Project Sleep Narcolepsy Nerd Alert
Brain Fog (Season 1, Episode 4)
Transcribed by Mirela Starlight

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In today's episode, Julie talks with guests Shannon Burkoth and Dr. Kiran Maski about brain fog and some of the other under recognized symptoms of narcolepsy. They discuss what brain fog feels like, some methods for helping to cope with and talk about brain fog with your family or loved ones and also mention some of the ways they hope sleep research can help to further understanding of narcolepsy for patients, researchers and doctors.

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 "Brain Fog" (Season 1, Episode 4) 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 talking in intro: Is brain fog a symptom of narcolepsy? In this episode we talk about some of the more invisible and under recognized aspects of living with narcolepsy, including brain fog, automatic behavior, micro sleeps, and mood instability. We discuss some current research in this area and tips for managing and communicating about brain fog. Today I'm joined by two special guests— Shannon Burkoth and Dr. Kiran Maski. Shannon Burkoth was diagnosed with narcolepsy type 1 in 2010. She's a trained speaker with the Rising Voices of Narcolepsy program and advocates for both narcolepsy and rare diseases. Dr. Kiran Maski is an expert in pediatric sleep neurology and a sleep medicine physician at Boston Children's Hospital, specializing in narcolepsy and sleep problems in children. Dr. Maski is also a sleep researcher and her work on improving the diagnosis of narcolepsy has been published in SLEEP, the official journal of the Sleep Research Society.

Julie: Hello everybody! So excited to have you with us today, we have an amazing group with us. So I'm Julie Flygare, I'm the president and CEO of Project Sleep and I am in Los Angeles. And let's see, we have Dr. Kiran Maski— hi Dr. Maski!

Dr. Maski: Hi there.

Julie: And where are you?

Dr. Maski: I'm in Boston, Massachusetts at Boston Children's Hospital.

Julie: Awesome. Hi Shannon.

Shannon: Hi everyone!

Julie: And where are you Shannon?

Shannon: I'm in Kenosha, Wisconsin. Very southeast corner.

Julie: Awesome. We're really excited to talk about brain fog today. These are some of the terms that we hear people say, that we want to just shed some light on— brain fog, mental fogginess, automatic behavior, micro sleeps— and then I did add mood instability because I think it's also this area of— is that a secret sign of sleepiness? Or is it something else that's going on. And please jump in, Dr. Maski if I— I couldn't exactly find, like, specific definitions of some of these things, so I just tried my best from a few different sources. But for brain fog or mental fogginess, the best definition I could come up with was cognitive functioning issues, such as difficulty thinking, remembering, concentrating or paying attention.

Dr. Maski: Yeah, Julie, I think you're right. There isn't really like a clear— definition of brain fog, and it probably does mean different things to different people. In that survey you mentioned, from the listening to the patient voices— we kind of went through and pulled out— people had an opportunity sort of for free text, and so some of these terms like difficulty thinking, remembering, were pulled out from— their description of brain fog. So I think that this is probably a comprehensive view but I've had people say, it feels like something's physically, like — on their head, or like it's almost like cotton is in their brain— and it just takes a lot of effort to speak. So again there could be much broader symptoms associated with brain fog.

Julie: Wow. Those are really powerful descriptions too. So for automatic behavior I do feel like this used to be a little bit more— discussed. When I was first diagnosed, I think this was somewhat of the fifth symptom that sometimes was mentioned. And, talked about the continuation of a routine activity with little conscious awareness— and often without memory of it. So the example that— comes to mind for me, is— obviously like, typing notes in class— and then, looking back later at the notes, and seeing that they'd kind of gotten quite— messy, and not quite legible. Shannon did you have any examples that you can think of for this one?

Shannon: Yeah, I know one of the things that, you know when you're trying to do things that you do every day, like I've poured orange juice into my cereal instead of my glass, kind of thing. Because I was just going through the motions, and not realizing, you know— what I had, or what I didn't have. And then you know, a lot of times like you mentioned, driving somewhere and then realizing, oh how did I get here. I feel like I'm alert when I'm driving— but then sometimes when I get there I'm just like, how'd that happen.

Julie: Yeah. That's a good example too. I was just thinking when you said the thing about the orange juice— has anyone gotten in the shower and like, you know, you take body wash and you start putting it in your hair— I mean maybe everyone does that. [laughs]

Shannon: I'll forget. I'll shampoo my hair and then I'm like, did I just shampoo it or condition it, what did I do. Where am I at— what step in the process am I at.

