



The Monthly Wake Up

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Message from WUN Executive Director

Greetings,

I hope everyone is enjoying their summer and finding time to recharge. Here at Wake Up Narcolepsy (WUN), we've had a busy but rewarding June!

The recent SLEEP 2024 conference in Houston, Texas, was wonderful! The WUN team thoroughly enjoyed sharing new patient resources with healthcare professionals, industry and community members.

As an organization that aims ambitiously, meeting our goals and receiving such excited feedback is incredibly motivating. We were also able to attend two CME courses that we collaborated on during the conference. It was wonderful to see so many HCPs eager to learn more about Narcolepsy! Progress is being made in spreading education and raising awareness.

While in the area, we hosted our Houston WUN Town Hall! Thank you to everyone who assisted with or joined us for this event. Our next one will be in Seattle on July 13th. We also had a booth at the Hypersomnia Foundation Conference. We always welcome those living with IH to participate in our events and programs!

I would also like to mention that we recently announced "Step Up For Sleep" fundraising events. These can be runs or walks tailored to the community that plans them! Make sure to mark your calendars for West Virginia on August 3rd and Colorado on September 28th.

As we continue to see growth in our community, I am thankful for each of you! People living with this disorder are at the center of everything we do. Your dedication and support of WUN's mission is heartwarming.

- Monica Gow



Monica Gow
WUN Co-Founder &
Executive Director

SLEEP 2024 Recap

Thank you to the American Academy of Sleep Medicine (AASM) and Sleep Research Society (SRS) for an amazing event!



Thank you also to Haymarket Medical Education and PeerVoice for collaborating with WUN on two enlightening CME dinners!



WUN Town Halls



Houston Wun Town Hall - June 2nd

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

Seattle // July 13th // 1:30pm - 4pm PT

Guest Speaker Matthias Lee, MD

Salmon Bay Community Lending,

[RSVP HERE](#)

7919 Greenwood Ave North, Seattle, Washington

Step Up For Sleep Events

Just like WUN Town Halls, these local fundraising walk/runs take place in different communities around North America and can include an educational component. There is something for everyone and each event can be tailored to the community planning it. There are two scheduled events currently with plans for more in the works!

West Virginia // August 3rd

Colorado // September 28th

[Learn More Here](#)

Thank you to our sponsors:



Jazz Pharmaceuticals



Announcing Gala Mission Family

Meet the 2024 Mission Family



www.photosbypaige.com

It is with great pleasure that Wake Up Narcolepsy introduces you to the 2024 Shadows to Light Mission Family.

Please meet the dedicated and remarkable Grisco family, who will take center stage during this year's 2024 Shadows to Light Gala. At the core of this extraordinary family stands Mia Grisco, a courageous individual who has faced the challenges of Narcolepsy head-on for the past two years, sustained by the unwavering support of her dedicated parents, compassionate physicians, and a network of loving family and friends.

Mia's journey commenced with an unexpected twist during her sophomore year of high school, turning her once seamless life into a daily struggle against extreme exhaustion and isolation. Unfortunately, she found herself misunderstood by peers and teachers, contending with judgment and whispers of laziness, all while unaware that Narcolepsy was the silent culprit behind her difficulties.

With a formal diagnosis came not only clarity but also the formidable task of managing this intricate condition. Mia's path to resilience was not a solitary one; it was a collaborative effort. With remarkable courage, she actively engaged her parents, brother, and medical team, tirelessly working to educate her friends and teachers about Narcolepsy.

Now, over a year after her diagnosis, Mia stands as a beacon of resilience. Despite the continued struggles, sacrifices and limitations imposed by Narcolepsy, she is constantly reclaiming her academic, work, and social life with stride, advocating for herself, and becoming a source of inspiration for others facing similar challenges. Mia's journey is not just a personal triumph; it has evolved into a testament to the incredible power of endurance.

The Grisco Family is deeply committed to shining a light on Narcolepsy, fostering understanding, and championing the strength inherent in every individual grappling with this condition. We proudly stand in solidarity with the Wake Up Narcolepsy community, joining forces to make a meaningful difference and inspire hope for a brighter future. With Lynn serving as the Vice Chair of the Board of Directors, the funds we contribute, along with those we actively help raise through WUN, serve as a beacon of optimism for individuals living with Narcolepsy, holding the promise for more treatment options and, one day, a cure!

We look forward to you meeting The Grisco Family, Todd, Lynn, Blake, and Mia

"Kevin Skateboards Across Colorado"



"My name is Kevin Yeatts and I invite you to watch as I skate across the state of Colorado on my skateboard. Days 6 and 12 are dedicated to Wake Up Narcolepsy and our son, Owen, who is a person living with narcolepsy, who developed sudden and severe onset of symptoms at the age of 10 1/2. He has had to face many challenging hills, valleys, and roads in his journey with narcolepsy but thanks to the love and support from friends, family, WUN, and the narcolepsy community, he is living his best life as a 19 year-old college student and lover of music, gaming, and history. Thanks for watching!"

Thank you to everyone involved in this series for thinking of us and raising awareness! The video series & WUN campaign can be found [here!](#)

Get Help for Narcolepsy – and Your Heart



If you are unable to sleep well due to a diagnosis of a neurologic sleep disorder such as narcolepsy, insomnia or idiopathic hypersomnia, talk to your health care professional about what it may be doing to your heart and what you can do about it. 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.

Upcoming Events

July 13th

Seattle WUN Town Hall

August 3rd

West Virginia Step Up For Sleep

August 8th - 2pm ET

*August Brown Bag Webinar:
Social Security Disability for
People with Narcolepsy*

Sept. 12th - 2pm ET

*September Brown Bag
Webinar: Describing
Narcolepsy Symptoms*

September 20th

WUN Shadows to Light Gala

ONGOING

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

Clinical Trials

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 Type2).

[*More info here*](#)

Stanford University and Mayo Clinic have partnered to evaluate the efficacy of low sodium oxybate on total sleep time in patients with idiopathic hypersomnia.

[*More info here*](#)

In efforts to modernize clinical measurements of sleepiness, Stanford physicians partnered with the UK biobank to develop the Situational Sleepiness Scale.

[*More info here*](#)

Boston Children's Hospital developed a website to help 10 to 17 year olds with narcolepsy or idiopathic hypersomnia and their families better understand how their sleep disorder could affect their social health (e.g., with friends, at school with teachers), and strategies to improve these relationships.

[*More info here*](#)

Thank you to our Sponsors: