

WUN NEWSLETTER

APRIL 2023



Message from Executive Director, Monica Gow

Greetings!

Wake Up Narcolepsy has had an incredible first quarter for 2023 and continues to thrive. WUN's 14th Boston Marathon team produced incredible efforts on Monday, April 17th. Each year our WUNners work incredibly hard to raise funds for Narcolepsy research and train to run 26.2 miles in the most prestigious marathon in the US. This year, our team of four runners raised \$45,000, all going to accelerate Narcolepsy research. Thank you to all of our supporters! There is still time to support this amazing group of runners - click the button at the bottom of this page to donate.

We recently launched our new Patient Advocacy and Engagement Program. With this program we plan to expand communication efforts to reach all people living with Narcolepsy, increase awareness of our patient community with additional support, and create "communities" across the country. We want to get to know YOU and connect you with others in the Narcolepsy community so be sure to visit our website and Join WUN at no cost. Help us to keep you informed! Coming soon ... more details about our new Volunteer Program.

Wake Up Narcolepsy continues to offer high quality programming and resources for our community. If you have any questions or need anything, please be sure to reach out to us!



Monica Gow

WUN Co-Founder &
Executive Director



127th Boston Marathon



Jimmy



Dr. Vince



Tom



Becky

Shoutout to #TeamWUN for raising \$45,000 for Narcolepsy research!

WUN 2023

Boston Marathon Team

WUN thanks you for your support!

April 17th, 2023



Newsletter Name Contest

Hi everyone! If you don't already know me, I'm Cara, the Marketing & Communications Coordinator for Wake Up Narcolepsy. I'm very excited to introduce our new newsletter format to you all and announce that we are searching for a newsletter name!

The name should be something to signify staying updated with the Narcolepsy community. Our previous name was "Awake & Aware." If you have suggestions, please email cweaver@wakeupnarcolepsy.org.

The person who submits the winning title for our newsletter will be mentioned in next month's issue when we announce the name, as well as receive WUN swag!

Please submit your name and title suggestion by May 5th, 2023.

I look forward to hearing all your ideas and getting to know you all throughout my work here at WUN!

Sudbury SleepZzz Recap

Since Lynn and Todd Grisco's 16-year-old daughter, Mia, was diagnosed with narcolepsy in October 2022, the Grisco family has worked hard to love and support Mia in her daily life as she balances school, sports, and a social life—all while dealing with the near-constant fatigue brought on by her Narcolepsy.

Not long after Mia's diagnosis, the Griscos reached out to Wake Up Narcolepsy, and credit WUN with providing much-needed support, information, and resources in the wake of Mia's diagnosis. The Griscos have made it their mission to raise awareness about the incurable sleep disorder. It was only fitting, they decided, to hold an educational event and fundraiser in their home.

On Sunday, March 19, the Griscos hosted the Sudbury SleepZzz Reception to benefit WUN. Around 100 people joined the Griscos at their home for the event, including about 20 people with Narcolepsy—offering them a unique chance to talk to one another and share experiences.

To learn more, check out the buttons below.

We Updated Our Website!

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Start Your Journey Here with WUN!

Check out our new pages by visiting wakeupnarcolepsy.org!

Program Reminders

MAY 11

BROWN BAG WEBINAR: PATIENT ASSISTANCE AND HOW TO NAVIGATE INSURANCE

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

ONGOING

WEEKLY SUPPORT GROUPS FOR PEOPLE WITH NARCOLEPSY AND IDIOPATHIC HYPERSOMNIA

visit wakeupnarcolepsy.org/events

Clinical Trials



RAISEUP STUDY AND SUNUP STUDY:

NOW ENROLLING – CLINICAL RESEARCH STUDIES FOR NARCOLEPSY

visit narcolepsystudies.com



NORTHWESTERN NARCOLEPSY NIGHTMARE STUDY:

THE BEHAVIORAL SLEEP MEDICINE LAB IS RESEARCHING BEHAVIORAL (NON-MEDICATION) TREATMENT FOR NIGHTMARES IN ADULTS WHO HAVE NARCOLEPSY.

email nightmarestudy@northwestern.edu