



The Monthly Wake Up

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Message from WUN Executive Director

Greetings,

With so many plans for September, we're bringing you a mid-month newsletter to share the latest Wake Up Narcolepsy (WUN) updates!

As you may already know, WUN's World Narcolepsy Day plans are already underway and you can get involved from anywhere across the globe.

For the entire month of September, community members are getting active while raising funds and awareness with Worldwide Step Up For Sleep! Over 70 participants have tracked nearly 4,000 minutes of physical activity. Thank you to everyone who has registered and if you haven't, there is still time.

Another part of our celebration just launched on Friday. We are proud to announce two WUN resources are available in 10 additional languages. Read more about the poster designs and PSA captions in this edition.

Our inaugural Shadows to Light Gala will take place at the end of this week in New York City. We are overwhelmed with the level of support for the event and look forward to welcoming partners to a pivotal night dedicated to Narcolepsy.

I'd also like to remind you that we are celebrating 15 years of WUN. The organization has grown tremendously since its inception in 2008, but has never strayed from its mission. Everyone involved along the way is united by our commitment to the cause.

Together, we are truly bringing Narcolepsy out of the shadows and into the light.

- Monica Gow



Monica Gow
WUN Co-Founder &
Executive Director

Translated WUN Resources


Celebrate World Narcolepsy Day 2024 with two Wake Up Narcolepsy (WUN) resources now available in 10 additional languages!

The “Do You Know Narcolepsy” poster from WUN and Hypersomnolence Support Network Japan outlines the symptoms of the often misunderstood disorder alongside illustrations. Designs are available in Brazilian Portuguese, Chinese (Simplified), French, German, Italian, Japanese, Sinhala, Spanish, Swahili and Tamil!

WUN’s Public Service Announcement showcases the reality of Narcolepsy and allows voices from all over the community to be heard. Captions are now available on WUN’s YouTube channel in the above languages!


The translations were a collaborative effort of many sources! By providing our resources in multiple languages, WUN hopes to increase accessibility for the global Narcolepsy community.

¿Conoce la narcolepsia?



wakeupnarcolepsy.org

Narcolepsy ni tatizo la kinyurolojia la usingizi maishani lenye sifa ya ubongo kushindwa kudhibiti mizunguko ya kulala na kuamka.



wakeupnarcolepsy.org

Les personnes atteintes de narcolepsie ne paraissent pas toujours SOMNOLENTES



La narcolepsie peut également se traduire par des pertes de mémoire, de la difficulté à se concentrer, de l'irritabilité et des comportements automatiques, qui peuvent entraîner en retour des troubles psychosociaux et affecter les relations, les performances académiques, les réussites professionnelles et les loisirs.

wakeupnarcolepsy.org


அதிகைவு பகல் தூக்கம்



அதிகைவு பகல் தூக்கம் (EDS), பகலில் விழிப்புடன் இருக்க முடியாமையைக் குறிக்கும்.

wakeupnarcolepsy.org

Interrupção do sono




A interrupção do sono (também conhecida como sono fragmentado) ocorre na forma de despertar frequente.

Indivíduos com Narcolepsia em geral passam por uma transição rápida para o sono REM, mas acordam com frequência, causando muitas transições mais do sono profundo para o sono leve ou vigília.

wakeupnarcolepsy.org

Paralisi del sonno




La caratteristica è una temporanea incapacità di muoversi o parlare nella fase dell'addormentamento o del risveglio.

Molto probabilmente, questo fenomeno è dovuto a un'intrusione nello stato di veglia della normale paralisi che avviene durante la fase REM del sonno.

wakeupnarcolepsy.org

Kataplexie



Hier tritt ein plötzlicher und unkontrollierbarer, kurzzeitiger Verlust des Muskeltonus auf, der durch das Erleben starker oder intensiver Gefühle verursacht wird. Kataplexie tritt nur bei Narcolepsie-Typ 1 auf.

wakeupnarcolepsy.org

幻覚



嗜睡症患者在入睡或醒来时可能会经历生动的梦境般的体验。

入睡时的幻觉称为入睡前幻觉；醒来时的幻觉称为醒后幻觉。

这些幻觉可以是多感官体验，感觉非常真实。

嗜睡症患者经常会从清醒状态直接进入快速动眼期睡眠，这可能是这种体验的深层原因。

wakeupnarcolepsy.org

Worldwide Step Up For Sleep

If you haven't already registered, there's still time to fundraise, track your physical activity throughout the month and have a chance to win prizes.

Check out our progress so far:

\$1,400 raised

77 participants registered

12 teams formed

3,937 active minutes tracked

Congratulations to our first two winners:

Week One Challenge Winner: Megan Kelly

Week Two Challenge Winner: Kristin Gagnon

Week Three Challenge: The participant with the **most active minutes this week** will win a \$25 Amazon e-gift card.

Ultimate Challenge: The individual who **raises the most money during the month of September** will win a \$100 Amazon e-gift card and two WUN Worldwide Step Up for Sleep t-shirts!

Looking for ways to get active? Our Worldwide Step Up For Sleep Ambassador **Belle Hutt** will be posting **4 mini workouts** under 5 minutes on her Instagram throughout the month that anyone can do! Check out her page for more information.

We've also provided **custom "How I'm #SteppingUpForSleep"** frames for sharing your photos on social media to encourage others to get involved.

Thank you to everyone who has been participating! Keep up the great work!

Thank you to our 2024 awareness sponsors:



Jazz Pharmaceuticals



Avadel

HB HARMONY
BIOSCIENCES



CENTESSA
PHARMACEUTICALS

Recent Community Events



Dallas-Fort Worth Family WUN Town Hall

Frisco, TX - September 7th

Thank you to all the volunteers who made this event possible!

Upcoming Community Events

Alberta Night Walk WUN Town Hall

Olds, Alberta Canada - September 21st - 6:30pm MT

Sponsored by:  **paladin**
une compagnie de endo
an endo company

Boston Red Sox WUN Town Hall

Boston, MA - September 22nd - 1:35pm ET

Colorado Step Up For Sleep

Golden, CO - September 28th - 8:00am MT

Syracuse WUN Town Hall

Baldwinsville, NY - November 9th - 11:00am ET

Thank you to our sponsors:



Jazz Pharmaceuticals



Upcoming Brown Bag Webinar

Register now for our October 10th webinar "Road Map to Understanding Service Dogs" with Miranda Williams! This is a great opportunity to ask the experts, so make sure you bring your questions for the live Q&A session.



Brown Bag
NARCOLEPSY WEBINAR SERIES

 Wake Up Narcolepsy INC.

Road Map to Understanding Service Dogs

-  Miranda Williams
Joyful Dog Training, Person with Narcolepsy
-  October 10th
-  2pm ET

*Pre-registration required

Thank you to our BBW sponsors:



Gala Sponsor Recognition

Thank You To Our Diamond Gala Educational Partners:



Thank You To Our Gold Gala Educational Partners:



Upcoming Events

September 1st-30th

Worldwide Step Up

September 20th

WUN Shadows to Light Gala

September 21st

Alberta WUN Town Hall

September 22nd

*World Narcolepsy Day 2024
& Red Sox WUN Town Hall*

September 28th

Colorado Step Up For Sleep

October 10th

October Brown Bag Webinar

ONGOING

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

Clinical Trials

XYLO Study: A clinical study looking at blood pressure in people with narcolepsy

We want to understand more about blood pressure when people with narcolepsy change from a high-sodium oxybate medication, like XYREM, to the study medication, XYWAV. XYWAV has the same active ingredients as XYREM, but with a much lower sodium content. To take part, you must be taking or will be taking a high-sodium oxybate.

[Learn more here](#)