



The Monthly Wake Up

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Message from WUN Executive Director

Greetings,

As we move into the final couple of months of 2023, I am happy to report that Wake Up Narcolepsy (WUN) has had a year of tremendous growth and will be celebrating our 15 year anniversary this November!

In 2023, WUN awarded \$165,000 to Narcolepsy researchers bringing our total to \$1,350,000 donated to advance narcolepsy research since inception in 2008. Thank you to all who supported our efforts to make this possible!

While continuing with our existing programs, monthly Brown Bag Webinar, Conference/Summit, Online Support Groups, Kids Camp, we introduced our Patient Advocacy & Engagement Program, welcomed over 80 volunteers and increased our staff and Board of Directors. We developed a robust compilation of resources for People with Narcolepsy (PWN), from a Monthly Wake Up Newsletter, Narcolepsy Perspectives Blog and "What Does That Mean?" series to make educating yourself and others easier, as well as resources for loved ones, healthcare professionals and those just looking to learn more.

We recently hired Alejandro Bruner-Solas, a Patient Advocacy Manager, who will be the point person for PWNs, managing our volunteer committees as well as other platforms that work directly with the community. We have several meet and greets scheduled throughout the country in 2023 and will be planning more for 2024 so be sure to watch in your area for an event!

October and November include trips to the NORD Conference, Behavioral Society of Sleep as a SWHR (Society of Woman Health Research) symposium panelist and to the Sleep Advocacy Forum in DC.

In closing, we will be closing out 2023 with our End of Year Giving Campaign which will launch with Giving Tuesday.

Keep an eye out for more on celebrating 15 years of Wake Up Narcolepsy in November!

- Monica Gow





BREAKING NEWS

Wake Up Narcolepsy welcomes a new staff member to the team!

Wake Up Narcolepsy is so excited to welcome **Alejandro Bruner-Sola, *Patient Advocacy Manager,*** to our team of staff!



Alejandro grew up in the San Francisco Bay Area. He has several years of experience in healthcare working for DaVita in people services. Prior to this, he worked for organizations managing volunteers and seeking philanthropic relationships. He has served on boards for the NAACP in youth outreach and the League of United Latin American Citizens. He and his wife enjoy photography and started their own business in 2013.

Alejandro had symptoms of sleep paralysis and excessive daytime sleepiness (EDS) from the age of 5, but was never clearly diagnosed until the age of 37 with Narcolepsy Type 1, Circadian Rhythm Sleep Disorder and Insomnia. He is excited to join Wake Up Narcolepsy to help bring awareness and resources to the community and sleep space. As a new staff member, he can't wait to meet others advocating for and living with these rare disorders.

Alejandro resides in the Denver, Colorado Metro Area, with his wife Melissa and their three rescue dogs. He enjoys the outdoors, hiking, gardening and spending time with his family and friends.

REGISTER NOW!!!
NO COST EVENT



2024 WAKE UP NARCOLEPSY NATIONAL SUMMIT

*Saturday, April 27th, 2024
Seattle, Washington*

REGISTER NOW:

[tinyurl.com/
WakeUpNarcolepsy2024](https://tinyurl.com/WakeUpNarcolepsy2024)



Breakfast, Lunch, Snacks &
Parking Included!

ALL DAY IN-PERSON & REMOTE

*Seattle Marriott Redmond
7401 164th Avenue NE,
Redmond, WA 98052*

HEAR FROM LEADING EXPERTS
IN THE FIELD!

Dr. Emmanuel Mignot

Dr. Michael Grandner

Dr. Anne Marie Morse

There is something for everyone at the event, whether you're a person with Narcolepsy or Idiopathic Hypersomnia, a loved one, healthcare provider or just want to learn more!

Schedule coming soon!

NORD 2024 Summit Recap

On October 15th-17th, representatives from Wake Up Narcolepsy (WUN) attended the National Organization for Rare Disorders (NORD) 2023 Breakthrough Summit in Washington, DC!

Wake Up Narcolepsy is proud to be a supporter & exhibitor of the event. WUN Director of Philanthropy, Deb Pollock, was joined by one of WUN's support group leaders, Rorey Smith, in attending!

Rorey & Deb were able to network, share information about our organization, attend informative sessions and see some of our corporate partners!

It's always wonderful to be around people from the rare disease community to raise awareness and support!

Thank you, NORD, for a wonderful event!



November Brown Bag Webinar

Join us for the last
Brown Bag Webinar
of the year!

**Taking Care of
Your Mental Health:
Strategies for
People with
Narcolepsy and
Supporters with Dr.
Jennifer Mundt**
*Pre-registration
required*



Brown Bag
NARCOLEPSY WEBINAR SERIES

TAKING CARE OF YOUR MENTAL HEALTH:
*STRATEGIES FOR PEOPLE WITH
NARCOLEPSY AND SUPPORTERS*

NOVEMBER
16TH

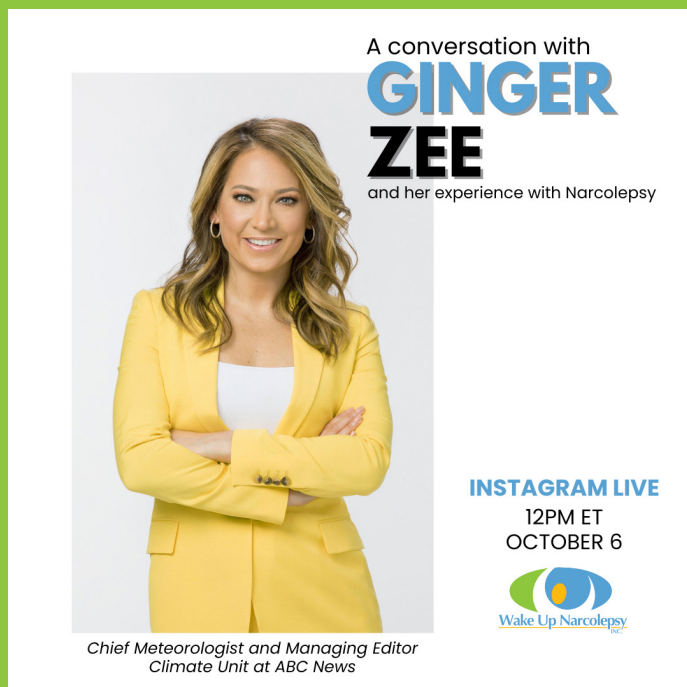
2PM
ET

JENNIFER MUNDT,
PhD

Thank you to our sponsors:

Jazz Pharmaceuticals | Avadel | H3 HARMONY BIOSCIENCES | Takeda | CENTESSA

Recording of Ginger Zee Q&A



A conversation with
**GINGER
ZEE**
and her experience with Narcolepsy

INSTAGRAM LIVE
12PM ET
OCTOBER 6

Chief Meteorologist and Managing Editor
Climate Unit at ABC News

On October 6th, Wake Up Narcolepsy had the second event in their Q&A Instagram Live Series. This time, our guest was Ginger Zee, Chief Meteorologist and Managing Editor Climate Unit at ABC News, who is also a person with Narcolepsy!

The recording of the conversation, as well as all other recordings of previous events, can be found on Wake Up Narcolepsy's YouTube channel!

Thank you, Ginger, for a wonderful conversation!

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

Upcoming Events

November

Wake Up Narcolepsy celebrates 15 years!

November 3rd

WUN presenting at Society of Behavioral Sleep Medicine - SWHR Symposium

November 16th

WUN @ Sleep Advocacy Forum & Hill Day

November 13th - 14th

Brown Bag Webinar: Taking Care of Your Mental Health

December 2nd

Texas Holiday Meet & Greet & Paint Party

December 3rd

Boston Meet & Greet

December 9th

Colorado Holiday Meet & Greet

ONGOING

Weekly support groups for people with Narcolepsy and Idiopathic Hypersomnia

Clinical Trials

XYLO Study

This is a clinical research 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.

Visit www.xyloforbp.com to see if you qualify.

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

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.

Contact
NeuroSleepResearch-dl@childrens.harvard.edu