



NARCOLEPSY AROUND THE WORLD

Created by:

projectsleep



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WELCOME!

We are so glad you are here. This toolkit is designed for people living with narcolepsy and their loved ones to offer new tools, tips, and perspectives on navigating narcolepsy. Project Sleep created this toolkit as part of the **Narcolepsy Nerd Alert** series.

Narcolepsy Nerd Alert is an educational series diving deeper into specific topics relevant to narcolepsy. Each month, Project Sleep broadcasts a live event via Facebook, hosted by Julie Flygare, JD, Project Sleep's President & CEO.

After each live broadcast, we create a corresponding toolkit (like this one!) to capture our collective knowledge to help others down the road. Quotes featured throughout the toolkit are from panelists and audience members who joined us for the live broadcast.

PLEASE NOTE

The **Narcolepsy Nerd Alert** series is intended for educational and awareness purposes and is not a substitute for medical attention. If anything in this toolkit sparks questions for you about your medical management, please bring those questions to your sleep doctor or narcolepsy specialist.



NARCOLEPSY AROUND THE WORLD

People around the world raised their voices for World Narcolepsy Day 2021!

On September 22, 2021, Project Sleep celebrated World Narcolepsy Day with "Narcolepsy Around the World," featuring an international panel of people living with narcolepsy to explore global perspectives on diagnosis, treatment, and support.

World Narcolepsy Day is dedicated to raising awareness of narcolepsy on a global scale. Co-sponsored by 29 organizations across 6 continents, World Narcolepsy Day unites the international narcolepsy community to inspire action, increase public knowledge, and elevate the voices of the 3 million people living with narcolepsy worldwide. Together, we can reduce delays in narcolepsy diagnosis, reduce stigma, and improve outcomes.

- Watch the [Narcolepsy Around the World](#) Video
- Learn more about the [Narcolepsy Nerd Alert Series](#)
- Learn more about [World Narcolepsy Day](#).



MEET THE HOST

Julie Flygare, JD, currently serves as President & CEO of [Project Sleep](#). She was diagnosed with narcolepsy with cataplexy in 2007 while in law school. Julie is an internationally recognized patient-perspective leader, an accomplished advocate, and the award-winning author of *[Wide Awake and Dreaming: A Memoir of Narcolepsy](#)*.



AUSTRALIA: BRAD



Dr. Brad McKay is a family doctor in Sydney, Australia. He works in a medical clinic that provides healthcare for anyone, but is especially focused on caring for the LGBTQI+ community. He also works in the media and presents health segments for TV, radio, and podcasts across the country.

Brad's narcolepsy symptoms started when he was about 19 years old. He remembers "trying to do hospital rounds and just getting exhausted by the end of the day" and trying to make it down the staircase of the hospital without tripping.

He visited his doctor many times, and had blood tests done, all of which came back normal. His doctor diagnosed him with post-viral fatigue. He accepted this diagnosis for about 6 months, but his tiredness did not improve. He went back to his doctor, and this time was diagnosed with chronic fatigue syndrome. He says, "I started seeing an exercise physiologist and trying to train myself back into health. I didn't really fit the criteria for chronic fatigue syndrome, so I felt like I was just going around in circles."

“ I went through a 10 year period of trying to find a diagnosis, trying different treatment measures, and not getting anywhere. I was going through medical school, then qualified as a doctor, then working as an intern, and then as a resident, and all this time we weren't really taught about sleep medicine at all.

- Dr. Brad McKay

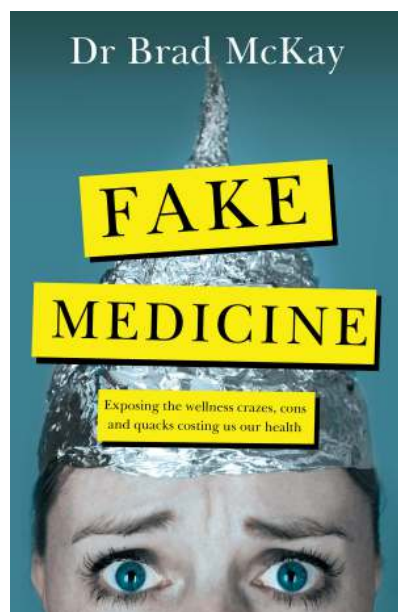


Brad ended up seeing a sleep physician who did an overnight sleep study and diagnosed him with obstructive sleep apnea, even though the results of the test didn't indicate this. Eventually he visited a chronic fatigue specialist, who recommended that he get a second opinion from another sleep physician.

The second sleep physician ordered a multiple sleep latency test (MSLT) and found that Brad was falling asleep within about four minutes at every opportunity to nap. He was then diagnosed with narcolepsy, *ten years* after first visiting his doctor about his symptoms.



Brad now lives in Sydney with his fiancé and their toy cavoodle, Humphrey.



Brad notes that Australian physicians largely prescribe stimulants and antidepressants for narcolepsy, as other medications are not available there. Even his own patients struggle to get a narcolepsy diagnosis because it's hard to find a specialist educated in a sleep framework.

He recently published a medical myth-busting book called Fake Medicine, into which he has woven the story of his own journey to narcolepsy diagnosis.



CHINA: DAVID



David Ma is a teacher living in Shanghai, China. He loves basketball and is proud of his Christian faith. David was diagnosed with narcolepsy in 2007 at the age of 14.

David remembers struggling to stay awake in classes and after dinner when he started his homework. He struggled with sleepiness for four years before seeking help at Peking Union Medical College Hospital in the summer of 2007.

“ I slept four or five times in the hospital, each time for maybe half an hour. I fell asleep during each nap period of my multiple sleep latency test, so I was diagnosed with narcolepsy.

- David Ma

When David and his family received his narcolepsy diagnosis, he was very worried. He recalls the doctor telling him that narcolepsy is a chronic condition -- not something he could recover from in his lifetime.

David's parents did not want him to disclose his narcolepsy to teachers or peers because they worried that we would be bullied. He says, "My parents love me but they don't know how to face this illness, so we don't talk about narcolepsy in my family."

“ I had many nicknames in my school, for example "Sleepy Man."

- David Ma



The medication David received from the hospital, a prescription stimulant, gave him headaches, so most school days he did not take it. He felt pressure from his family to maintain his grades, but struggled to learn mathematics. He says, "Both my body and my heart were ill. I got angry easily, especially when I woke up on my desk. Every day I had many bad dreams — worse than you could imagine in a movie."

In university, David found friends who accepted him, and he was happy to be able to tell them the truth about his narcolepsy. He started going to church, which brought him peace. Now David is sharing his story, and hopes for better quality of life for children with narcolepsy.

“ I'm still a patient, but now my life is full of colorful dreams, and I have hope.

- David Ma



David celebrating his 28th birthday with friends.



GERMANY: ANTJE



Antje Voutta lives in Darmstadt, Germany where she is a part time freelance university lecturer, non-fiction author, musician, and mother of two boys. She was diagnosed with narcolepsy at the age of 18, after experiencing symptoms for a year. She has a variety of hobbies, such as writing, composing and performing music, writing poetry and prose, dancing, and yoga.

Antje's symptoms, which started at age 17, included excessive daytime sleepiness, cataplexy, and nightmares with sleep paralysis. Remarkably, she received a type 1 narcolepsy diagnosis within one year of the onset of her symptoms. She credits the second neurologist she saw, saying, "The doctor had a friend who had narcolepsy. That's actually the reason he recognized my symptoms."

“ It’s not typical to be diagnosed so quickly, so I am very grateful. Even one year of narcolepsy symptoms affected me a lot.