Julie: So there's automatic behavior and then there's micro sleeps, is another term that you'll hear sometimes— so I just thought we should include both, here— although— I guess I'm not always sure the difference. Definition I could find was, periods of memory lapse, or blackouts, caused by very short periods of sleep.

Dr. Maski: You know, both automatic behavior and micro sleeps there just, hasn't been a lot of research, on these specific symptoms. And again, it's sort of based off— patients' descriptions of what happens. It is probably that people are kind of going into these very brief periods of sleep and then are able to wake up. But, those little micro sleeps aren't necessarily refreshing or intended.

Shannon: I think of it as, when I'm in the middle of a conversation and I completely forget about what I'm talking about, like I just had a complete— split second— episode, of where am I and what am I doing. What was I talking about? And then I also find like during that, I'll repeat myself a lot. Like, "What was that? What was that? What was that?" and people have to repeat themselves to me for me to actually get it to stick.

Julie: I feel like micro sleeps and automatic behavior— they both generally happen for me when when I know I'm sleepy, and I'm trying to fight through— [laughs] possibly— whereas, possibly something more like— brain fog, and— I've heard people describe that is around their sleepiness or sometimes just in general even they might not feel sleepy, but they might have some of those issues. Mood instability, which I think is just good to just mention as well. Moodiness, irritability, less positive mood— internalization, aggressiveness, hyperactivity or impulsivity. I think this was important for me to—recognize, that— I think especially for me around my sleepiness that I could be moody. So one example is coming home from a movie, late at night, with my boyfriend at the time— and just knowing I was really tired, so I just said, "I can only be a person, I can only be a human in the car right now. I can't really talk, I can't engage, 'cause I'm just not— I'm going to be a crab." [laughs] And there's just— it was hard for him, I think he still kind of felt like he could somehow put me into a positive mood— and engage me more, as opposed to just let me— just be a physical human. I wasn't really here mentally. At least I— I've learned to recognize that, and to call it out. That's kind of the best I think I can do.

Dr. Maski: This is something that I think we hear a lot from parents of pediatric patients with narcolepsy— just like, how moody they are towards the end of the day— or they pick fights with their siblings, or friends— and in rare cases we even see sometimes aggression happen. And it really does seem like, you know, the kids really— regret the behaviors— they feel better after they sleep, but I think again, it's probably a manifestation of that sleepiness.

Shannon: Yeah. I feel like— you're— any person who goes without sleep is going to be moody, you know. I remember being at a conference and I think it was Molly Einen that said— to have a, safe word. You know, to use with your family— so that you don't get offended. Because they'll be like, "You need to go over there— until your mood is better. Because I can't stand you." So you know, developing like, safe words with your family. Like, okay I'm really tired and when I'm acting aggravated like that maybe tell me, "Mom, maybe you should go lay down for

a little bit," kind of thing— and just make it kind of— a nice way of saying— go be by yourself until you're happy again.

Dr. Maski: Yeah— I mean in kids we oftentimes advocate quiet time— because they really don't like the idea of naps, in many cases. But you know just a little quiet time, rest— if you sleep, great. If you don't, fine. Usually they will fall asleep even for like 10-15 minutes— and that's usually enough to kind of get them through that kind of period.

Julie: I love that. Quiet time! Because I never want to take a nap either. So I'm like, I'm not doing great, but I just— I'm just going to keep going. So I need some quiet time which can lead to a nap. That's perfect! Yeah actually I think some of this I really got from Judy Owens when she was in D.C. and seeing a presentation from her— about pediatric patients with narcolepsy, but— it really kind of resonated with my own experience too. So I think, some of this wording was something that she really brought to my attention. So it was really— it was from the pediatric perspective, but— important for everybody I think.

Julie: You know, what is excessive daytime sleepiness. Periods of extreme sleepiness during the day that feel comparable to how someone without narcolepsy would feel after staying awake for 48-72 hours. That's the definition that Project Sleep uses right now and— I think, maybe— does that capture all those experiences? I don't know— um, and I guess what worries me is I think often people hear excessive daytime sleepiness and they think of falling asleep. Being asleep. Being sleepy means, by definition you're not asleep. Because you're feeling sleepy. So if you're asleep, you don't— you're not sleepy. So I guess, you know, I wonder sometimes if— thinking of sleepiness as just falling asleep— we're missing that huge gray area, which is— the gap between being, feeling, fully awake, and— cognitively functioning perfect— and being asleep. You know that gray area may be where some of this lies.

Julie: So we have some discussion questions— and, you know we really want to kind of talk through, are these concepts interrelated? Are they linked to excessive daytime sleepiness— are they something else? How might we better manage these symptoms— how can we better communicate about them, and are they well enough represented in the symptom list. So. I know it's a lot to get to. And Dr. Maski I know that you had some thoughts. You've done even some research— some new research that you're going to share with us about some of this.

Dr. Maski: Yeah, I mean I think that— as you were saying, the concepts are probably interrelated and probably sleepiness is what relates them all. Daytime sleepiness and you know, again, these are sort of symptoms that patients report and might mean different things, but I think as people are sharing, you know, there is obviously like a common theme— as to the impact that it has on people, and— the consequences to their job, and to their family and their social life and things like that, so. I completely agree that these are symptoms that are so important to study and as you were saying, I think from a medical perspective— we sort of are trained to talk about the narcolepsy specific symptoms— cataplexy and the sleepiness and the sleep paralysis.

Dr. Maski: And I think that there might be other things, other than sleepiness, during the day that are contributing. So, you mentioned disrupted nighttime sleep. You know, somewhere between 50 to 90 percent of narcolepsy patients report disrupted nighttime sleep, so some difficulty staying asleep during the night. So we've been looking at how that relates to some of these symptoms— more specifically memory. Which I can share, but there are other things that might be contributing you know— in terms of inflammation or immune mechanisms or autonomic functions. So things like orthostatic hypotension can sometimes cause these types of problems with thinking and thinking clearly. So— these symptoms in themselves are not necessarily specific to narcolepsy, we hear about them in— you know, other sleep disorders—

we hear about them in neurologic diseases, like multiple sclerosis. We hear about them in the long covid patients. You know so these are sort of new symptoms that are shared across many disorders, but in narcolepsy I think we're focusing on looking at not just daytime sleepiness but disrupted nocturnal sleep.

Dr. Maski: Basically we're studying like, what does that even mean [laughs] because when we talk about it, again we want to—when we want to study it we want to have very specific measures as to like how to define it. So we worked with the Plotsy group in Italy, I worked with a colleague, Fabio Pisa on this paper where we tried to define what nocturnal sleep disruption could be defined as. And so, have a patient who is a normal person who came in for a sleep study for rule out of sleep disorder breathing, but is otherwise healthy— and then the narcolepsy type 1 patient.

Dr. Maski: And so the control person— healthy person— basically goes to sleep, and has a few wakings during the night, that total about 10 wakings. But the patient with narcolepsy, you know has— many, many more transitions into wake— or N1 sleep— this is sort of drowsy state sleep, that's not considered refreshing. You can see sort of this patient is maybe an extreme version of this, but this is the sleep that is commonly reported in narcolepsy, where they kind of — have these frequent wakings, but they're relatively short so they can go back to sleep quickly. And so we were interested in defining that.

Dr. Maski: I think specific to our conversation today, we were looking at like, what are these measures that are associated with daytime sleepiness. So based on questionnaire data of how sleepy patients reported themselves— their historical mean sleep latency test, an objective test of sleepiness— and then their self-report of disrupted sleep— it seemed like, how many arousals they had— so arousals are basically, a pattern where the brain comes to a waking pattern within 10 seconds and then returns back to sleep. So, number of wakings is whether the brain woke for at least a 30 second period and then went back to sleep. And the amount of non-REM 1 sleep, so drowsy sleep.

Dr. Maski: So these were the measures again that more related to daytime sleepiness than the other measures. And these are things that people can get from their— sleep studies. You know these are commonly reported. I will just say that you know, many people, we sort of focus when people have sleep studies on did you have sleep apnea or not— and aren't really looking at the details of the sleep architecture.

Dr. Maski: So then we went on to look at sort of how— sleep is affected by this waking pattern. So if you wake up many, many times during the night, what sleep stages is this really affecting. And these are survival curves, where basically we looked at how long a period of a certain type of sleep stage lasted before it transitioned to another— sleep stage. So it's kind of getting a sense of— almost like the decay of sleep, if you will.

Dr. Maski: So, essentially people with narcolepsy— they would have these frequent wakings, but the survival of those wakings was really short— so they would come into waking, but able to come right back into sleep. So it was like— you know and I think this is what we hear from patients a lot. They'll say they woke up like four or five times during the night, but it actually was like 40 to 50 times a night. And it's probably because the waking periods are so short and they're able to return back to sleep, that it's like really different than say insomnia— where people have like these long waking patterns during the night.

Dr. Maski: And specifically this waking pattern disrupted non-REM 2 sleep and REM sleep in narcolepsy with cataplexy. In narcolepsy without cataplexy the sleep actually looked pretty normal— except that when people with narcolepsy

type 2, were asleep they tended to have longer periods of non-REM 1 sleep— again that drowsy, non-refreshing sleep— and, sort of, when they entered non-REM sleep it would kind of go on and on and on— so that too might feel un-refreshing to patients.

Dr. Maski: So we're interested in this because there is a relationship between sleep and memory. So there's over 40 years of data coming from— people like Robert Stickgold— who have shown that sleep is really a necessary function, for sustaining a memory trace. So that means that when I teach you something, over time there's going to be a decay in it. So basically this is an experiment where children and adults were given a learning task. In this case word pairs. So when they were taught something, they basically were asked to remember that after a 10 hour period of wakefulness. And you can see that there was some improvement in their memory— after that 10 hours of wakefulness. And there was actually a loss, in the adults, so you know there was a little bit of forgetting. But overall, compared to a period of sleep when these children were given, and adults were given, something to remember right before they fell asleep— and then tested again after an eight or ten hour period of sleep there was almost like a 10% improvement— in their ability to sleep. And so we call that consolidation — that that memory trace got strengthened over time. And we call it sleep dependent consolidation, to really signify that sleep is necessary for that process to occur.

Dr. Maski: So, we're doing an experimental study at Boston Children's Hospital that's sponsored by the NIH and Jazz Pharmaceuticals. Of children with narcolepsy type 1 who are aged 8 to 19 years of age— and basically we're bringing them into our sleep lab, we give them a memory test, a vigilance task— before they fall asleep, and then retest them after their period of sleep. And we also test their impulse control, so this test called a Go/No-go task, and what we really want to see is if any of those measures I talked about— related to the disrupted nighttime sleep, impact any of these memory function tests— or their impulse control, to know if— really, we should be more aggressive about treating sleepiness rather than just focusing on daytime sleepiness itself.

Dr. Maski: If anyone's in the Boston area— [laughs] and interested, we certainly would love to work with you.

Julie: I think it's— so important! So basically, or well, basically— [laughs] there's a lot but, that the nighttime disruption— could also be a big factor in— some of the memory issues, that people are experiencing?

Dr. Maski: That's what we're investigating, yeah.

Julie: That's so cool. I also know that you've done— I guess I don't know how much you can talk about it, but aren't you doing some research too to unders— to look at patient reported outcomes in children?

Dr. Maski: And I think this came from— the work that you've done, and that listening to the patient voices report, from the FDA— really trying to understand better how physicians and clinicians and health care providers in general can improve narcolepsy care. Now we're doing this specifically in pediatrics, because that's where I sit, but essentially we're interviewing patients with pediatric narcolepsy to find out what symptoms are most important to them. Similar to how they did with the FDA report, and then trying to develop an outcome survey— that can tell us like, you know, that a kid is having, you know— although they can stay awake, and their cataplexy is under control— and they're not having sleep paralysis— what we really care is how they're functioning in school. And if they're making social connections, and if they're finding like, you know, that overall their life is good. You know, and so that way we can sort of tailor our treatments— and sometimes it's not going to be medication, sometimes it's

going to be— drawing on resources from our cognitive behavior colleagues, to help people understand their condition and how to advocate for themselves, and— come up with behaviors that might be helpful for managing things like brain fog.

Julie: Yeah. Well that goes to another question which is how can we better manage these symptoms.

Julie: Night time disrupted sleep could also be— affecting some of these things. And how we might better manage these— I guess my only way I've thought of is really that— just learning how to communicate better about them, you know. [laughing] And that that's that's— a really big piece, is the awareness. There could be other things like cognitive behavioral therapy interventions, that could also just— becoming a nerdy person that makes reminders, and lots of different things like that. I don't know, Shannon, do you have any tips or— anything that you've helped to better manage these symptoms

Shannon: Yeah, I— set a lot of alarms on my phone. [laughs] Anytime I have an appointment or a meeting, I set an alarm on my phone. Because otherwise you know it kind of seems like, oh! three hours just passed by— you know, it only felt like an hour, or something like that. And then adapting to—I find that I need to like, take notes when I'm doing things— so that I can go back and remember what I did. 'Cause I could've like, listened to a whole hour webinar and then— not remember most of it. Unless I'm taking notes. Taking the notes will help me recall— what it is I heard and learned.

Julie: Yeah, that reminds me too, I had— when I— worked at one job, they supplied these for us, the— those pens that record the— forget what they're called, but the smart pen sort of. So it recorded the conversation, and I had to ask permission because I was interviewing doctors— and they— every single word that I feel like they said, was— so specific, and so on point. But it was it was just kind of, almost too fast anyway, for anyone. But some of those meetings I was entering some— some sleepiness issues. I could still stay awake through it, and I had to because you have an appointment with them, and you have to get the information from them, but— I was so glad afterwards that the pen was recording the conversation so that I could then go back and listen to it, and look at my— notes and put it together. So that was really helpful.

Dr. Maski: Other things that I've learned, from patients, actually— and disseminate— are things like movement breaks, standing up— or even some people's stand desks can be really helpful, for just kind of— combatting sleepiness. But movement breaks, alludes to like taking, little breaks. A little walk around the office, or around the classroom or— for younger kids for instance we ask the teachers to make them the teacher helper— so that they kind of are like distributing the handouts or walking around the classroom— to kind of, keep them awake more — and those kind of things can be really helpful.

Dr. Maski: Fidget spinners could be helpful just to kind of keep the motions going through the time the patients are listening— can be very helpful too— and I think teachers really understand this concept, I think— although we're focused on narcolepsy about 25 to a third of their classroom is sleepy for other reasons [laughs]— usually insufficient sleep. And so they're always looking for ways to kind of, have movement breaks integrated in the class that works out well.

Dr. Maski: Patients with narcolepsy— about a third, at least based on the literature, can have true attention deficit disorder— so that's more like, difficulty with the, what we call executive function— working memory, you know, attending to something, and focus— and that's probably also related to sleepiness and other factors. But, at least in the pediatric population when we're really not clear if it's sort of just like general fogginess or if there's a real learning

disorder we'll encourage formal testing with neuropsychological tests— to differentiate like, where there's an exact problem. And that might make a pediatric patient more eligible for additional services.

Julie: Wow! I had no idea. That's really great then, that you can like look into it more. I feel like everyone needs that! [laughs] To like, better understand what we need and what are— where are our like, issues, you know.

Dr. Maski: You know, where I sort of have heard a sort of, a shift in it is— with, you know, the long haul COVID patients, you know, and this degree of brain fog and sleepiness— it's kind of being talked about as a neurologic symptom— and you know, I think that a lot of patients with hypersomnia conditions really relate to that, so. I think the framing of it now is more considered — this is a neurologic process, this is a real, debilitating symptom— not just, you know, I went to bed late and— feel a little foggy today, kind of thing.

Julie: Well that's encouraging— we get more recognition.

Shannon: So, I remember— on my diagnostic odyssey— that I would express to my doctor in words, I'm too tired to function. But, we never considered it— a sleep disorder. We never considered— being tested for a sleep disorder, for several years. And I feel like, you know, when does that— symptom of fatigue then, transfer from a symptom to an actual diagnosis. And I think that's where there's a lot of frustration— in our community, is 'cause— we're telling our doctors we're tired and, you know, a lot of them don't think of narcolepsy.

Dr. Maski: Yeah— I think that is such an important point. Because I think tiredness and fatigue are so common—in every disorder that we see or talk about, or in general population— but sleepiness is really something different, in some way. You know sleepiness is the inability to stay awake— and that is a little bit more rare. Now of course, not getting enough sleep is the most common cause, and— you know, sedating medications being right there with it— but I think teasing apart those terms— fatigue, from— sleepiness, and inability to stay awake, is kind of important because it sort of— helps a clinician kind of, recognize a more rare— problem, than say tiredness or fatigue.

Julie: When you say though that sleepiness is an inability to stay awake, I always worry 'cause I feel like a lot of my sleepiness, I was falling asleep— but I— there was a lot that I could fight through— not remembering the time exactly. And so that's where I get worried about the language because— that you could be fighting the sleepiness but your eyes are still open.

