WUN NEWSLETTER

MAY 2023



Message from Executive Director, Monica Gow

Greetings!

I am pleased to announce that a new treatment for Narcolepsy was approved by the FDA this past month. A once nightly sodium oxybate therapy, LUMRYZTM, will soon be available to people with Narcolepsy. We are working on bringing access related specifics on this new treatment to the Narcolepsy community.

If you haven't yet, be sure to check out WUN's Online Support Groups. We are continually assessing feedback and making necessary improvements to keep them relevant and well run. A comorbidity group will be added to the line up of eight groups that meet weekly. We have also changed our model to have co-facilitators. Pre-registration is required.

Next month's Brown Bag Webinar is one you won't want to miss! Dr. Thomas Scammell, neurologist and professor, will be reporting on the differences between Narcolepsy Type 1, Type 2 and Idiopathic Hypersomnia - June 15th at 2:00pm - <u>Pre-registration</u> required.

Our free membership and volunteer program is gaining momentum. These programs are opportunities for you to stay informed and connected with WUN. We can definitely use your help so be sure to check out our volunteer opportunities. These program can be easily found on our <u>website</u>.

Lastly, we hope to see all of our sleep friends at SLEEP 2023 taking place in Indianapolis on June 3-7th. Be sure to stop by booth #104 at the conference. Take care and reach out to WUN with any questions or comments.

Take our <u>súrvey</u> to help us create a welcome packet for those newly diagnosed with Narcolepsy

Marica Sew
WUN Co-Founder &
Executive Director



May is Mental Health Awareness Month

Find community through WUN's online free support groups!



ONLINE SUPPORT GROUPS

GROUP	all times in ET	DAY
• Parents of PWN (ev	very other month) 8pm	Tues.
 College and Caree 	rs with Narcolepsy 7pm	Tues.
• Pregnancy & Paren	ting with Narcolepsy 8pm	Tues.
• Living with Narcole	psy 7pm	Wed.
• Living with Narcole	psy (West Coast) 10pm	Wed.
• Living with Narcole	psy (Canada) 6:30pm	Thurs.
• Living with Narcole	psy (LGBTQIA+) 4pm	Fri.
• Living with Narcole	psy 1:30pm	Sat.
• Living with Narcolepsy (Comorbidities) COMING SOON		

Thank you to our generous sponsors













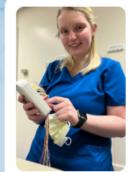
Register for a Support Group today by scanning the QR Code, or go to www.WakeUpNarcolepsy.org

or https://heypeers.com/organi zations/2



NEW BLOG POST

WUN Blog Posts



Navigating College & Careers With Narcolepsy

Tana Bao MSN, NP, RN

Wake Up Narcoleg

wakeupnarcolepsy.org

Check out our <u>website</u> for a new blog post every month about a topic related to living with Narcolepsy!

MOTHER'S DAY BLOG POST



Reflections from a Mother and Daughter Duo

Tana Bao MSN, NP, RN



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wakeupnarcolepsy.org

Newsletter Name Contest

In the previous edition, we announced that we were holding a contest for a name for our newsletter. We originally planned to announce the winning name in our May edition, but have found that we got so many great submissions, we need more time to make a final decision!

We have narrowed it down to a few finalists, and will be announcing the winner in our newsletter's June edition.

We thank you for your patience!



Upcoming Conferences



Join WUN at APSS
SLEEP 2023 in
Indianapolis, Indiana!

Our booth is #104 if you'd like to stop by!

WUN's 2023 National
Conference is September
9th in Rochester,
Minnesota!

See the QR code or the click here for more details on registration!





Program Reminders

JUNE 3 - 7

WUN Attending APSS SLEEP Conference

JUNE 15

Brown Bag Webinar: Understanding the Differences between Narcolepsy Type 1, Type 2, and Idiopathic Hypersomnia

JUNE 30 - JULY 3

WUN attending National Association of School Nurses Conference

ONGOING

Weekly support groups for people with Narcolepsy and Idiopathic Hypersomnia

visit wakeupnarcolepsy.org/events

Clinical **Trials**



RAISEUP AND SUNUP STUDY:

NOW ENROLLING — CLINICAL RESEARCH STUDIES FOR NARCOLEPSY

visit narcolepsystudies.com



INTERVIEW STUDY OF FATIGUE IN NARCOLEPSY:

ENROLLING ADULTS WITH NARCOLEPSY WHO EXPERIENCE FATIGUE

> contact Godwin Igbinedion at Fatigue@fortrea.com



PATHOPHYSIOLOGY OF NARCOLEPSY AND IDIOPATHIC HYPERSOMNIA: A MULTIMODAL **NEUROIMAGING STUDY:**

contact Mehdi Es-sounni at mehdi.es.sounni.ccsmtl@ssss.gouv.qc.ca