- Antje Voutta

As a student, some teachers believed Antje's diagnosis and some dismissed it. She says, "Luckily the other pupils did not mock me, so I'm very grateful for that, even though sometimes you fall and even hurt your head on the table when you fight not to fall asleep, and that's kind of embarrassing." Early in her journey, Antje started going to meetings of a self-help organization for youth with narcolepsy in Germany, and later began leading a self-help group in Darmstadt.



Antje has to travel three hours by train to see her doctor, as he is one of the few narcolepsy experts in the country. However, she says public awareness of narcolepsy has increased in Germany since she was diagnosed, which she is happy to see.

“ We have the same disease and we're all so different, which is why I think it's so important to share experiences. We are the experts, and we can help each other.

- Antje Voutta

Antje earned an M.A. in American Studies and German Literature and a PhD in Literary Theory. She is a mother of two boys, ages 11 and 14. She says, "The most challenging part was when they were little. You need a village to raise kids as a person with narcolepsy."



For World Narcolepsy Day, Antje shared a poem, Narcoleptic (Naptime) Lullaby. You can find Antje's music on her [soundcloud account](#).

Narcoleptic (Naptime) Lullaby

**Sing me a lullaby
without the moon
one which
is not about the night
or the morning to come**

**Sing me a lullaby
about light dreams
that exiles my demons
and drowns out
their whisper**

**Sing me a lullaby
of courage and confidence
one which
catches my sleepiness
like spilled milk**

**Sing me a lullaby
about sleep as a friend
that makes me close my eyes
surrendering
without regret**

(a poem by Antje Voutta)



POLAND: AGATA



Agata Zadora is an engineer and mother of a three-year-old daughter living in Wrocław, Poland. She loves kickboxing and dance, and designs dance clothes. Her symptoms started when she was 19 years old. When Agata shared her story on World Narcolepsy Day, she was still seeking a diagnosis. Since then, she has been diagnosed with type 2 narcolepsy without cataplexy and is now able to start receiving treatment.

Agata's tiredness started in high school. She saw doctors who told her the cause could be stress or anemia, and she had blood tests done that all came back normal. Soon after, she graduated and started a family, still with no explanation for her excessive sleepiness.

“ It was really the hardest part of my life to be a young mom and not know why I was sleeping on the floor.

- Agata Zadora

Two years ago she decided to take control of her sleepiness, and started looking for a diagnosis again. She visited various specialists, telling them, “I'm really tired. I sleep in my car. Please help me.” Doctors still did not take her concerns seriously and told her, “It's only in your mind” and “Don't worry so much.”

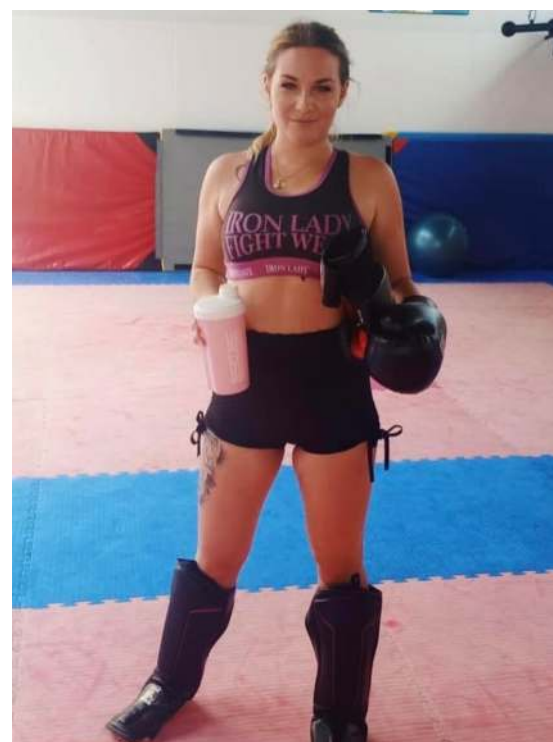




Agata says, "I thought maybe it wasn't a problem with my tiredness, but maybe it was a problem with my sleep. And I started looking for an explanation." She found Project Sleep online and watched videos of narcolepsy advocates sharing their stories, which helped her realize she could have narcolepsy. She also connected with other young Polish women experiencing similar symptoms, and they continue to provide each other information and support.

Agata made an appointment with a sleep specialist, but the soonest available was six months away, leaving her without treatment for another half a year. In October 2021, shortly after sharing her story during our World Narcolepsy Day broadcast, Agata had her visit with the sleep specialist and was diagnosed with type 2 narcolepsy without cataplexy. She is relieved to finally have a diagnosis and be able to receive proper treatment for her symptoms.

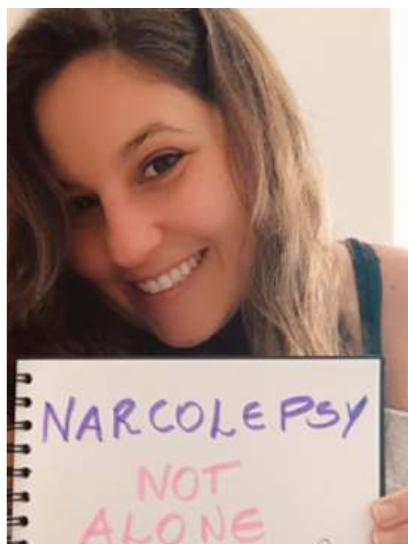
“ Now that I know why I'm so tired, I am living. I'm a happy person. - Agata Zadora



Of kickboxing, Agata says, "Until I realized I have narcolepsy, I never understood why during one training I could be so powerful, focused, fast, and dynamic, and the next I'd fall asleep after a 15-minute warmup."



BRAZIL: JULIANA



Juliana Angelim Neves is a lawyer from Bahia, Brazil, who loves dogs, music, movies, and reading. She was diagnosed with narcolepsy at age 24 and hopes to bring understanding and acceptance to people with the same condition. Juliana is the first person from Brazil to become a trained speaker with Project Sleep's Rising Voices of Narcolepsy program, and is a leader in sharing her story with Portuguese-speaking audiences.

Juliana doesn't remember exactly when her narcolepsy symptoms started. She says that as a child she had scary, vivid nightmares almost every night. As a teenager she started to experience disrupted nighttime sleep, waking after an hour or two of sleep. Later on she developed occasional dizziness and hypnogogic and hypnopompic hallucinations, and even thought she was going crazy. Juliana's mom, who also has a narcolepsy diagnosis, recognized some of the symptoms, and took her daughter to a neurologist in Sao Paolo.

At age 24 Juliana received a diagnosis of type 2 narcolepsy. Later she developed cataplexy, and had to find a new specialist because the one who diagnosed her had retired. Eventually she found another doctor who believed her and changed her diagnosis to type 1 narcolepsy with cataplexy.



Juliana with her mother, who is also living with narcolepsy and helped Juliana find her diagnosis.



“Most of my family and friends are very supportive. And I have an amazing boyfriend. He is very understanding when I say I'm not okay to go someplace.

- Juliana Angelim Neves

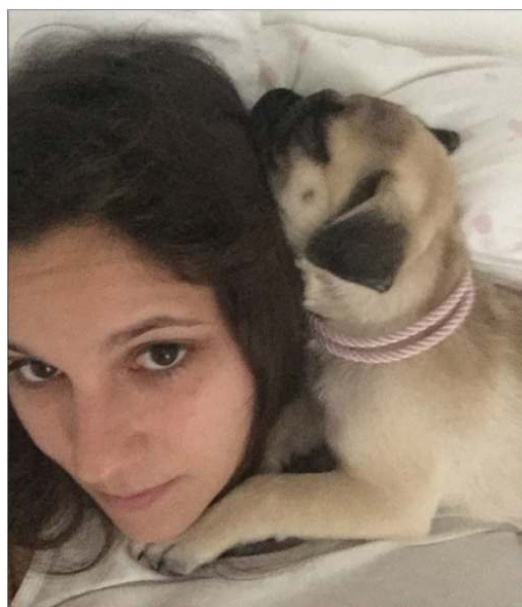


Juliana says, "I have support, but that's not true for the majority of Brazilian people with narcolepsy." In Sao Paulo there is a big center for narcolepsy that offers treatment and medication, but in other parts of Brazil there is no public support. Some people have to spend more than \$1000 to get a diagnosis and cannot afford medication.

