends on leaderboards!

Example challenges can be found below. Learn more, register & spread the word today: p2p.onecause.com/worldwidestepup

Week One Challenge: The participant who tracks the longest continuous movement session this week will receive a WUN apparel item of their choice.

Ultimate Challenge: The individual with the most consecutive active days logged during the month of September will win two WUN apparel items of their choice.



READ AVAILABLE BLOG EDITIONS:

wakeupnarcolepsy.org/blogs/

AUGUST BLOG AVAILABLE NOW!

-She is not me-

*I am not who I appear to be,
I am not she, she is not me.
I was like wildfire, beautifully untamed -
Quick, unyielding, a bright burning flame.
A mind that took me far, and fast,
Though apparently not one meant to last.*

*That was then, this is now -
I'm still me! I'm just different somehow.*

*As now I drift - unmoored, unseen
Trapped somewhere deep in the in-between.
My face you know, my smile, my wit,
But my fire fades, sputters and spits.
The lights are on, but dim and low,
And sleep comes fast, where thoughts won't go.*

Read the full poem in this month's edition of Narcolepsy Perspectives - "Narcolepsy and the Fractured Self: Grieving, Growing, and Reclaiming Identity" by Tasha Hill, RN!

BROWN BAG WEBINARS

Thank you to Dr. Hodges for a incredible webinar on "Navigating Communication about Invisible, Chronic Illnesses!"

Missed the live discussion? Don't worry! The recording will be available soon on our YouTube channel and website.

Have you registered for our upcoming webinar yet?

September 22nd - 10am ET

Understanding & Managing Cataplexy

Michael Thorpy, MD | Montefiore Medical Center

Join Dr. Thorpy as he breaks down the details of cataplexy in Narcolepsy Type 1. Whether you're living with cataplexy, supporting someone who is, wondering if you may have it or just hoping to learn more about this commonly misunderstood symptom, you won't want to miss this!

Register today & bring your questions for Dr. Thorpy!



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Therapeutics, Knight
Therapeutics & Takeda
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WUN TOWN HALLS

WUN Town Halls are local events in North America tailored to the community and planned by staff and volunteers!

Whether you have a sleep disorder or simply want to expand your knowledge, these are fantastic chances to connect with a supportive community and gain expert insights.

Thank you to everyone who attended our recent event in Denver! Check out more information about upcoming events by visiting Wakeupnarcolepsy.org/get-involved

Olds, Alberta, Canada - September 6th

Boston, Massachusetts - September 14th

Dallas-Fort Worth, Texas - September 20th

Ottawa, Ontario, Canada - October 18th

NEW SUPPORT GROUP OPTION NARCOLEPSY 101: WHERE DO I START?

Are you looking for Narcolepsy support and wondering where to begin? We're excited to announce a NEW online support group that will take place in 3-week sessions alternating with our Pregnancy & Parenting group.

Whether you're newly diagnosed, have been diagnosed for years, think you might have Narcolepsy or just want to learn more, we hope you'll join us!

For the first session, meetings start **Thursday, September 4th at 8pm ET**. Check out the full schedule, including other groups, on our website!

We have groups for everyone and want to make sure no one feels alone in navigating their disorder. Individuals with Idiopathic Hypersomnia are always welcome!

ONGOING:

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

ONLINE SUPPORT GROUP SPONSORS:

Avadel Pharmaceuticals, Harmony Biosciences, Jazz Pharmaceuticals, Centessa Pharmaceuticals & Takeda Pharmaceuticals

**CHAMPION SPONSORS:**

Diamond:  **Avadel.**

Gold:  **HARMONY BIOSCIENCES**

Gold:  **Jazz Pharmaceuticals**

Silver:  **CENTESSA PHARMACEUTICALS**

UPCOMING EVENTS

September 1st - 30th

Worldwide Step Up For Sleep 2025

September 4th - 8pm ET

Narcolepsy 101: Where Do I Start? Support Group 3-week Session Starts

September 6th - 5 - 8:30pm MT

Alberta Night Walk WUN Town Hall

September 14th

Boston Red Sox WUN Town Hall

September 20th - 1 - 3pm CT

Dallas-Fort Worth WUN Town Hall

September 22nd - 10am ET

World Narcolepsy Day

September BBW: Understanding & Managing Cataplexy

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 the link below or call 855-836-4759 to speak with a research coordinator and see if you qualify.

THE ALBA STUDY

Is it time to rethink the daily routine for those living with idiopathic hypersomnia (IH)? Clinical research may help find new possibilities. The ALBA Study is seeking ways to awaken the potential in people with IH. Visit sleepdisorderstudies.com/WUN to learn more.