

Project Sleep Narcolepsy Nerd Alert
Narcolepsy Around the World (Season 1, Episode 10)
Transcribed by Mirela Starlight

Julie Flygare, JD is the President & CEO of Project Sleep, a leading narcolepsy advocate, speaker, award-winning author, and Stanford Medicine X ePatient Scholar diagnosed with narcolepsy and cataplexy in 2007. She received her B.A. from Brown University in 2005 and her J.D. from Boston College Law School in 2009.

Brad McKay is a GP and family doctor currently living and working in Sydney, Australia. Dr. McKay seeks to bring more awareness of narcolepsy to Australia and works with the media to do so. Dr. McKay is also passionate about and involved in the LGBTQI+ community, and was diagnosed with narcolepsy at 19 years old, after making it through medical school undiagnosed.

David Ma is a person living with narcolepsy and teacher living in Shanghai, China. He was diagnosed with narcolepsy in 2007 after struggling through school for years with undiagnosed narcolepsy. A strong Christian faith has helped David to come forward and be able to speak up for those undiagnosed or still hiding their diagnosis in China.

Antje Voutta has her M.A. in American Studies and German Literature and a PhD in Literary Theory. Antje is a university lecturer, author and freelancer living in Darmstadt, Germany. Ante was diagnosed with narcolepsy in 1992 and has developed many coping mechanisms over the years. Antje also lead a support group for narcolepsy for several years.

Agata Zadora lives in Wroclaw, Poland, and was diagnosed with narcolepsy after sharing her story and struggle to find diagnosis on Project Sleep's podcast. Agata believes diagnosis is the key to being able to cope and live a happy life with narcolepsy.

Juliana Angelim Neves lives in Bahia, Brazil and is a passionate advocate working to raise awareness of narcolepsy in Brazil. Juliana was also the first trained Rising Voices of Narcolepsy speaker in Brazil. Juliana also has a mother who is living with narcolepsy as well.

Iris Vasconcelos lives in Angola and strives to advocate for and educate about narcolepsy in a country that has very low awareness around narcolepsy. Iris had to seek diagnosis and treatment abroad, and hopes to change the state of narcolepsy awareness in Angola for future generations.

Dana Harel lives in Israel and was one of the first three people to begin receiving sodium oxybate therapy in Israel. It took at least 16 years for Dana to be diagnosed with narcolepsy with cataplexy and Dana hopes that more awareness of narcolepsy will reach Israel.

In today's episode, Julie and other guests around the world celebrate World Narcolepsy Day by coming together to share their unique narcolepsy journey stories, including symptoms, pre-diagnosis, and how varying and different treatment options exist or don't exist in different parts of the world. From China, Australia, Angola, Brazil, Germany, Poland and Israel, people living with narcolepsy have so many differences as well as similarities all over the world.

The Narcolepsy Nerd Alert series invites listeners to dive deeper into specific topics relevant to living with Narcolepsy. This is a written transcription of the podcast "Narcolepsy Around the World" (Season 1, Episode 10) from Project Sleep.

Project Sleep is a 501(c)3 Nonprofit Organization, dedicated to raising awareness and advocating for sleep health, sleep equity and sleep disorders.

All guests and speakers express their own opinions. While medical diagnoses and treatment options are discussed for educational purposes, this information should not be taken as medical advice. Each person's experience is so unique, which is why it's so important to always consult your own medical team when making decisions about your own health.

Julie in intro: Every year, we raise awareness and celebrate our international community on **World Narcolepsy Day**, September 22nd. In today's podcast, you'll hear incredible stories from people living with narcolepsy, around the world. In China, Australia, Poland, Germany, Israel, Angola and Brazil. I think you'll find listening to this podcast that our experiences are more similar than we might've imagined. We may be spread out over many continents and time zones, but we are connected in very profound ways, around the world.

Julie: Happy World Narcolepsy Day, everybody! We have this amazing panel here of people from around the world, sharing their stories— and we're so grateful to them. For some people English is not their first language, and we're really grateful for their willingness and their bravery to come on here, and— and— to share their story, about narcolepsy— and in English [laughs] for our audience. Before we go into hearing people's stories, I just want to quickly say hi to everyone around the world. So, we have Brad in Australia, or Dr. Brad McKay— Hi, Brad! [laughs]

Brad: Hi, everyone!

Julie: We have David, in China— Hi, David!

David: Hi.

Julie: Thank you so much for joining us from China, David. And, really excited because Narcolepsy China is a non-profit organization in China that has recently reached out and been part of our coalition. So it's a new organization, that joined our coalition, leading World Narcolepsy Day. And we have— Antje, here in Germany— Hi Antje!

Antje: Hi, glad to be here today.

Julie: And we have Agata in Poland. Hey Agata.

Agata: Hi everyone, hello from Europe! [laughing]

Julie: And we have Iris in Angola, hi Iris! And will you share with people where Angola is, in case they don't know?

Iris: Yes, hi everyone! [laughing] So in case nobody's ever heard of it, Angola's in— southwest of Africa, so— obviously everybody knows south Africa, that's the best reference, we're— four hours from there.

Julie: Awesome, thank you for joining us. And we have Juliana, in Brazil! Hey Juliana.

Juliana: Hi, happy Narcolepsy Day! [laughing]

Julie: Thank you, and where are you in Brazil?

Juliana: I'm in Salvador, Bahia.

Julie: Awesome. So, why don't we go ahead and get started with— Dr. Brad McKay, we'd love to hear a little bit about your experience, in Australia— with your symptoms developing, first— how long did it take to get diagnosed— what were the symptoms that were bothering you— yeah, let's start there.

Dr. McKay: Okay, so— Hi, I'm Brad. I'm a GP, a family doctor in Sydney, Australia, at the moment. And yeah, like going back to when I started getting narcolepsy symptoms would've been when I was about 19. I just started feeling really tired and was trying to do hospital rounds — just getting exhausted by the end of the day, having to like, try to make my way down the staircase of the hospital without tripping, and then would get into my car and have a little bit of a nap before I would drive home— and then have another nap, and then have dinner— and then try to study and then fall asleep studying, and then— [laughs] have another sleep. Um, so, [laughs] I was— I went and saw the GP, for quite a few times, and they sort of said, oh we don't really know what's going wrong— your blood tests are all fine. Maybe you've had glandular fever at some stage and maybe you've just got this post-viral fatigue. And so I sort of went along with that diagnosis for a while, and then about 6 months later was still feeling tired. Then, yeah— they said, well maybe you've got chronic fatigue syndrome. So I started seeing an exercise physiologist and trying to train myself back into health— but I didn't really fit the criteria for chronic fatigue syndrome [laughs] so I felt like I was going around in circles with this strange treatment criteria which probably doesn't work for chronic fatigue syndrome anyway, but that's another story— [laughs] and then, um— I went and sort of like, trying to like cross things off the list. So I sort of went, oh well am I depressed? Yeah, okay well let's go and get some treatment for that. And so I got loads of counseling and so I wasn't really depressed anymore, and wasn't anxious, but I was still really tired. And then I ended up seeing a sleep physician and doing an overnight sleep study and said oh maybe you've got obstructive sleep apnea, even though your sleep study doesn't really show this. And then maybe you should try a mandibular advancement slip to try and keep your airway open at night time. And then I tried that for about 6 months and that didn't really improve anything, I still felt tired all the time. And then, eventually saw like a— chronic fatigue specialist, which is a weird— sort of like, physician — they're very rare in Australia anyway. And then he wanted me to see a different sleep physician because he didn't trust the last sleep physician's advice. Then I went and saw a different sleep physician and then had a MSLT— so mean sleep latency test, and then yeah just found that I was falling asleep within about four minutes, every time I was like sort of having the lights turned off, and during the day. So it wasn't until, like— it was like a 10 year period of time of just trying to find a diagnosis, and trying different treatment measures, and not really getting anywhere at all. And this was really weird because I was like going through medical school, then qualified as a doctor, and I was working as an intern, and then as a resident— and all this time we weren't really taught much about sleep medicine, at all. So, our teaching on narcolepsy was pretty much zero— throughout my whole medical career. Even going into general practice training and becoming a family doctor, like we still don't have— much. We're taught about obstructive sleep apnea, and we're taught about CPAP machines, and how you need to really be diagnosing that, because it's a major risk for hypertension and — and— heart disease. And just sort of like skimmed over all the other sleep disorders that there are. It wasn't until I sort of started getting an education, from a sleep physician who knew what the hell they were talking about— and then I started sort of like entering into this whole world that really wasn't— discussed. And even with my own patients now, I find it's quite difficult to try to get a diagnosis because you've got to find a sleep physician who's educated within like, a sleep frame work. 'Cause often they are sort of like trained as anesthetists or in respiratory medicine, and then they're really focusing on airways and breathing, and they're not

really focusing on hypocretin and other sort of hormonal responses that can go on, or— idiopathic hypersomnia.

Dr. McKay: So it's— it's, really like it seems like a niche area but if it's one in 2,000 people, you sort of think it's not really that niche, maybe just missing a whole lot of diagnoses. And yeah, this is why it's really important to talk about it, as we are today— because yeah, it's really difficult, down under, to get a diagnosis.

Julie: Wow. So—

Dr. McKay: That's my short story. [laughing]

Julie: Yeah, it's unbelievable even to think that even you as a doctor now, a primary care doctor that's obviously passionate about, you know, probably, I would think that you'd be extra passionate about helping people that might have a sleep disorder get help— and even that's hard.

Dr. McKay: Yeah, yeah— exactly. 'Cause if— if somebody comes in saying that they're tired, like— being tired can be— there's a whole range of different reasons that can make somebody tired. And then like, sleepy is sort of a bit of a subsection of that— and you don't really have many people coming in saying, "I'm feeling sleepy all the time," which is sort of yeah, a bit of a differential. That even if you're sending somebody to a sleep physician, a sleep specialist— then yeah, you— it's a little bit hit and miss— if you don't know, if you're not in the know of who is trained in what regard, like you just consider them all the same. And so you could be sending your patients to somebody who really doesn't know all that much about narcolepsy, it's not on their radar— and they'll just say, oh yep— you do or don't have obstructive sleep apnea— and then that's sort of the end of the conversation. So, yeah. It's sort of, it's a weird measure.