Juliana is now a trained speaker with Project Sleep's Rising Voices of Narcolepsy program. She is also part of the Brazilian narcolepsy patient organization, ABRANHI, and says "It's a real hope for change in Brazil."

“It's rare to find a doctor in Brazil who knows what narcolepsy is, so we are trying to make it better step-by-step.

- Juliana Angelim Neves



Juliana snuggles up with her pug, Luna.

ABRANHI, which was founded in 2019, is raising awareness about narcolepsy in Brazil and helps its members get access to treatment. They also have partnerships with several house bills, as currently the Brazilian government does not provide any assistance or protection for people with narcolepsy. For more information, visit their website listed in the resources section.



ANGOLA: IRIS



Iris Vasconcelos is an avid advocate for invisible illnesses, freelance writer, and blogger from Portugal. She grew up in the UK and currently lives in Angola. She was diagnosed with narcolepsy at 28 years old, after experiencing symptoms for 13 years. She is a speaker with Project Sleep's Rising Voices of Narcolepsy Program, and shares her story with the hope of empowering others to do the same.

Iris's symptoms started when she was about 15 years old and included cataplexy, sleep paralysis, and hypnagogic/hypnopompic hallucinations. Around age 21, when she was in university, she began having trouble with excessive daytime sleepiness as well. She still had no idea that her sleepiness could be caused by a serious medical condition.

When she was 24, Iris moved to Angola to live with her sisters. When she arrived in Angola, her symptoms immediately became more severe. After two major incidents related to falling asleep during routine activities, Iris started looking for the cause of her sleepiness.

“ I didn't realize it when I moved there, but now I know that the heat in Angola makes my symptoms so much worse.

- Iris Vasconcelos

“ I started researching, typing everything I could think of into my search engine: 'Why do I keep falling asleep at work?' and 'Why am I sleeping when I'm not tired?' Somehow I came across the word 'narcolepsy.'

