



The Monthly Wake Up

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Message from WUN Executive Director

Greetings,

April is National Volunteer Month and we want to recognize the amazing volunteers who make our mission possible. Whether you're a board member, support group facilitator, event moderators, speaker, fundraiser, committee member or just someone dedicated to helping us spread awareness, we appreciate you!

Thank you for all you do and your commitment to the Narcolepsy community.

It's nearly time for our 2024 National Summit and we are excited to see those attending in Seattle! Remember that virtual registration is still open. You can look forward to wonderful speakers presenting on new topics, insightful panels and connections with other attendees! Don't forget about our Canada Brown Bag Webinar happening this Wednesday as well. Registration is still open.

Our Tennessee Town Hall took place March 23rd, followed by our Toronto Town Hall on April 6th. This brings us to 6 successful WUN Town Halls where we have connected with local communities and built strong foundations! Thank you to the volunteers who helped plan these and to all those who attended.

You may remember us sharing that Vincent Arthur races with his WUN car weekly in the 2024 NORA season. We're excited to update that he finished 1st on April 9th! Congratulations, Vincent, and thank you for letting us be a part of your journey!

All of our programs are supported by the volunteer community! If you want to learn more about how you can help, visit wakeupnarcolepsy.org/get-involved.

- Monica Gow



Monica Gow
WUN Co-Founder &
Executive Director

Philadelphia Sleep Conference

On March 22nd, Wake Up Narcolepsy representatives attended the 2024 Philadelphia Sleep Conference hosted by BreakAway Media Group, LLC! WUN Director of Philanthropy, Deb Pollock, was joined by Sakhara Johnson, WUN volunteer. They had a great time meeting people with Narcolepsy and other sleep disorders, physicians and exhibitors. They even got to meet "Rocky!" Thank you to those who attended and thank you to the organizers for such a great event!



Sleep Issues Are Heart Risks: Learn More



A diagnosis of neurologic sleep disorder can serve as an independent risk factor for developing heart disease, so reducing cardiovascular risks in other ways while managing your sleep disorder is essential. 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.

Recap of WUN Town Halls



Nashville, Tennessee - 03/23 WUN Town Hall

Thank you to all the volunteers that made this event possible!

Thank you to our sponsors:  Jazz Pharmaceuticals 



Toronto, Canada - 04/06 WUN Town Hall

Thank you to all the volunteers that made this event possible & thank you to our guest speaker Dr. Brian Murray!

Thank you to our sponsors:  paladin
the company of endo international
an endo international company

Volunteer Recognition Day - April 20th

WUN TOWN
HALLS

INSTAGRAM
LIVE Q+A'S

ONLINE
SUPPORT GROUPS

MEDICAL
ADVISORY BOARD

FUNDRAISERS

AWARENESS
CAMPAIGNS

BOARD OF
DIRECTORS

BROWN BAG
WEBINARS



Thank you to our

VOLUNTEERS

who make it all possible!

FAMILY
WEEKENDS

NATIONAL
SUMMITS

Announcing Gala Honorees

Shadows to Light Honorees



Trailblazer Award

Burt Zweigenhaft

Founder & Executive Director, AVBCC

EVP, FFF Enterprises

This distinguished honoree is being recognized for their unwavering commitment to ensuring that patients have access to life-changing and life-saving treatments, a mission that deeply aligns with the core values of Wake Up Narcolepsy (WUN). Their dedication to assisting WUN in achieving the ambitious goal of raising \$500,000 and raising community awareness for children and adults living with Narcolepsy and other often debilitating rare sleep disorders is truly commendable. Please see our Award Honorees link for the complete bio of Burt Zweigenhaft.



Research Pioneer Award

Kiran Maski

MD MPH

This prestigious award is bestowed upon an outstanding individual who has pioneered highly innovative approaches in the realm of Narcolepsy and other rare sleep disorders research. Their relentless dedication to unraveling the intricacies of Narcolepsy's physiology has not only expanded our understanding but has also substantially contributed to the advancement of education and awareness. Moreover, their groundbreaking work has led to the development of crucial tools that hold the promise of unlocking the science of Narcolepsy, ultimately leading to improved treatments for those grappling with rare sleep diseases. Please see our Award Honorees for more information about Dr. Maski.



Patient Advocate Award

Anne Marie Morse

DO

This esteemed award recognizes an exceptional individual whose influence has profoundly touched the lives of patients living with Narcolepsy and other rare sleep disorders. Their exemplary standards of patient care have set a high benchmark, and their unwavering advocacy for the health and well-being of both children and adults living with Narcolepsy is truly exemplary. Utilizing a myriad of channels within the healthcare system, social media platforms, public appearances, and individual patient interactions, this outstanding advocate has been a tireless force in spreading awareness and knowledge about Narcolepsy. Through their tireless efforts, they have provided critical education, support, and hope to countless individuals affected by Narcolepsy, making a significant impact on their quality of life. Please see our Award Honorees link for more information about Dr. Morse.

Wake Up Narcolepsy (WUN) is proud to announce our 2024
Shadows to Light Gala Honorees!

Trailblazer Award: Burt Zweigenhaft
Research Pioneer Award: Kiran Maski
Patient Advocate Award: Anne Marie Morse

For more information about the event and the full bios of our honorees, visit the link below!


Upcoming Brown Bag Webinars

Brown Bag NARCOLEPSY WEBINAR SERIES



Canada: Medications & Access to Care

 Laurel Charlesworth, MD
Assistant Professor, University of Ottawa
Kelsey Bingham
Person with Narcolepsy

 April 24th

 2pm ET

*Pre-registration required




There's still time to register for our April Brown Bag Webinar happening **THIS WEDNESDAY!**

Don't miss out on learning about Canada Medications & Access to Care!

Brown Bag NARCOLEPSY WEBINAR SERIES



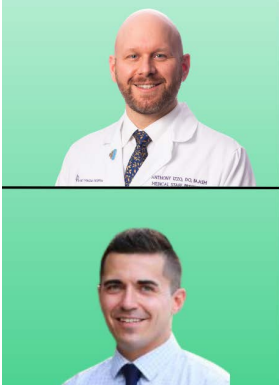
Narcolepsy Diagnostic Journey

 Anthony Izzo, DO, FAAN, FAASM
UMass Memorial Health
Jason Todd, MD
Mass General Brigham, Person with Narcolepsy

 May 9th

 2pm ET

*Pre-registration required



Register now for our May 9th webinar where you can learn all about the Narcolepsy Diagnostic Journey!

This is a great opportunity to ask the experts, so make sure you bring your questions for the live Q&A!

Thank you to our BBW sponsors:



Upcoming Events

April 24th - 2pm ET

*April Brown Bag Webinar:
Canada Medications &
Access to Care*

April 27th

2024 WUN National Summit

May 9th - 2pm ET

*May Brown Bag Webinar:
Narcolepsy Diagnostic
Journey*

June 1st - 5th

WUN attends SLEEP 2024

July 13th

Seattle WUN Town Hall

ONGOING

*Weekly support groups for
people with Narcolepsy & IH*

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*

Child Neurology Foundation (CNF) Needs Assessment Surveys

These CNF surveys help understand caregivers' clinicians' and providers' experiences in child neurology and can be completed through May 3rd. Results will be shared with advocates and health care providers, so they are better able to serve families.

Learn more below.

Thank you to our Sponsors: