



The Monthly Wake Up

Contents

1. Message from Director
2. WUN's 15th Anniversary
3. Summit & Family Weekend
4. Gala Announcement
5. November Recap
6. Partnerships
7. Reminders
7. Events & Clinical Trials

Message from WUN Executive Director

Greetings,

November is a great time to express my gratitude to family, friends, people in the Narcolepsy community, corporate sponsors and others for supporting Wake Up Narcolepsy (WUN) since day one!

WUN was born 15 years ago to fill an unmet need in the community to accelerate Narcolepsy research, increase awareness, provide education and offer support.

We've done this and continue to do this by adding new programs as needed and appropriate. I hope you had a chance to watch our 15 year anniversary video to see all we have accomplished. We've also recently released a highlight video of our 2023 Family Weekend session where we announce the 2024 dates. If you haven't had a chance to see these yet, they can both be found on our YouTube channel or website!

This month, a few WUN staff members represented the Narcolepsy community at conferences in San Diego and Washington DC to spread awareness about this misunderstood and misdiagnosed medical disorder.

I presented on Narcolepsy and maternal health as part of a Society For Women's Health Research panel at the Society of Behavioral Sleep Medicine Conference. Deborah Pollock, Director of Philanthropy, and Cara Weaver, Marketing & Communications Coordinator, attended the Sleep Advocacy Forum in DC, to learn and share about Wake Up Narcolepsy.

Wake Up Narcolepsy will participate in #GivingTuesday on November 28th, which will kick off our End of Year Appeal. By supporting this important initiative for WUN, you will help us to make more progress toward reaching our mission.

Please watch for our donation links and give generously. I appreciate your support!

- Monica Gow



Check out WUN's Anniversary Video!



15TH ANNIVERSARY CELEBRATION VIDEO

This month, Wake Up Narcolepsy (WUN), a national leader in Narcolepsy awareness and research, celebrates 15 years of dedication to individuals with Narcolepsy and their loved ones.

Over the past 15 years, Wake Up Narcolepsy has been supported by countless individuals, both with and without connections to Narcolepsy, businesses, organizations, medical professionals, researchers, pharmaceutical companies, donors, volunteers and so many more.

We want to share our 15th Anniversary Celebration Video with you all to show you some of the things WUN has accomplished over the years with your support and generosity.

2024 WUN National Summit

Join us in Seattle, Washington, on April 27th, 2024!

Register now at no-cost for in-person or virtual!



**REGISTER NOW!!!
NO COST EVENT**



REGISTER NOW:
[tingurl.com/
WakeUpNarcolepsy2024](https://tingurl.com/WakeUpNarcolepsy2024)

2024 WAKE UP NARCOLEPSY NATIONAL SUMMIT

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

ALL DAY IN-PERSON & REMOTE
Schedule coming soon!



HEAR FROM LEADING EXPERTS IN THE FIELD!

- Dr. Emmanuel Mignot
- Dr. Michael Grandner
- Dr. Anne Marie Morse

Family Weekend 2024 Dates

Keep an eye out for registration opening in December!



2024 WAKE UP NARCOLEPSY FAMILY WEEKEND



OCTOBER 18TH - 20TH

A NO-COST OPPORTUNITY FOR
KIDS & TEENS WITH NARCOLEPSY
& THEIR FAMILIES!



Watch our 2023 highlights on our YouTube channel!

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

Wake Up Narcolepsy

SHADOWS
TO LIGHT

Gala

SAVE THE DATE

Friday, September 20, 2024

Event Honoree: Trailblazer Award

BURT ZWEIGENHAFT, PHD
EVP, FFF ENTERPRISES
FOUNDER & CO CHAIR AVBCC

Research Pioneer Award

KIRAN MASKI, MD, MPH

Patient Advocacy Award

ANNE MARIE MORSE, DO

NEW YORK ATHLETIC CLUB
180 CENTRAL PARK SOUTH, NEW YORK, NY 10019

For event details, contact nycgala@wakeupnarcolepsy.org.

INVITATION TO FOLLOW

SWHR Symposium

Wake Up Narcolepsy Executive Director & Co-founder, Monica Gow, presented alongside Irene Aninye, PhD, and Katherine "Katie" Sharkey, MD, PhD for the Society for Women's Health Research (SWHR) Symposium, "Addressing the Intersection of Maternal Health & Narcolepsy Care," at the 2023 5th Annual Scientific Conference sponsored by the Society of Behavioral Sleep Medicine (SBSM).

Monica presented on the topic of "Engaging the Patient Voice in Health Care Policy Solutions," and had a wonderful time making connections and spreading education about Narcolepsy. Thank you to Jennifer Mundt, PhD, DBSM, for introducing the panel!



Sleep Advocacy Forum

Wake Up Narcolepsy had the pleasure of sending representatives Deb Pollock, Director of Philanthropy, and Cara Weaver, Marketing & Communications Coordinator, to the 2023 Sleep Advocacy Forum!

The event was organized by Project Sleep to bring sleep advocates and policymakers together and took place in Washington, DC!

While attending, representatives were able to hear from amazing speakers from different organizations and universities on topics centered around sleep equity and public health.

Cara presented the organization update on behalf of Wake Up Narcolepsy, discussing WUN's approach and advancements concerning public and professional awareness, as well as health equity.



LPA Partnership

Wake Up Narcolepsy & Living Proof Advocacy partnered to bring an opportunity to those living with Narcolepsy who are also members of the LGBTQIA+ community!

Read the recap on our website for more! Thank you, Living Proof Advocacy!

Craving Good Sleep? So's Your Heart

People with common sleeping disorders such as obstructive sleep apnea or insomnia also are far more likely to have heart arrhythmias, plaque buildup, heart failure and coronary artery disease. Visit heart.org/sleepdisorders to learn more about your potential risks and how we're partnering with the American Heart Association to highlight this important link.

Reminder: Clinton, MA

For the entire month of November, store leadership at Hannaford's Clinton, MA location has selected Wake Up Narcolepsy to receive a \$1 donation from every purchase of the \$2.50 Hannaford Community Bag.

Head over to Hannaford to support WUN!

Upcoming Events

November 24th

WUN's 15th Anniversary

November 28th

*Support WUN for
GivingTuesday!*

December

*Family Weekend 2024
registration opens!*

December 2nd

*Texas Holiday Meet & Greet &
Paint Party*

December 3rd

New England Meet & Greet

December 5th

*Pregnancy & Parenting Support
Group starts*

December 9th

Colorado Holiday Meet & Greet

ONGOING

*Weekly support groups for
people with Narcolepsy and
Idiopathic Hypersomnia*

Clinical Trials

DUET Study

The DUET Study will evaluate daytime and nighttime effects of XYWAV® (low-sodium oxybate oral solution), also known as JZP258, in people with idiopathic hypersomnia (IH) or narcolepsy (Type 1 or Type 2).

Contact: 215-832-3750
ClinicalTrialDisclosure@
JazzPharma.com

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.