Julie: And so how is treatment in Australia?

Dr. McKay: So, treatment is— interesting. [laughing] So at the moment, in Australia, the main treatment is stimulant medication. So— if somebody is diagnosed, then— we're treated with, um— modafinil, armodafinil, or dexamphetamine. Those are sort of like the main— medications that we use. Eh, over in America, I understand that the first line treatment would be something like Xyrem, so— you're using like sodium oxybate to help your sleep time— to getting better sleep— so then during the day time you're actually functioning more like a human being. So— at the moment in Australia they're trying to sort of get it across the line, they're trying to sort of bring— different drugs into government funding, and make them more freely available— but there is a lot of roadblocks at the moment. So the TGA, the Therapeutic Goods Administration of Australia basically says, oh, well narcolepsy is a sleepiness problem, so you need to be using stimulant medication. They don't really see that not getting appropriate deep sleep, is really the— the issue— [laughing] that's, well part of the issue— that's behind it. So the focus is completely different and even the language that they use— that they obviously don't really realize what narcolepsy is— is part of their framework of understanding what the disease process is. So I think one of the documents also, instead of cataplexy, they're talking about catalepsy. So they don't even know how to spell the word.

[Julie laughing]

Dr. McKay: —Never mind what it means. So we don't have those medications— uh, I think a lot of patients are put on tricyclic antidepressants or different antidepressants to sort of knock out their dream life. So that's sort of what I have at nighttime, so not getting petrified, every

night when I shut my eyes and— have movie length dreams that I'm struggling to fight my way through, and survive— every evening, like I did previously. So I'm quite happy without a dream life at— [laughs] — at the moment. But it's still not brilliant, and there's lots of side effects as well that you can get from other medications. Yeah, it's sort of like— it seems like we're treating half of the disorder, in Australia, and we're just forgetting everything that's happening at night.

Julie: Wow. That's really frustrating. And quickly just want to give a shout out to both Brad and I think, **Narcolepsy Australia**, the organization, has been advocating for years on this issue and also one of the biggest proponents of World Narcolepsy Day— [laughs] so, I'm really grateful to our friends in Australia for being so supportive of this event, and active in trying to make change. David, hello! We are so excited you're joining us from China. So, can you share a little bit about your experience?

David: Yeah. I'm happy, I'm happy for can join this meeting— but maybe my English speaking is not very fluently. [laughs] So, just listen, if you can't understand, you can tell me and I will just to explain— [laughs] okay? I'm David, nice to meet you— [laughs] everybody. I'm from China. Before my diagnosis, I used to sleep in my school class. Especially when the class lesson is very boring. I just feel— start to sleep— in the lessons. And when I started to do my homework, maybe after dinner— I feel— I felt very sleepy. I'm just very sleepy when I was a boy. And just period for maybe, three years— before I went to the hospital. And in the summer of 2007 I went to the hospital, I went to Peking Union Medical College Hospital. This hospital is maybe, one of the best hospitals in China. So, after medical examination— I slept for all five times in the hospital. Every time, maybe— half an hour. Every time I fall asleep— I fall into sleep. And so I was diagnosed as my sleep latency was very short— maybe just one minute to two minutes. Less than five minutes. So— on the— when my family and I got the results, I felt very worried then, because the doctor told me, maybe you can't recover from this illness in your life time. You are like this. And I was very sad. That was in the summer of 2007, and we bought some medicine from the hospital. The name of the medicine was MPH. Its english word is so hard for me— [laughing] so I choose the shortened form, MPH. When I faced the— important examinations, I would take a pill. Because, after having pills, I have a headache. So I take medicine very carefully— just when I felt it important, the examinations. Back to my school, my parents don't want me to tell the truth to the— teachers, and the classmates. Because they're worried about me. They thought my classmates, or my friends would give me nicknames. I had many nicknames in my school. For example, Sleepman— Sleepyguy. [laughing] And in my family, my parents loved me, but they don't know how to face this illness — they don't know how to talk with me. So, we don't talk this topic, in my family. And I feel much pressure. I felt much pressure in my family. But— in my high school, my grades dropped very quickly. Because, I can't learn mathematics very well— because when I learn mathematics I felt very sleepy and tired. It's really hard for me [laughs] and uh— both my body and my heart were ill. I got angry easily— especially when I woke up on my desk. It's really hard. I think God is unfair to me.

David: I went to a nearby university, and in my university time, I met some kind people and friends. They let me know the gospel. And they were full of love. When I met my friends, I can tell the truth to my friends— it's really a happy thing for me. I can tell my secret to the people— to the person who loves me. When I go to church, or when I went to church, I felt peaceful in church. I was attracted by the love of Jesus. And my heart became open to others— I can make friends, I didn't get angry easily— and I became real to other people. And my heart feel more peaceful. My bad dreams became— fewer and fewer. When I was in my high school, every day I had many, many bad dreams.

David: And though I'm still— now I'm still a patient, but— I know my life is full of colorful dreams, not bad dreams. And I have hope. And, but when I went to the hospital I saw many boys and girls so young— they slept on the lap of their parents. I felt so depressed. I wish they can be loved— because they are not as energetic as other children. But, I wish they can, when they are not sleepy— they are happy. And when they are not tired, they can play games, they can play basketball— they can play football— and I hope they can be cared about in the family and school. And later, recently— I joined this group of— organization. I felt very grateful. I can communicate with my friends, and I can give my suggestions, and I can tell my stories and others can tell their stories— we can feel the friendship.

Julie: Yes! We're so grateful, David! David, we were diagnosed in the same year— 2007.

David: Yeah. [laughs]

Julie: So we were diagnosed the same year, 14 years ago! That's so long ago!

David: Yeah, it's a long time.

Julie: We're so grateful for you for sharing so honestly! Big hearts, I love these hearts.

David: Thank you, thank you for your patience.

Julie: Oh, it's such an honor to hear your experience, and thank you for being vulnerable and open to sharing.

Julie: We'll move along now to Europe, and hear some stories from Europe. So, Antje! Please join us from Germany here, to share a little bit about your experience.

Antje: Hi, well I'm very pleased to be here with you guys, and been very moved by David's story. My symptoms before diagnosis were actually— excessive sleepiness and then I thought, well, I just need to sleep for a couple of weeks, like really much, like— coming home from school, sleeping— eating, going back to bed— but, as everybody knows, it doesn't help. [laughs] The opposite is happening, actually— your system is going down. Because, yeah. If you don't move, and only in bed, it's not very helpful. And actually then— what was the toughest for me were the dreams. I had terrible dreams and problems with sleep paralysis. It took me a while to really find out that it was sleep paralysis and not just an intensive dreaming. And when I figured out that it was— happening, that I was— lying on my desk among other pupils and I could actually listen to what they say, and then afterwards I would ask them, did you talk about this? Or did you say this? And then they were like, yes, but you were sleeping, weren't you? And I was like, well I don't know. [laughs] And that was actually increasing the dreams— the nightmares, because I was actually thinking that I must be— going crazy, or something— [laughs] but luckily, and this is actually super extraordinary is that I got my diagnosis in— 1992, within a year. [laughing] Yes, I mean that's not the— the typical case, I know, so I'm very grateful for that! Because even one year of feeling how I felt and noticing all these strange things, like strange appearances in my bedroom and stuff like that, was— actually— already, it was effecting me psychologically, a lot. So—

Julie: How old were you then? How old?

Antje: I was 17 when symptoms started and 18 when I got the diagnosis. I'd just been to a neurologist, the second one— [laughs] and the doctor just had a friend who had narcolepsy. It's actually the reason why— yeah, so— everybody's impressed, I know— [laughing] but it was a

relief at first, of course— but at the same time, as you know— learning that you have a chronic disease, that— that until now, is not— curable— is also hard. So, it took me a while to— actually, find out— I had all the symptoms, but— my cataplexy is, as the same I think with Brad, it's not the main symptom and I don't usually fall. I never hurt myself or I never like, I was never like lying there— as I read in your book, Julie— as happens with a lot of people who have cataplexy as a main symptom, or one of the biggest symptoms. But we are all so different— we have the same disease and we're all so different. Which is actually one of the main reasons why I think it's so important to share experiences, because— we are the experts, I think.

Julie: How is the treatment there? And the understanding, in Germany? I really don't know.

Antje: Oh, uh, actually, back then— the teachers also I think, what David said kind of like, it's not the same as in China, but— also— some teachers— I had then like, a certificate, and some teachers said, I just wanted to make myself— uh, more interesting, or something— [laughing] they didn't believe that— they thought like, maybe— I don't know, I was just— just bored, and just wanted to get like, a certificate which excused me from— being awake during class or something. I don't know. But, luckily other peoples did not like, mock me or something, so— very grateful for that. Sometimes you fall and you even hurt your head on the table, when you start to stay awake, right. And you fight not to fall asleep, and then— boof!— that's kind of embarrassing thing happening, but, okay. So I think that it was very unknown when I had the diagnosis. Well, a lot of people know more about narcolepsy now. And, I am very happy that— when I started out with a health support organization, but first I was terrified, about all these people falling down with cataplexies— so— [laughing] after my first meeting with other youth, and young people, from Germany— I was actually, avoiding meetings for years. Because— it frightened me so much, because I didn't know that, probably— I just thought, I'll be like that too, in the future— and that— I was also already very busy with the symptoms I had. It just— it still moves me a lot actually when I see it happening. But I can now see that more, it's more a normal thing now. And then I actually led a self help group, for two years, in Darmstadt. Which was also you know, very good experience, but also— not always very easy— [laughs] because a lot of people think that a self help organizer has to— do everything, and like— it's all— it would be nicer if it would be like, everybody's participating, everybody's contributing thing, but. That's another topic. Anyway, so yeah! I kind of made my way, and I did everything I wanted to do— and I take, um— modafinil. Which I think was also one question? About therapy, therapy in Germany— what Germany has— I think a good medical system, but there's only a few doctors who really know about narcolepsy. So my doctor's far way, I have to go for— three hours by train, to see him, once a year and then we do online sessions and he just sends me the prescriptions which is really nice. Anyway, so I'm— I have a good doctor, and— it's not decreasing, it's staying stable, so— I'm just coping, I think I'm really good now with coping, because— you know, 1992 and today— yeah. So, I have a lot of coping strategies, and I— I think it's good to have a disease that's not decreasing. Decreasing is not the right word— it's um, increasing, actually— it's getting worse. I mean something that's degenerating, or something. So I think it's always good to look at it from the most possible positive point of view. [laughing] Yeah. Thank you very much!

Julie: Well thank you Antje for joining me, it's so fun to see you again! I got to Skype with Antje a few years ago, about an article for Germany so I'm really glad that we were able to reconnect and do this. Why don't we go to Agata first, and so we'll stay in Europe for a little bit, and then we'll go down to Africa and visit Iris. [laughing] So, Agata, 'cause I'm really excited to have you with us too. Agata is somewhat at a little bit of a different part of her journey, and we've been communicating over the last few months, and I'm really excited to include Agata because— So, share Agata, where are you in your journey?

Agata: Hi everyone. My story is, mmm— quite long story, because it took me 12 years to be diagnosed, and I'm still waiting. It was really hard for me to live my life with narcolepsy and not knowing about it. Because whole life it was like— pretending that I am not tired. It's— mmm— it's ruined my all relationships, all achievements, all dreams. But now I think it's a, huge— I don't know how to say— Abyss? It's different between people who are diagnosed and not diagnosed. Because, when you are diagnosed, you can live— you can be happy, because you know why you are tired. And without this knowledge, you think, oh my god— I am wrong, I am not working. I'm different, I don't know why. And it's— I think this is the reason of kind of, depression, and— if you don't have people who can help you and support— it's really hard to function in a normal way. My problems and tiredness started in high school. Then I started visiting the doctors and they told me that it's stress, it's anemia, it's— depression, maybe. They made me some blood tests and said, oh it's okay. Then I graduate— I started my family, I also become a mom, and— it was really the hardest part of my life to be a young mom and don't know why you are sleeping on the floor. I was crying, I was asking everyone to help me— and they said, okay, I can take your baby for a walk for an hour. You can rest. No, I can't rest in an hour. Now I know, but— a few years ago it was really hard to understand me, and I was so— stupid, that when I would, this hour— I'd make laundry, I started doing cleaning— nothing goes okay, because I— have no energy, and it was all— all— it was going wrong, and— it was worse and worse.

Agata: My biggest problems started two years ago. And then I said, okay, I take control of it. I'm going to all specialist doctors. I told everyone that I'm tired, I'm really tired. I sleep in my car — please help me. Make some tests, or something. I do— my test results are this kind of— I really do everything I can and, all correct— I'm super healthy person! And so they started to tell me, like— Mmmm, you're— don't be so— so sick. You're a very healthy person, please— it's only in your mind. Sleep well, and feel good. [sighs] And last six months, it was— horrible. I slept 18 hours per day. And couldn't do anything through this. Then I thought maybe it's not problem with my tiredness, but maybe it's problem with my sleep. And, I don't sleep— I sleep inefficient. And I started looking for a reason. Then I heard about narcolepsy and thanks to Project Sleep, and all people who write your stories, share there— there was one girl on YouTube, tell story, and she use words— “I am so tired.” And when I heard, I— I— go just to my parents, I said, listen her—listen her, she's like me. I'm so tired. There's— and doctors ask it, what are you doing in your free time? Nothing. I am so tired. And this— your stories, your people who have narcolepsy, helped me to understand that this could be a disease. I started to reading about it, but in Polish— it was like, oh— maybe there is some disease. Nothing like this. I started reading articles, ehh— searching for my blood tests, some hormones, finding this connection. Then I made an appointment to a doctor who specialized in sleep medicine. But I had to wait six months. I still have got one month to this visit. And during this time I couldn't sit, I was looking for my own symptoms— Make MSL test at home, with my mom— five naps and watching how fast I fell asleep. Remembering my dreams, that I can dream even if a short nap. My nightmares, I always thought that my interest in dreams and that I told my friends in high school, ah, dreams are perfect! You can, it's like movie, you can make some changes in it? And now I know, it's because of narcolepsy. Then I thought, I am kind of strange. And all this situation in my life, it comes at, yeah— this must be narcolepsy. I started to read more and more and communicate with people with Project Sleep and, yes— I'm sure it is narcolepsy.

Agata: And thanks this, now I am living. I am happy person— I can tell everyone that, wait a minute— I need to sleep, and it's okay. Before driving car I can take a nap and I can drive just 10 minutes, it's okay. I'm no longer responsible, because if you don't know you can sleep, you are fighting this. And if you are narcoleptic, you know, it's not working, this fight. You will lose. And when you know it, you just take your nap and you can function normally. “Normally.” But the most important thing I want to say, it's problem in my country, in Poland, with doctors, because— after I knew it's narcolepsy, I visited about 10 doctors and they told me no, it's not

narcolepsy. It's too rare to have it. It's not narcolepsy because you are not falling down. It's not narcolepsy because you can postpone the sleep, about a few minutes, but— their arguments were so— I don't know all of the word— it was stupid, and— they're not educated. They're not, mmm— not even, want to interested, what I am talking to them. When I said, please— check my hormone, I don't have growth hormone— it's strange, I sleep 18 hours per day. Can you look on my— medical test? No, no, no. Please, go home. And it's— and I'm still waiting this five, six months, to have one visit with a specialized— doctor specialized, in sleep medicine, and I'm still waiting.

Agata: I started to talk about it in Poland, to get to know people that narcolepsy is a real disease. It exists. People are real. It's not like in the movies, it's not only cataplexy. Thanks this I found four girls— young girls, in my country, who are also in my situation. They have kids, they have no energy— they— different kind of tiredness. It's not, I'm tired because I was doing something. I'm tired because I wake up. And it's— when you talk with these people, you know — this is, this kind of problem. And ask them few question, have you ever been in doctor? How many? And they say two, three, four times. And they're all misdiagnosed. And I ask another question, when's the last time you feel that you are not tired? I don't remember, I don't know. I can help them because now they know that narcolepsy exists. And they can make their test even if it tooks one year, but they can do it in their life. They are 24, 22, 26. I'm 31. And my life was horrible. And that's why I am in Project Sleep and that's why I want to talk about it and that's why I want to help other people. And thank you guys— you are all with me, and I think in the world we can change this— that narcolepsy, it's not only like— whoop!— [laughing] thank you!

Julie: [laughing] Oh, Agata, thank you so much for joining us! So glad that you joined because it's this reminder about that part of the journey. I think you're in a situation that resonates with a lot of people. And— we've all been there. And thank you for educating yourself, and thank you for — and for advocating, and working through this time, and also going on TikTok, and— raising awareness on TikTok, and finding other people— TikTok is— I'm 38, so it's like— I can't do TikTok, I don't think they let 38 year olds be on TikTok— but I'm just so grateful for all you're doing— and thank you for being such a strong voice. We're just so glad that you're here! And we hope for an update, soon.

Julie: Let us go to Angola! So, share with us about your experience!

Iris: I'm Iris, from Angola. My experience is a little bit— I'm not going to say long— Because I think— who's isn't? But it's definitely confusing. I think I've had my narcolepsy, I think— since I was 15. So basically, I had cataplexy and I think initially a lot of sleep paralysis, hallucinations, at 15. And I didn't really start having my excessive daytime sleepiness until about the age of 21. And that's when I was in university, and— partying a little bit, and— I just, had no clue. So basically like, I went about 12 years— undiagnosed. And I grew up in the UK, but I'm from Portugal, and Angola. [laughing] So most of my life I did grow up in the UK. So at the time I was studying in the UK, but at the age of 24 I decided to come to live with my sister— and, I came to Angola for the first time. And that's when my symptoms just— just got completely so much worse. Like, from the very first day. And, obviously now, I realize that— the heat really, really makes my symptoms so much worse. So obviously living in a tropical country probably wasn't the best idea— and I just started working full time and literally from the very first day, I just slept every single day at work. And that was at the age of 24 [laughing] it wasn't until about the age of 28 that I got my diagnosis. And I'm still living in Angola, and I think it was just, obviously— I had two major— uh, incidents, that kind of helped me get diagnosed. So, one of them, I was driving in my car and it was about 12 in the afternoon, I was with my friends— and I literally just fell asleep. Luckily my friend was in the car because— the wheel just started turning, and you know— it was really, very dangerous, and— luckily, there was nobody else,

you know on the right hand side of the car— of the street, otherwise— it couldn't been deadly. Then two days later I went home and I was literally just trying to cook some food, I sat down on the couch for about, two seconds, I think— and then suddenly, I woke up and I could smell burning, and I was really confused— I thought it was the neighbor. I couldn't even remember what I was doing, really. And that's when I kind of realized, okay— something is— definitely not right. It sounds so weird 'cause you're 12 years with this, and you think, for 12 years you didn't realize something was wrong? [laughs] Somehow, no. But, yeah— and then I just started researching. I started researching, typing literally everything I could think into the internet, like — why do I keep falling asleep at work? Why am I sleeping when I'm not tired. Somehow— I got to the word narcolepsy. And unfortunately, in Angola we have— zero— I mean zero, awareness. Zero medication. Zero, like medical— support. We don't even have the ability to get diagnosed here. So, obviously I'm very lucky, I have a family who they would support me. So I flew to Portugal, where my mum lives. And, luckily, I was able to obviously pay privately, because— if you go public in Portugal, it will probably take you a couple of years, as well. But going directly to a sleep clinic, paying an absurd amount of money— at least that, I got my diagnosis very quickly. So I didn't really have to go through the doctors and the getting the wrong diagnosis, luckily. And then flew back to Angola— [laughing] and literally, you know, I was lucky because in a way my doctor used to ship me the medicine, you know, so— she, my mum used to buy it— so she used to get the prescription, and my mum gets the medication, which is what I do now— 'cause I'm here again— and then somebody, we have to find somebody who's flying out, because we can't send it through the post— it's not very reliable. And— usually, then I get my medication, so— it's a little bit complicated, but— we deal. Here, there really is nothing. There's no options here. I mean I don't know how deep you want me to go into this, but then I had— [laughing] a really bad experience, left Angola, went to the UK, went to Portugal, back to Angola— so, you know— [laughing] but, I think I'm okay now. And—

Julie: Have you met other people in Angola, that— So I guess if there's no way of getting diagnosed, then— there's probably not— a lot of other people with diagnosis. So, you probably haven't met other people? [laughing] With narcolepsy?

Iris: No, I don't even think they know the words. [laughing] Yeah.

Julie: Wow.

Iris: We have a long way to go. But it's a battle I'm willing to fight, and— you know, one step by step, we'll get there. [laughs]

Julie: Yep, yep. I think, I said about myself, recently that— narcolepsy, you messed with the wrong girl, about myself—

[Iris laughing]

Julie: —and I'd say Iris— Iris, probably the same— narcolepsy messed with the wrong girl, in Angola— [laughing]

Iris: [laughing] I will fight it in my sleep, you know.

[Julie and Iris laughing]

Julie: Well, in the interest of time, Iris— I know people should also check out, Iris has shared her story, with us— so check her out on social media, as well. She put out a beautiful video about different people's stories, working with narcolepsy. So, incredible. Another opportunity to

hear different stories from around the world. Really quickly we're going to take a flight, uh— just in a few seconds— from— Angola, to Brazil! And hear from Juliana. Hey Juliana!

Juliana: Hey! [laughing] So let me tell you about my symptoms. Actually, I don't know when it started, because when I was a child I had really scary and vivid nightmares— almost every night. And— when I was a teenage, I started having interrupted night sleeps. I woke up every hour, or— every two hours, and then— I would sleep again— and— it was weird. I even took a few tests when I was a teenage, but— they, I think they weren't the right tests, to detect narcolepsy. So, I had to move on with my life. And when I was about 24 years old, I started feeling some dizziness. They were not like a low blood pressure, they felt different. And I start having hallucinations. Hypnagogic and hypnopompic hallucinations, a lot of them. I even thought that I was going crazy. It was really weird and scared, but— I'm lucky, I like to think I'm lucky, because— my mom has a narcolepsy diagnosis, so— she detected some similar symptoms in me and she took me to a neurologist in San Pablo, here in Brazil, in another city. He diagnosed me when I was 24, with type 2 narcolepsy. And it was fine, of course I had to change my life, my routines, my— my everything, but— [laughing] —I had a diagnosis. But a couple of years later, I started having cataplexy episodes. That was the worst part. I really didn't feel safe to do anything, I didn't know what was happening, and then— I start, um— googling things, about it, and— that was when I realized that it was related to the narcolepsy, because my mom is actually a type 2 narcoleptic. And I start looking for a doctor because the doctor that diagnosed me was already retired, and— after— a lot of wrong doctors that said to me that I didn't have narcolepsy, that I had to do chemo therapy, and— treat my disease some other ways— I finally find a neurologist here, in Salvador, that told me that I had cataplexy episodes, and that my actual diagnosis was type 1 narcolepsy with cataplexy. So— that was— I was 26 by then, and I started the process of finding the right medications to get me through it, but I— as I said, I'm very lucky, because my family was very understanding, most of all because my mom is a person with narcolepsy, too. My father maybe was scared, he tried to deny my symptoms— but, most of my family and friends were very supportive. I have an amazing boyfriend, he is with me always. He gave me— he gives me my meds, every morning — and he is very comprehensive, when I say I'm not okay to go some place, and— he's amazing. Actually amazing.

Juliana: So— that's my reality, but that's not the truth for— the majority of Brazilian people with narcolepsy. Here, we have no public support, at all. We have actually, in San Pablo, a big center of narcolepsy that is really good, it offers treatment, and medication— it's a reverence in Latin America, but in other cities and other states we have no public support. Some people had to spend more than \$1,000 to get— to have a diagnosis— and, they cannot afford the medication. Some of them have to sue the government to— to have meds, and— I think most of them, spend their lives without meds. It's really hard. Our association, our Brazilian association— started in '19— in 2019, so— now we are trying to pass some bills, to help people with narcolepsy, because we have none here. And we have now some partnerships with some hospitals, and— we are helping some people to have their treatments— but this is— too little, when I think about all the things we have to do here. Narcolepsy is not um, a disease— a condition, that people know here. They don't know anything about it. It's really rare to— to find someone who knows what is narcolepsy, that— really ever heard something about narcolepsy. So, we are trying to— step by step— make it better.

Julie: And you're a big part of that, by recently becoming a **Rising Voices of Narcolepsy** speaker, and—

Juliana: Yes! [laughing]

Julie: We're so glad that you're going to be sharing your story, and you translated our slides, into Portuguese— so we're very grateful for that— and we can't wait to have you back to share your full story— in English and in Portuguese. And Iris, too. We got to get you to do that as well, in Portuguese. And thank you, big thanks to the Brazilian organization— I want to say ABRANHI? Is the acronym?

Juliana: Yes, ABRANHI, yes.

Julie: They are a force of nature! That have just— floated on social media. Their passion and advocacy is just so cool and gives me so much hope, Juliana, like you said— there's a long way to go, but I think with— the energy and enthusiasm, and— well, I know, our energy's all limited— [laughs] but— with the passion of this group, I think we're going to see a lot of change in Brazil, so.

Juliana: Yes, I'm very proud of them— the ABRANHI is very— it's an actual hope, of changing here.

Julie: Thank you so much!

Julie: I do want to share from Dana, who is in Israel. Dana and I have been in touch for many years. She's touched my heart for— for many years, actually— and she didn't want to necessarily join us live, because of— worrying about English language, but— I'm really excited to share this with you, and share a little bit about her story with you, from Israel. Her first symptoms started at the age of 18, maybe a little bit earlier. "I was already starting to feel daily drowsy, on some level. I needed at least 1 nap a day," and she was diagnosed at age 34. "At least 10 years after I realized I had a significant problem. Previously, I could feel less symptoms because the lifestyle allowed me to. But I was diagnosed with inflammatory bowel disease, Crohn's disease," and she learned from home, and she was able to sleep during the day without interruption, and worked a few hours per week. Especially from home. She was diagnosed at 34 with type 1 narcolepsy and, "This is supposedly my luck, otherwise I probably would not have received a diagnosis, until now." I'm imagining maybe 'cause of the cataplexy. I asked her about her family and friend support, she said this is a difficult question, "I want to believe that they understand and also generally support, but never will anyone be able to understand what I'm dealing with. Only someone who lives close to me can probably understand. Even the difference between being very tired and being sleepy. Sometimes it seems to the environment that if I take my medication, the problem should no longer exist. Despite the diagnosis, everyone is tired. I know that it is very difficult for them to see me in different situations, and that they take it very hard sometimes." And then I asked her about awareness in Israel, she said in Israel, narcolepsy is a rare disease, that has hardly been heard of, even in doctors, even neurologists— and most cases are type 1, ah, no, sorry— type 2. Type 1 is very rare. There are very few sleep doctors in Israel and it takes years to get a correct diagnosis. She says she's lucky because thanks to a colleague who worked at a sleep lab, among excellent sleep doctors, and suspected that she had narcolepsy, she was able to go to that doctor and get diagnosis and treatment.

Julie: There is no specific specialist for narcolepsy, and only last year the first drug for narcolepsy was approved, and entered the market, which was Wakix. Despite this, she is also receiving sodium oxybate, with delivery directly to Israel, free of charge. She and only two or three other children from the whole country are currently on sodium oxybate. I remember her telling me that she was the second person ever in Israel that was on sodium oxybate. And right now her symptoms, the most challenging one is mostly brain fog, inability to stay awake in the evening, and hot weather [laughing] so— shout out to hot weather, Iris— um, is a trigger for her sleep attacks. And so in recent months, she's barely left the house. Israel is a very hot country,

and she would like to live in Europe, I think, is what she says. [laughing] “One of the most difficult challenges is being a mother of two children, during the Corona period, when they are not regularly in school, and my daily routine can be disrupted. I think I’ve been relatively balanced lately, since I left work and I am barely out of the house. It was very difficult for me to get my previous job. The travel was difficult, sometimes I had a hard time being alert and focused, even at 11 in the morning, or being at work on time. And my direct manager sometimes treated me like a person without motivation. He said he would bring me back to work when I agree to stay for staff meetings at noon.” And thank you to Dana for sharing this.

Julie: Gosh, guys, this has been incredible! Does anyone have any last thoughts? I was going to say, how are you going to celebrate World Narcolepsy Day besides this? I think Brad’s probably going to head to sleep, I hope, soon.

Brad: It is quarter past midnight, so I’m going to head off to sleep. It is just passed World Narcolepsy Day for me, I hope everybody else has an amazing day— [laughing] thank you so much for having me! I haven’t fallen asleep, yet. So— [laughing]

Julie: Yes! I know, well we’re very grateful. You’re at that late end, I’m at the early end, so. Thank you again for being here, from Australia. This has been a wonderful, wonderful, discussion and I am— just so grateful to all of you for taking this time— and sharing so openly — on a topic that, you know— isn’t something that we maybe talk about every single day, so— or in English! [laughing] So— big hearts, and lots of love— and just keep connecting with each other around the world, guys. And have a great **World Narcolepsy Day!** Thank you again!

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