

Wake Up Narcolepsy
INC.

The Monthly Wake Up

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Message from WUN Executive Director

Greetings,

Wake Up Narcolepsy has had a particularly busy September this year! We hope you were able to celebrate with us in some way, whether it be attending one of our events or celebrating World Narcolepsy Day (WND) 2023 with us online! We hosted many events this month and are looking forward to more to come! Wake Up Narcolepsy also joined Tik Tok in preparation of the busy month and would love to connect with you there!

Early September, we welcomed people virtually and in-person to our 2023 conference with Mayo Clinic in Rochester, Minnesota! It was so wonderful to see everyone who came out for the event and all the connections that were formed. Save the date for our 2024 National Summit, April 27th, 2024 in Seattle, Washington!

We also launched a webpage for mental health resources in observation of Suicide Awareness Month. Those can be found at wakeupnarcolepsy.org/about/resources/narcolepsy-mental-health/

Later in September, we celebrated World Narcolepsy Day with our Awareness Week leading up to the event! During this week, we announced the milestone of Wake Up Narcolepsy donating \$1.35 million to Narcolepsy research since inception in 2008! We appreciate everyone who has made this possible. We also launched our new blog, Narcolepsy Perspectives, with a special World Narcolepsy Day edition.

The day before WND, we held an International Panel with representatives from 6 continents and 3 North American countries! This was a wonderful experience to hear about Narcolepsy around the world! On the big day itself, we had a Q&A on Instagram Live with Katie Morton, hosted by Wake Up Narcolepsy's own board member, Kelsey Biddle. We also shared lots of our community's content and the start of our camp!

Be on the lookout for a special edition letter that will be going out soon regarding a research award!

- Monica Gow



Monica Gow
WUN Co-Founder &
Executive Director

Wake Up Narcolepsy would like to say



THANK YOU



to all our sponsors throughout 2023!



Without our generous sponsors, we wouldn't be able to do the work that we do. Thank you to everyone who supports our mission!

Nicole Jeray - WUN Board Member Competes in 2023 U.S. Senior Women's Open Championship

Make sure to check out our article about our very own board member, Nicole Jeray, who is a retired professional golfer.

Nicole competed 2023 U.S. Senior Women's Open Championship in early September and talked with us about the connections between golf & her Narcolepsy.

Visit wakeupnarcolepsy.org/news/nicole-jeray-2023/ for the full article & link to the news coverage!

October Brown Bag Webinar

Pre-registration is required. Visit our website to reserve your spot today!



Brown Bag
NARCOLEPSY WEBINAR SERIES

THE BENEFITS OF PROPER SLEEP HYGIENE

OCTOBER 12TH  **2PM ET**

SHELBY HARRIS, PSYD, DBSM

Thank you to our sponsors:

    



BREAKING NEWS

Wake Up Narcolepsy is now on TIK TOK! Follow us @wakeupnarcolepsy for more!

Conference & Patient Summit Recap

The 2023 Wake Up Narcolepsy National Conference & Patient Summit took place on September 9th, 2023, in Rochester, Minnesota, in association with Rochester Mayo Clinic!

The event was a great success! Around 130 people attended in person and over 350 attended virtually!



Camp Recap



Wake Up Narcolepsy had our annual family camp for kids and teens with Narcolepsy at The Center for Courageous Kids on September 22nd - 24th!

Check out our social media for more!

Our speakers were Dr. Luis Ortiz and Liz Guckian. Mary Beth Guckian, Wake Up Narcolepsy Board Chair, also attended with her daughter!

World Narcolepsy Day 2023

This year, Wake Up Narcolepsy counted down the days to World Narcolepsy Day, September 22nd, with an awareness week!

Each day, WUN shared a piece of the organization for our community to learn more!

*Happy World Narcolepsy Day
2023!*



From Wake Up Narcolepsy

Monday was kick off day, Tuesday was philanthropy day, Wednesday was Community Day, Thursday was Education Day and Friday was World Narcolepsy Day!

Check out the next page for a summary of each day, including where to find recordings of any events that took place.

Thank you to everyone who got involved and made this all possible!

Read about it at
wakeupnarcolepsy.org/news/wun-world-narcolepsy-day-2023/

World Narcolepsy Day 2023 Cont.

Philanthropy Day

#WUNWorldNarcolepsyDay Awareness Week 2023

In 2023, Wake Up Narcolepsy donated \$165,000



This brings the total donated since inception to...

 **\$1.35 MILLION!** 

THANK YOU to everyone who has made this possible!

Donate: tinyurl.com/wun-world-narcolepsy-day

Community Day

On Wednesday, we launched our new blog, **Narcolepsy Perspectives!**

Education Day

On Thursday, we had our Early Access International Panel, hosted by Matt Horsnell!

World Narcolepsy Day

To celebrate the big day, we had a Q&A with Katie Morton, a person with Narcolepsy from The Bachelor, shared the start of our camp and had some influencer surprises!

The blog post can be found at wakeupnarcolepsy.org/blogs

Recordings from our September Webinar, our conference, the International Panel and the Katie Mo Q&A can all be found on the **Wake Up Narcolepsy YouTube Channel**

Upcoming Events

October 12th

Brown Bag Webinar: The Benefits of Proper Sleep Hygiene

October 15th - 17th

WUN @ Nord Breakthrough Summit

November 3rd

WUN presenting at Society of Behavioral Sleep Medicine Conference

November 13th - 14th

WUN @ Sleep Advocacy Forum & Hill Day

November 16th

Brown Bag Webinar: Taking Care of Your Mental Health

ONGOING

Weekly support groups for people with Narcolepsy and Idiopathic Hypersomnia

Clinical Trials

Psychometric Validation Study of three Patient-Reported Outcome Measures for Narcolepsy (NT2) in the United States

We are looking for participants who have been diagnosed with Narcolepsy Type 2 (NT2) to complete two surveys regarding their experience with NT2-related symptoms and the impacts on their lives.

Contact
natasha.schumacher@clinoutsolutions.com
or 520 325 9510.

Northwestern EXPLAIN-2 Study

The Behavioral Sleep Medicine Lab at Northwestern University is researching how relationships are affected by idiopathic hypersomnia and narcolepsy (IH/N).

Contact
explain@northwestern.edu