May 2024



CELEBRATING 15 YEARS

The Monthly Wake Up

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Message from WUN Executive Director

Greetings,

At the end of April, we welcomed virtual and in-person attendees to our 2024 National Summit near Seattle! There was space for sharing experiences, forming connections and learning from each other. It was rewarding to observe the growth in our community since last year's event and we appreciate everyone involved! Save the

date for next year's Summit on April 26th, 2025 near Raleigh, North Carolina. If you missed this year's sessions, recordings are available on WUN's YouTube channel.

Thank you to our recent Brown Bag Webinar speakers: Dr. Charlesworth and Kelsey Bingham in April, and Dr. Izzo and Dr. Todd in May! The April and May topics were "Canada Medications & Access to Care" and "Narcolepsy Diagnostic Journey," respectively. Both were incredibly insightful and have recordings that are available now on YouTube. The series is taking a break for the summer, but will return in August with more fantastic opportunities for our community to ask the experts!

Looking forward, the WUN team is kicking off summer in Houston to attend SLEEP 2024 June 1st - 5th. If you're attending the conference, be sure to stop by booth #232 to connect with us! We have lots of new resources for healthcare professionals, which are highlighted on our new website page.

While in the area, we are also having a Houston WUN Town Hall on June 2nd. Come by to connect with others living with Narcolepsy or Idiopathic Hypersomnia and loved ones! Don't forget we have an upcoming Seattle WUN Town Hall on July 13th as well.

Are you interested in planning a WUN Town Hall in your local community? Visit wakeupnarcolepsy.org/get-involved to learn more. We look forward to hearing from you!



Marica Ser

WUN Co-Founder & Executive Director



National Summit Recap

The Wake Up Narcolepsy (WUN) 2024 National Summit took place on April 27th, at the Seattle Marriott Redmond near Seattle, Washington! The event was a tremendous success with an amazing turnout both in-person and virtually. Thank you to everyone who made this possible!



Thank you also to our 2024 Summit Sponsors:



Save the Date: 2025 National Summit

April 26th near Raleigh, NC

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

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Upcoming WUN Town Halls

Houston // June 2nd // 1pm - 4pm CT

Pickles Social Club,

RSVP BELOW

13915 Kluge Rd, Cypress, Texas

Seattle // July 13th // 1:30pm - 4pm PT

Guest Speaker Matthias Lee, MD

RSVP BELOW

Salmon Bay Community Lending, 7919 Greenwood Ave North, Seattle, Washington

Thank you to our sponsors:

Jazz Pharmaceuticals. Takeda

Physician & HCP Page Launch

WUN is excited to share the launch of our new website page, **Resources for Physicians & Healthcare Professionals!**

This new page is designed to support professionals in providing optimal care for individuals with Narcolepsy. It is divided into two main sections: Office Resources and CME Courses.

Find no-cost options for printing and/or ordering our materials and see what current Narcolepsy CME credits are available to you!

Thank you to our Physician Education sponsors:



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



Announcing Gala Honorary Emcee

Shadows to Light Honorary Emcee



Ginger Zee

Chief Meteorologist & Chief Climate Correspondent, ABC News

Ginger Zee is the chief meteorologist and chief climate correspondent at ABC News. Zee has been there before, during and after almost every major natural disaster reporting for "Good Morning America" and across ABC News broadcasts and digital platforms. From Hurricane Katrina to recently being in the eye wall of Hurricane Ian, Zee has covered wildfires from California, France and Australia, blizzards across the nation and tornado outbreaks from Alabama to Oklahoma. Zee has employed her lifelong passion for the atmosphere and married it with compassion and humanity as these stories are always about the people the storms impact.

She is the author of five books, including the bestseller "Natural Disaster" (2017) and her recent memoir "A Little Closer to Home: How I Found the Calm After the Storm" (2022), along with a trilogy of middle grade books based in STEM called "Chasing Helicity."

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

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Brown Bag Webinar Recordings



Thank you Dr. Charlesworth & Kelsey Bingham for a wonderful webinar!

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



Thank you Dr. Izzo & Dr. Todd for a wonderful webinar!

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

> H3 HARMONY BIOSCIENCES

Thank you to our BBW sponsors:



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Upcoming Events

June 1st - 5th

WUN attends SLEEP 2024

June 2nd Houston WUN Town Hall

July 13th

Seattle WUN Town Hall

Interested in planning a WUN Town Hall in your local community?

Visit wakeupnarcolepsy.org/ get-involved

August 8th - 2pm ET

August Brown Bag Webinar

ONGOING

Weekly support groups for people with Narcolepsy & IH

Diamond:

Clinical Trials

Two-Part Study of MK-6552

The purpose of this study is to evaluate the safety, efficacy, pharmacokinetics (PK), and pharmacodynamics (PD) of MK-6552 in participants with Narcolepsy Type 1 (NT1).

More info below

Global Survey on Narcolepsy

Global Perspectives, an organization specialized in healthcare studies, is conducting a study to understand the relationship between narcolepsy symptoms and their effect on well-being.

More info below

Vibrance-1 clinical study for narcolepsy type 1

The Vibrance-1 Study is researching an investigational oral study drug for the potential treatment of excessive daytime sleepiness symptoms.

More info below

XYLO Study

This is a study looking at blood pressure in people with narcolepsy.

More info below

Silver: HB HARMONY 6

Thank you to our Sponsors: Jazz Pharmaceuticals. **Gold:** Avadel.