



The Monthly Wake Up

Contents

1. Message from Director
2. Worldwide Step Up
3. Recent & Upcoming Community Events
4. Family Weekend Updates
5. Brown Bag Webinars
6. Events & Clinical Trials

Message from WUN Executive Director

Greetings,

As summer comes to a close, there are lots of ways to get involved with Wake Up Narcolepsy (WUN) this fall! We have many community events coming up in September. These are wonderful opportunities to connect with others who understand what you're going through, and learn about what WUN has to offer to support you on your journey. Make sure you are following WUN on social media for the latest announcements and updates.

As we develop future events, we are taking your feedback into account. I appreciate that people are willing to share what went well and what else they would like to see, so that we can best meet the needs of our community. Thank you for making this possible!

Last year, WUN held an awareness week to celebrate World Narcolepsy Day 2023. This has been such an exciting year that our celebration couldn't fit into just one week. I invite you to celebrate with us throughout the entire month of September by participating in Worldwide Step Up For Sleep! I've already set up my profile and would love for you to join us.

I look forward to welcoming those of you attending the inaugural Shadows to Light Gala next month in New York City, and to sharing the impact of the event with our community. This innovative event will place Narcolepsy in the spotlight, highlighting our focus on research, awareness and education.

The consistent support of our community continues to amaze me. Thank you to each and every one of you who believes in the work we are doing. The progress we have made is because of you and the future looks even brighter!

- Monica Gow



Monica Gow
WUN Co-Founder &
Executive Director

Worldwide Step Up For Sleep

Join us for a global campaign to raise awareness and vital funds around World Narcolepsy Day 2024 (September 22nd)! The campaign will run for the entire month of September. Register to fundraise, track your physical activity and have the chance to win prizes! There are also t-shirts available to order.

The participant who raises the most funds at the end of the month will win a \$100 Amazon e-gift card and two Wake Up Narcolepsy Worldwide Step Up for Sleep t-shirts! Additionally, weekly challenges and prizes will be announced throughout the month.

Thank you to our 2024 awareness sponsors:



It's Not Only a Bad Night's Sleep; It's Bad for Your Heart



An estimated 50 to 70 million American adults have a chronic sleep disorder. Studies show that poor sleep quality and duration can be associated with high blood pressure, elevated cholesterol, stroke, and heart attacks. Getting high-quality sleep can lower your risk of chronic disease and type 2 diabetes, strengthen your immune system, improve your mood, and increase your energy.

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.

Recent Community Events



Night At The Races WUN Town Hall Newton, NC - August 3rd

Congratulations, Vincent Arthur & thank you to WUN Representative, Blake Grisco!



West Virginia Step Up For Sleep Barboursville, WV - August 3rd

Thank you to all of our volunteers who made this possible!

Upcoming Community Events

Dallas-Fort Worth Family WUN Town Hall Frisco, TX - September 7th - 1:30pm CT

Alberta Night Walk WUN Town Hall Olds, Alberta Canada - September 21st - 6:30pm MT

Sponsored by:  **paladin**
une compagnie de endo international
an endo international company

Colorado Step Up For Sleep Golden, CO - September 28th - 8:00am MT

Thank you to our sponsors:



Jazz Pharmaceuticals



Narcolepsy Family Weekend Updates

We have exciting news about the upcoming 2024 Narcolepsy Family Weekend, taking place October 18th- 20th in Scottsville, Kentucky!

If you aren't familiar, the event takes place at the Center for Courageous Kids (CCK). Their Family Weekend Retreats are "designed to provide respite, recreation and support programs for families who have a child with a chronic or life-threatening illness." They provide summer camp experiences while also allowing parents to connect with those who understand them.

Narcolepsy is just one of the conditions that they serve. Others include Asthma, Autism, Cancer, Diabetes, Heart/Cardiovascular Disease, Transplants and more.

Although this Wake Up Narcolepsy (WUN) Family Weekend is usually for families of children and teens with sleep disorders, we recognize that there are other conditions that affect our community. If you're a parent with Narcolepsy and your child or teen is affected by one of these conditions, we invite you to join us at camp! Apply today to see if you're eligible.

2024 Family Weekend Speakers:



Luis Ortiz, MD

Dr. Luis Ortiz is an Assistant Professor of Pediatrics at Johns Hopkins University and Physician in the Sleep Center at Johns Hopkins All Children's Hospital. He joined the medical staff in 2018. He was diagnosed with Narcolepsy at age 21.



Kelsey Biddle

Kelsey graduated from Dartmouth College in 2017 with a bachelor's degree in neuroscience and was diagnosed with Narcolepsy in 2018. Her personal experience has fostered her passion for disability advocacy and empowering others. Kelsey is now in her final year at Harvard Medical School and plans to pursue a career in psychiatry.

Thank You To Our 2024 Family Weekend Sponsors



Jazz Pharmaceuticals




Recording - Social Security Disability

Brown Bag
NARCOLEPSY WEBINAR SERIES



**Social Security Disability
for People with Narcolepsy**

 Anjel Burgess, JD

 August 8th

 2pm ET

Thank you to Attorney Anjel Burgess for an insightful webinar on a highly requested topic! The full recording can be found on the Wake Up Narcolepsy website & YouTube channel.

Upcoming Brown Bag Webinar


Register now for our September 12th webinar where you can learn all about describing Narcolepsy symptoms with Dr. Stultz! This is a great opportunity to ask the experts, so make sure you bring your questions for the live Q&A.

Brown Bag
NARCOLEPSY WEBINAR SERIES



**Describing
Narcolepsy Symptoms**

 Debra Stultz, MD
Stultz Sleep & Behavioral Health

 September 12th

 2pm ET

*Pre-registration required

Thank you to our BBW sponsors:



Upcoming Events

September 1st-30th

Worldwide Step Up

September 7th

DFW Family WUN Town Hall

Sept. 12th - 2pm ET

*Describing Narcolepsy
Symptoms Webinar*

September 20th

WUN Shadows to Light Gala

September 21st

Alberta WUN Town Hall

September 22nd

World Narcolepsy Day 2024

ONGOING

*Weekly support groups for
people with Narcolepsy &
Idiopathic Hypersomnia (IH)*

Clinical Trials

**Vibrance-2 clinical study
for narcolepsy type 2**

*The Vibrance-2 Study is
researching an investigational oral
study drug for the potential
treatment of excessive daytime
sleepiness symptoms. Adults
18-70 years of age with
narcolepsy type 2 are invited to
learn more about this important
sleep disorder research.*

[Learn more here](#)

**IQVIA Survey and
Interviews in Narcolepsy
and IH with Xywav**

*IQVIA is currently looking for
adults (≥ 18 years of age) who
have been diagnosed with
narcolepsy or IH currently taking
Xywav® to take part in a paid
research study.*

[Learn more here](#)

Thank you to our Sponsors: