



The Monthly Wake Up

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Message from WUN Executive Director

Greetings,

As we reach the end of March, Wake Up Narcolepsy (WUN) is in the midst of busy but exciting times! We had a very successful Sleep Awareness Week and are now moving closer to our 2024 National Summit on April 27th. We were delighted at the level of

support and engagement with our #NarcolepsyInSixWords contest and would like to thank everyone who submitted an entry and/or voted! Make sure to check out all the information from Sleep Awareness Week in this edition including recordings of our live events and a limited podcast series!

Thank you to Dr. Sharkey, Ashley Starr Frechette, Emily Clegg Barker and Kelsey Biddle for a wonderful March Brown Bag Webinar: Narcolepsy & Maternal Health!

Thank you to Vincent Arthur for sharing his Narcolepsy journey and to Brian Mahn for interviewing him during our Instagram Live Q&A! If you haven't already tuned in, Vincent races weekly on Tuesdays at 8:30pm ET in an online series streaming on YouTube. He recently finished in the top 5 with his new WUN car design!

Looking to April, we hope you will join us at our NO-COST 2024 National Summit at the Seattle Marriott Redmond! Spots are continuing to fill up and we'd love to see you there. There is a virtual option available for those who cannot attend in-person.

As our community continues to grow, we look forward to connecting with you all and expanding our programs and resources to meet your needs.

We are thankful for your support!

- Monica Gow



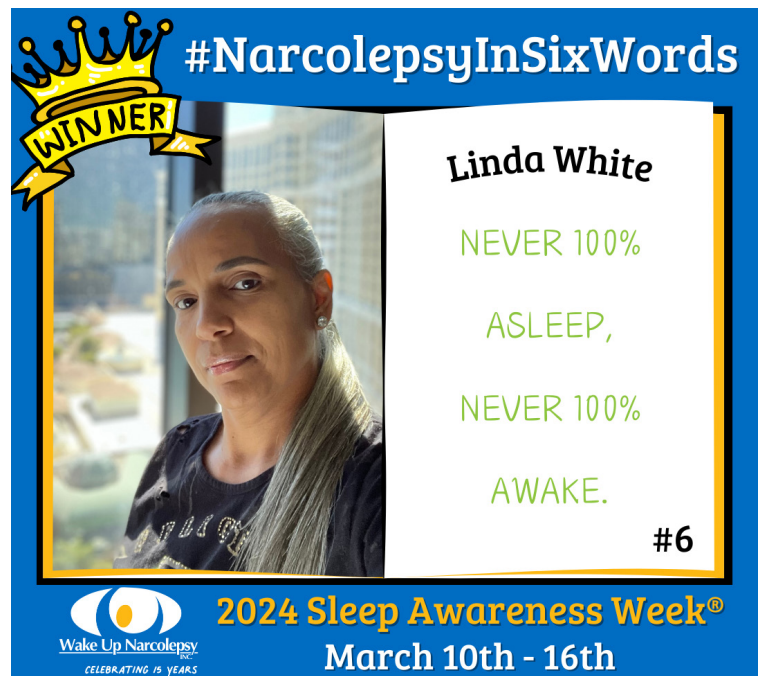
Monica Gow
WUN Co-Founder &
Executive Director

Sleep Awareness Week Recap

#NarcolepsyInSixWords Contest

Each year, we host a contest for Sleep Awareness Week that gives community members a chance to win exciting prizes and vote for their favorite submissions! This year, we brought back the #NarcolepsyInSixWords contest and got 44 entries!

Congratulations to our winner, Linda White, whose submission received 75 votes across Instagram & Facebook!



Congratulations also to our 2nd & 3rd place winners!

2nd place: Jill Hetrick - 48 Votes
"Perseverance, Struggle, Follow-through, Dedication, Unique, Neverending"

3rd place: Brittany Sorrentini - 44 Votes
"Never Truly Awake, Never Truly Rested"

Sleep Awareness Week Recap

Narcolepsy Nightcaps: Soothing Stories with WUN

Each weeknight, we released a new episode featuring voices across the Narcolepsy community sharing bedtime stories! Listen wherever you get your podcasts or watch on YouTube!

Episode 1:

"Farkle Finds His Furever Home"

Authored & Read by Wendy Johnson

Episode 2:

"The Tale of Peter Rabbit"

Read by Tre Burge

Episode 3:

"Cinderella"

Read by Katy Scruton

Episode 4:

"Jack and the Beanstalk"

Read by Tom Heckmaster

Episode 5:

"Ann I Am"

Authored & Read by Ann Klaas

Instagram Live Q&A with Vincent Arthur

Missed the live interview? Don't worry! It's available on our Instagram page or YouTube channel to watch now! Thank you to Vincent for sharing his journey with Narcolepsy and congratulations on another great race during the week!

Thank you to our 2024 awareness sponsors:



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Recording - Narcolepsy & Maternal Health

Brown Bag NARCOLEPSY WEBINAR SERIES



Narcolepsy & Maternal Health

 Katie Sharkey, MD, PhD, FAASM, FACP
Ashley Starr Frechette MPH (PWN)
Emily Clegg Barker PhD (PWN)
Kelsey Biddle MD Candidate (PWN)

 March 14th

 2pm ET

*Pre-registration required

Thank you to Dr. Sharkey, Ashley Starr Frechette, Emily Clegg Barker & Kelsey Biddle for a wonderful webinar!

The full recording can be found on the Wake Up Narcolepsy YouTube channel!

Upcoming Brown Bag Webinar

Register now for our April 24th webinar where you can learn all about Canada Narcolepsy medications & access to care!


This is a great opportunity to ask the experts, so make sure you bring your questions for the live Q&A!

Brown Bag NARCOLEPSY WEBINAR SERIES



Canada: Medications & Access to Care

 Laurel Charlesworth, MD
Assistant Professor, University of Ottawa
Kelsey Bingham
Person with Narcolepsy

 April 24th

 2pm ET

*Pre-registration required

Thank you to our BBW sponsors:



Summit Registration Reminder

Have you registered yet for the
2024 Wake Up Narcolepsy National Summit?

Keynote & Featured Speakers

**EMMANUEL
MIGNOT**
MD, PhD



**MICHAEL
GRANDNER**
PhD, MTR, CBSM,
FAASM



**ANNE MARIE
MORSE**
DO



Join us at the Seattle Marriott Redmond in
Washington on April 27th, 2024!

Register now at no-cost! Virtual option available.

Thank you to our 2024 Summit sponsors:



Upcoming Events

April 6th

Toronto WUN Town Hall

April 24th - 2pm ET

*April Brown Bag Webinar:
Canada Medications &
Access to Care*

April 27th

2024 WUN National Summit

May 9th - 2pm ET

May Brown Bag Webinar

June 1st - 5th

WUN attends SLEEP 2024

ONGOING

*Weekly support groups for
people with Narcolepsy
and IH*

Clinical Trials

**Boston Children's
Hospital Narcolepsy
Research Study for
Kids Ages 9 to 17**

Narcolepsy symptoms in children and adolescents extend beyond sleepiness alone. Narcolepsy symptoms commonly affect academic function, social relationship, mood, and sleep. In order to develop an outcomes scale that reflects values and experiences of kids with pediatric narcolepsy, we are testing a survey among kids 9-17 years with confirmed narcolepsy diagnosis.

Learn more below

*Questions? Contact
NeuroSleepResearch-dl@
childrens.harvard.edu*

Thank you to our Sponsors: