

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, LUMRYZ™, 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 - Pre-registration 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 website.

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 survey to help us create a
welcome packet for those newly
diagnosed with Narcolepsy**



Monica Gow
WUN Co-Founder &
Executive Director



May is Mental Health Awareness Month

Find community through WUN's online free support groups!



ONLINE SUPPORT GROUPS

| GROUP | <i>all times in ET</i> | DAY |
|--|------------------------|------------|
| • Parents of PWN (every other month) | 8pm | Tues. |
| • College and Careers with Narcolepsy | 7pm | Tues. |
| • Pregnancy & Parenting with Narcolepsy | 8pm | Tues. |
| • Living with Narcolepsy | 7pm | Wed. |
| • Living with Narcolepsy (West Coast) | 10pm | Wed. |
| • Living with Narcolepsy (Canada) | 6:30pm | Thurs. |
| • Living with Narcolepsy (LGBTQIA+) | 4pm | Fri. |
| • Living with Narcolepsy | 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/organizations/2>

NEW BLOG POST



Navigating College & Careers With Narcolepsy

Tana Bao MSN, NP, RN



wakeupnarcolepsy.org

WUN Blog Posts

MOTHER'S DAY BLOG POST



Reflections from a Mother and Daughter Duo

Tana Bao MSN, NP, RN



wakeupnarcolepsy.org

Check out our [website](#) for a new blog post every month about a topic related to living with Narcolepsy!

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!



FREE EVENT 
Presented with
Mayo Clinic, Rochester, MN
2023
**WAKE UP NARCOLEPSY
NATIONAL CONFERENCE**

| | |
|--|--|
| JOIN US & HEAR FROM LEADING EXPERTS IN THE FIELD | HYBRID ALL DAY IN-PERSON & REMOTE SATURDAY, SEPTEMBER 9, 2023 |
|  REGISTER AT https://whova.com/portal/registration/wunmc_202304/ | THE KAHLER GRAND HOTEL, 20 2ND AVE SW, ROCHESTER, MN |

Included: Breakfast, Lunch, Snacks, Parking
Schedule to follow

 
  

Reserve Your Room:
<https://tinyurl.com/2023WUNBookRoom>

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](http://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](mailto:Godwin.Igbinedion@fortrea.com) at
Fatigue@fortrea.com



PATHOPHYSIOLOGY OF
NARCOLEPSY AND IDIOPATHIC
HYPERMOMNIA: A MULTIMODAL
NEUROIMAGING STUDY:

contact [Mehdi Es-sounni](mailto:Mehdi.Es-sounni@ssss.gouv.qc.ca) at
mehdi.es.sounni.ccsmtl@ssss.gouv.qc.ca