

The Monthly Wake Up

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Message from WUN Executive Director

Greetings,

June has been an incredibly productive month. The Wake Up Narcolepsy team attended SLEEP 2023 conference in Indianapolis where we met with health care providers, industry, people with Narcolepsy and had time to be together as a team. As a virtual organization, we interact through video calls so having our

team together was an incredible opportunity to share ideas about other ways we can make a positive impact for our patient community. Interactions at this conference confirmed that Wake Up Narcolepsy is the leading national Narcolepsy advocacy organization for patient resources. Our robust website, resources, education platforms and 1-1 touch points all support our patient community as they navigate their way through diagnosis, finding a doctor and living with Narcolepsy.

Dr. Thomas Scammell of Harvard Medical School presented at our June Brown Bag Webinar on Understanding the Differences between Narcolepsy Type 1, Type 2 and Idiopathic Hypersomnia. The highly attended session was packed with information and lots of questions were answered throughout. This is a relevant topic in the Hypersomnia world. If you didn't catch the session, be sure to watch the recording on WUN's YouTube channel and subscribe while you're at it!

Looking ahead, I invite you to Dream With Us! Wake Up Narcolepsy will be hosting Dream With Us events where local communities will engage with each other in person. Keep an eye out for events in your local area! If you would like to volunteer or share ideas, please reach out at info@wakeupnarcolepsy.org and someone from our team will be in touch with you.

- Monica Gow



Monica Gow
WUN Co-Founder &
Executive Director

APSS Trip Recap



WUN had an amazing time making connections, educating about Narcolepsy and sharing our mission and programs with the community at APSS SLEEP 2023!

We were able to host a physician breakfast and attend many events with our sponsors.

If you were able to attend and stopped by to see us, be sure to be on the lookout for the resources you requested in an email soon!

Webinar Recordings

Did you know that Wake Up Narcolepsy has recordings of our monthly Brown Bag Webinars available on YouTube?

Head over to our channel to check them out. Latest topic:



Understanding the Differences Between Narcolepsy Type 1, Type 2 and Idiopathic Hypersomnia

Wake Up Narcolepsy

by Dr. Thomas Scammell



The Monthly Wake Up

September Conference & Patient Summit

September 9th, 2023 in Rochester, MN, is Wake Up Narcolepsy's annual conference and patient summit! Join us in person or virtually to hear from speakers of all backgrounds regarding Narcolepsy. There will also be a specific "Teen Track" for those attending including activities to bond with other teens with Narcolepsy.



WAKE UP NARCOLEPSY 2023 NATIONAL CONFERENCE

September 9th - The Kahler Grand Hotel, Rochester, MN

KEYNOTE SPEAKER

9:05 - 9:50 AM

Medications for Narcolepsy:
Present & Future

MICHAEL H. SILBER, M.B., CH.B

SPEAKER 1

9:50 - 10:35 AM

Narcolepsy Symptoms &
Diagnosis

MITHRI JUNNA, MD

SPEAKER 2

10:45 - 11:30 AM

Person with Narcolepsy
Co-Presentation

NICOLE JERAY

BREAKOUT SESSION 1

12:30 - 1:30 PM

Transition of Care from Pediatrics
to Adult **JULIE BAUGHN**

Pregnancy, Parenting with
Narcolepsy **MELISSA LIPFORD, MD**

Patient Perspective **EMILY ROBINSON**

BREAKOUT SESSION 2

1:40 - 2:40 PM

Mental Health & Narcolepsy

BHANUPRAKASH KOLLA, MD

Medical Comorbidities & Narcolepsy

DIEGO Z. CARVALHO, MD, MS

Comorbid Sleep Disorders
& Narcolepsy

ERIK ST. LOUIS, MD

INDUSTRY SPEAKERS

2:50 - 3:20 PM

WUN BREAKOUT SESSION

3:25 - 4:30 PM

Youth Breakout **TARA O'CONNOR**

PWN Breakout **TBA**

Parents/Loved Ones

Breakout **ANNE SAMARAWICKRAMA**

**FREE HYBRID EVENT - JOIN US: IN PERSON OR VIRTUAL
BREAKFAST, LUNCH & PARKING INCLUDED**

THANK YOU TO OUR SPONSORS





The Monthly Wake Up

New Support Group!

Living with Narcolepsy - Comorbidities

**Starting July 3rd -
Every Monday @ 7pm ET**

Register & Learn More @
heypeers.com/organizations/2

Full Support Group Schedule



ONLINE SUPPORT GROUPS

GROUP	all times in ET	DAY
• Living with Narcolepsy (Comorbidities)	7pm	Mon.
• Parents of PWN	8:15pm	Mon.
• 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.

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>



The Monthly Wake Up

Newsletter Name Winner!

In our April edition, we had a contest to help us rename our newsletter.

We're happy to announce that our winner is Syd Vincent with the submission of "The Monthly Wake Up!"

Thank you to Syd and everyone else who entered our contest. We're very excited to move forward with this newsletter and continue to spread awareness and education through our monthly editions.

2nd Annual Wicked Cornhole Tournament

Wake Up Narcolepsy

2023 CORNHOLE TOURNAMENT

To Support "Send A Kid to Camp" Fundraiser

**Saturday
August 19th
4pm**

Worcester Country Club,
2 Rice Street
Worcester, MA



**\$150 per Team
of 2, includes
tournament,
food, drink &
music**

*Proceeds will send up to 30 kids with Narcolepsy to
Courageous Center for Kids Camp - Sept 22nd-24th 2023*



Register with the
QR code or visit
tinyurl.com/WUN-Cornhole



Visit WakeUpNarcolepsy.org or connect with us on Instagram, Facebook, Twitter, LinkedIn or YouTube.



The Monthly Wake Up

Upcoming Events

June 30th - July 3rd

WUN attending National Association of School Nurses Conference

July 3rd

First meeting of NEW SUPPORT GROUP: Living with Narcolepsy - Comorbidities at 7pm ET

August 19th

2nd Annual Wicked Cornhole Tournament

September 9th

Wake Up Narcolepsy 2023 National Conference & Patient Summit

ONGOING

Weekly support groups for people with Narcolepsy and Idiopathic Hypersomnia

Clinical Trials

RaiseUp & SunUp Studies:

Now Enrolling - Clinical Research Studies for Narcolepsy

Visit narcolepsystudies.com

CATNAP® Pediatric Narcolepsy Registry

The Narcolepsy Assessment Partnership - Recruiting Now

Visit catnap.healthie.net

POLARIS Clinical Development Program

Visit polaris.nlspharma.com/polaris-clinical-program/