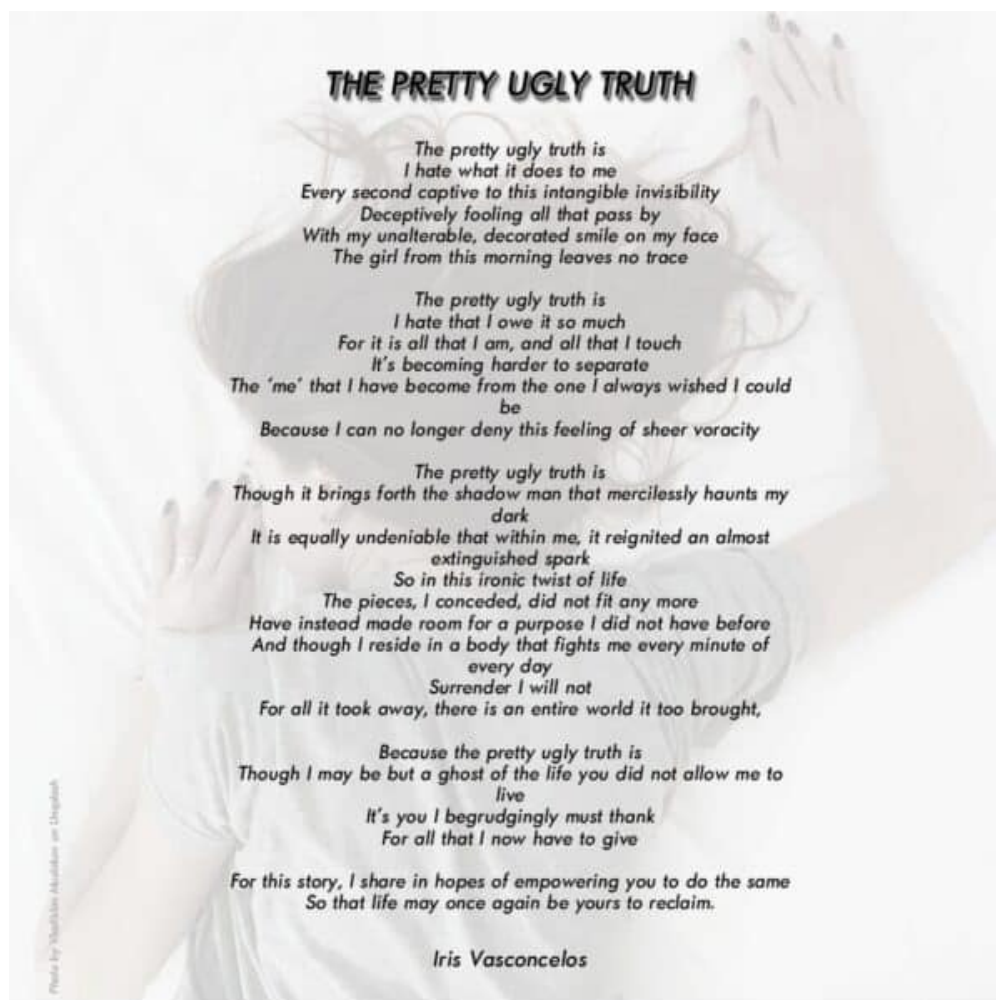
- Iris Vasconcelos



There was no way for Iris to get a sleep study in Angola, so she flew to Portugal, where her mom lives. She was able to pay privately to see a sleep specialist, and was diagnosed with narcolepsy soon after.

Narcolepsy medications are currently not available in Angola, so Iris's mom picks up the prescription in Portugal and sends it to her. Iris says the Angolan postal service is not reliable, which is an additional challenge in managing her care.

The challenges of getting diagnosed and accessing treatment motivated Iris to help others navigate life with invisible illnesses. She has become a trained speaker with Project Sleep's Rising Voices of Narcolepsy program, and helps facilitate online support groups for people with narcolepsy and their loved ones. She also raises awareness in English and Portuguese through her blog, [Life in Flashes](#), and on social media.





ISRAEL: DANA



Dana Harel lives in Israel with her husband and two children. She is a developmental psychologist and an artist. Her artwork primarily involves paper craft, scrapbooking and mixed media. Dana's symptoms started when she was about 18 years old, and she was diagnosed with type 1 narcolepsy with cataplexy several years ago, at age 34.

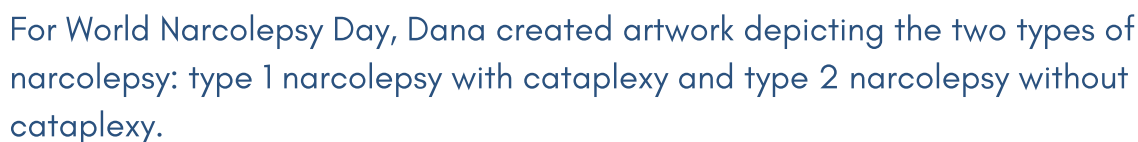
While her diagnosis was delayed at least 16 years, Dana says, "I am fortunate because a colleague of mine worked in a sleep lab and suspected I had narcolepsy, so I was able to see an excellent sleep doctor and get diagnosed and treated."

