January 2024



CELEBRATING 15 YEARS

The Monthl Wake U

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Message from WUN Executive Director

Greetings,

Happy New Year! I hope you all had a wonderful holiday season and that your year is off to a happy and healthy start.

Wake Up Narcolepsy (WUN) is starting off 2024 with exciting news! Tammy Anderson, former Program Manager, has been promoted to Assistant Director! Read more in this edition about Tammy's work with WUN.

Throughout the last few months of 2023, WUN raised \$53,000 for our End of Year Giving Campaign! I thank you for your generosity and dedication that allows us to continue bringing our programs and resources to the community at no cost, all while funding Narcolepsy research for better treatments and a cure.

As you may have seen on social media, we have also been announcing the dates for the first half of our 2024 Brown Bag Webinar Series. Join us to hear about the latest topics regarding Narcolepsy and have a chance to ask an expert your questions! The first webinar will take place on February 8th at 2pm Eastern Time and will be a Narcolepsy 101 presentation by Thomas Scammell, MD. Pre-registration is required so make sure you click here to secure your spot.

We have many other exciting events coming up, such as the 2024 Philadelphia Sleep Conference WUN representatives will be attending in March, and Wake Up Narcolepsy's own National Summit on April 27th in Redmond, WA! Check out the schedule featuring our keynote speaker, Emmanuel Mignot, PhD, MD, and many other amazing voices from the Narcolepsy community! Please join us in person. Virtual option available too.

Thank you again for your support & make sure to register for our exciting upcoming events!



Marica Am WUN Co-Founder



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Congratulations, Tammy!



Wake Up Narcolepsy (WUN) is excited to announce that former Program Manager Tammy Anderson has been promoted to Assistant Director, effective January 2024!

When her daughter was diagnosed with Narcolepsy at age 10, Tammy and her husband set out to find answers, treatments, therapies and ways that their daughter could live the fullest life possible. She has been involved with WUN since 2018 when their family first attended the

annual WUN Family Weekend at the Center for Courageous Kids!

"Tammy's leadership and guidance have significantly contributed to Wake Up Narcolepsy over the past few years," says WUN Co-founder and Executive Director Monica Gow. "We are thrilled about her transition to the role of assistant director."

Prior to joining WUN, Tammy worked as a development director at a nonprofit and as a student advocate in public, private and home education settings, building upon her belief that every child deserves an education and opportunities that fit their individual needs and where they are most likely to succeed.

"It has been rewarding to see firsthand the impact of this important work," Tammy said about her time at WUN. "I believe it changes lives. Stepping into this role, I'm eager to contribute even more meaningfully to our community's growth and well-being."

Read more on our website!



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Save the Date - 2024 Webinars



REGISTER NOW

to secure your spot for the February 8th webinar & ask Narcolepsy expert Dr. Scammell your questions!

Thank you to our 2024 sponsors:

🔿 Avadel.



2024 National Summit Schedule

REGISTER NOW

to join us on April 27th virtually or in-person at the Seattle Marriott **Redmond!**

Take advantage of our group rate by booking your room by March 29th!

Thank you to our 2024 sponsors:



9:00 - 9:45 AM

Keynote Speaker EMMANUEL MIGNOT MD. PHD

10:00 – 11:15 AM

People with Narcolepsy Perspectives Panel KATY SCRUTON. BRIAN MAHN, STEPHANIE MANULI, TRE BURGE MODERATOR: NICOLE JERAY

12:15 - 1:00 PM

Managing your Mental Health MICHAEL GRANDNER PHD, MTR, CBSM, FAASM

1:00 - 1:45 PM **Advocating for Yourself**

ANNE MARIE MORSE DO

1:45 - 2:30 PM

Sleep Inequities & Inclusion Panel

'ONY BENNAE RICHARD. TATIANA MARIA CORBITT MODERATOR: MICHAEL GRANDNER, PHD, MTR, CBSM, FAASM

3:00 - 3:45 PM

Breakout Sessions: Navigating Parenting & Family Life with Narcolepsy EMILY ROBINSON, ELISA WIRKALA, TIM STROUD MODERATOR: ANNE MARIE MORSE, DO What to Know about Narcolepsy NICOLE JERAY, Emmanuel Mignot, MD, PHD

3:45 - 5:00 PM

Support Groups: People with Narcolepsy Loved Ones Teens

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



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Thank You!

From the team at Wake Up Narcolepsy, we want to say a huge THANK YOU to everyone who helped us with our End of Year Giving Campaign!

Your generous donations help us:

- Accelerate Narcolepsy research

- Bring the 2024 National Summit to 500+ people virtually & in-person
- Send **30 children with Narcolepsy & their families** to our annual Family Weekend Camp
 - Provide support to 50+ weekly attendees of our 9 online Narcolepsy support groups

- Spread education & awareness through **8 Brown Bag Webinars** where community members directly ask experts their questions

Thank you for helping us continue our mission of driving Narcolepsy awareness, education and research towards improved treatments and a cure! We couldn't do it without the ongoing support of our community.



The Monthly Wake Up

Upcoming Events

February 8th - 2pm ET

February Brown Bag Webinar: Narcolepsy 101 by Thomas Scammell, MD

February 29th

Rare Disease Day 2024

March 14th - 2pm ET

March Brown Bag Webinar: Narcolepsy & Maternal Health

March 22nd

WUN attends the 2024 Philadelphia Sleep Conference!

April 24th - 2pm ET

April Brown Bag Webinar: Canada Medications & Access to Care

April 27th

2024 WUN National Summit

ONGOING

Weekly support groups for people with Narcolepsy and Idiopathic Hypersomnia

Clinical Trials

Clinical Trial For Patients 18 to 65 with Narcolepsy Type 2 or Idiopathic Hypersomnia (IH) by Alkermes Being Conducted by Biotrial Inc. in Newark, NJ

To help advance medical research, participate, or refer a friend!

Contact luz.stevens@biotrial.com

Northwestern EXPLAIN-2 Study

The Behavioral Sleep Medicine Lab is researching how relationships are affected by idiopathic hypersomnia and narcolepsy (IH/N). We are recruiting adults (age 18 or older) who have IH/N and want to participate with a parent.

Email: Explain@northwestern.edu Principal investigator: Jennifer Mundt, PhD

Thank you to our 2024 sponsors:



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