Before getting her diagnosis and receiving treatment, Dana experienced severe cataplexy every day. Currently, some of the main challenges of her narcolepsy are brain fog, sleepiness disrupting plans with friends and family, and not being able to leave the house much because Israel's hot climate triggers her sleep attacks

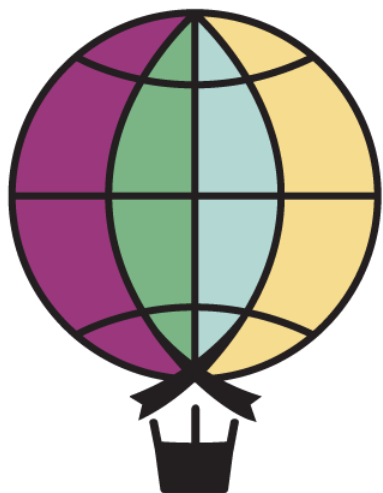
Dana says that in Israel, narcolepsy is very rarely diagnosed, and even neurologists have hardly heard of it. There are very few sleep doctors, and no narcolepsy specialists in the country. Only one medication is currently approved for narcolepsy in Israel, but she receives additional medication via international delivery.

“ There are misperceptions about narcolepsy here — others sometimes think my symptoms shouldn't be a problem because I take medication, or that my extreme sleepiness is the same as general tiredness.

- Dana Harel



Right – Narcolepsy: boredom, complex relationship of sleep and wakefulness. The man is a silhouette in the dark, with circuits all over his body. The D.R.E.A.M falls apart, the puzzle pieces don't fit together anymore. The proper connection between sleep and wakefulness has been lost. The man is handcuffed, he feels bound. In between, the rain doesn't stop, the umbrella is already in tears. A ghost is sitting on his shoulder and doesn't want to leave. Some bright stars and moon give some light. And in some of the cracks are written the symptoms that characterize his disorder.



WORLD NARCOLEPSY DAY

SEPTEMBER 22

HUGE thanks to our panelists and everyone around the world who raised their voice for World Narcolepsy Day. Your stories raise global narcolepsy awareness, fight stigma, and inspire others to do the same.

We can't wait for next year's World Narcolepsy Day on September 22, 2022!



INTERNATIONAL NARCOLEPSY RESOURCES

29 organizations around the world participated in World Narcolepsy Day 2021. Is there a narcolepsy patient organization in your country?

- [Associação Brasileira de Narcolepsia & Hipersonia Idiopática \(ABRANHI\)](#)
- [Asociación de Narcolepsia e Hipersomnias de Argentina \(ANHA\)](#)
- [Asociación Española de Narcolepsia e Hipersomnias Centrales](#)
- [Asociación Leonesa de Enfermedades Raras \(ALER\)](#)
- [Association Française de Narcolepsie Cataplexie et d'Hypersomnies rares \(ANC\)](#)
- [Associazione Italiana Narcolettici e Ipersonni \(AIN\)](#)
- [Dansk Narkolepsiforening](#)
- [Day4Naps](#)
- [Families and Children Experiencing Symptoms \(FACES\) of Narcolepsy](#)
- [Narcolepsie Vlaanderen](#)
- [Hypersomnia Foundation](#)
- [Japan Narcolepsy Association](#)
- [Narcolepsy Africa Foundation](#)
- [Narcolepsy Australia](#)
- [Narcolepsy China](#)
- [Suomen Narkolepsiayhdistys ry](#)



- [Narcolepsy Ireland](#)
- [Narcolepsy Network](#)
- [Narcolepsy UK](#)
- [Nederlandse vereniging narcolepsie](#)
- [Narkolepsie Netzwerk](#)
- [Neuro Narcolepsy](#)
- [Project Sleep](#)
- [PWN4PWN](#)
- [Narkolepsiföreningen](#)
- [SNaG](#)
- [Sufferers of Unique Narcolepsy Disorder \(SOUND\)](#)
- [TATU](#)
- [Wake Up Narcolepsy](#)



THANK YOU!

We are so grateful that you took the time to check out this toolkit!

Project Sleep is a 501(c)(3) nonprofit organization dedicated to raising awareness about sleep health and sleep disorders.

More resources at: www.project-sleep.com