Dr. Maski: Right. And I think that— the truth is, and I think also in that patient's voice survey, fatigue is very common in narcolepsy too. So it's not like you know, you can have one or the other— it's really that they have both, and— but I'm just saying like, I think from a clinician's standpoint— just hearing, "I'm tired all the time," is something that's hard to like, it doesn't trigger the alarm bell— so much as sort of like, "I can't stay awake." This is the consequence of that— like, "I can't think, I can't perform at my job because I'm falling asleep," like that is a little bit more alarming

Julie: Yeah— I feel like I've heard the distinction of like, okay well— you feel tired during the day but if you had the opportunity to sleep like, would you be able to. And then a lot of people say no, I wouldn't be— I wouldn't— I feel fatigued, but I wouldn't be able to actually lay down and actually fall asleep. Whereas maybe sleepiness is more like, oh actually yes, if I had the opportunity then I could— fall asleep during the day. I wonder too about— there's you know a concept in the more general sleep field, about— kind of the diversity of— that some people could be quite sleep-deprived, and that they could be able to be more— awake seeming, that

there's diversity basically, in how we can— different people can— manage sleep deprivation, even. So I wonder too if that's like, some people experiencing this certain level of sleepiness, they can't really do much— kind of— and then other people might be able to— stay conscious longer? I don't know if that's anything.

Dr. Maski: Yeah, I don't know, you know, the underlying mechanism of that. I mean some of it might be— how much hypocretin or orexin levels you have, that differentiate you know, the function— but you're right, like I see many patients where we've done CSF testing and they have no orexin and just the differences in how they present is really striking so— we don't really understand that. You know, it'd be a great study, to study people who are— doing well with narcolepsy, in many ways. To find out you know, what are— if there's any distinguishing factors

Julie: As far as communicating, you know I think that— Shannon and Dr. Maski, you know some of these terms that you guys have said about feeling like your brain isn't with you— but the more kind of analogies I think we come up with, the better, in a way. There's not going to be one exact one. But I think that the idea— the analogy that kind of worries me is thinking of sleep as a switch— because, it makes it as if being awake or being asleep is just a switch, on and off, and that's all there is— when it's, to me more like—

Shannon: One of those dimmable light bulbs, where it's different settings. [laughing]

Julie: Or so, I've thought like maybe even like a strobe light? [laughing] You're like, am I awake, am I asleep? [laughing] You know, this is very disorienting. But that space in there, for what the — gray zone, between being fully conscious and fully asleep— the more ways we can think of to communicate about that.

Dr. Maski: Yeah, I mean I think just to add to that, I've heard people say that you know, sleep— we have these distinguishing sleep stages— non-REM 1 to non-REM 3 and REM. Like why don't we have something similar for wakefulness? In terms of staging that.

Julie: That's amazing! I love that idea. That would really help to show, because it's not always the full— whatever it's supposed to be— feeling. Are they well represented enough. So, I guess — my feeling is, is that I'm not sure that these are— well represented enough, and I know Dr. Maski you're talking about well, they're maybe not distinguishable from other things. But I do worry that we might be— at least in thinking about, kind of like what Shannon was saying— for the years prior to my diagnosis, I never would have thought narcolepsy could be me, 'cause I thought it was falling asleep very quickly. And so I worry that some of those things— like typing and not realizing— what I was typing, and— driving to school and not remembering the end of the drive—

Dr. Maski: I think you're right, I mean I think, you know whether you want to— people want to add it to the major symptom list, or have it recognized as a very common comorbidity. I think it's sort of something the field hasn't really reconciled, but— one of the reasons for instance we're doing the patient reported outcomes is so we kind of shift the focus from, just finding out like what's your sleepiness on this scale—to like, what are some of the associated symptoms of that. And, that are more impactful to patients, so some of these symptoms are all on there— because they really do impact like a child's ability to learn, for instance.

Julie: Yeah and I just want to thank you so much for— really listening [laughing] and letting the letting the patient voice guide some of your actual, real research, guys. I mean that's huge! That's why I was just so happy that Dr. Maski would join us today because— not everyone lets

that patient voice really truly guide some of their research focus and— such a huge joy to have you share about some of it, ‘cause— it’s really special. [laughing]

Dr. Maski: Thank you. No, we’re— our work is inspired by the patients, and for the patients, so. We really appreciate all the support we get from— from you, and from the patients themselves, so thank you.

Julie: Well um I just want to share this poem that Ana Lara wrote. “Open the door, like I did once before. Nothing's new or has changed, just the thoughts in my brain. I'm confused, let's rewind, lost my moment in time. Will I finish my tasks while my brain— while my mind feels detached?” Visual images, poetry, analogies— there's just so many great ways that we can— talk about this, so I just wanted to share Ana's poem.

Julie: So we don't really have too many resources on this topic. Usually we have a long thing of resources— but we will definitely include Dr Maski's research projects— and publications in the toolkit. But of course we just always want to give a shout out to all the different organizations. The Hypersomnia Foundation, I think their website even goes into other things— about— sleep inertia and some different concepts around sleep, and I think they do a really beautiful job in this area. And a focus also on idiopathic hypersomnia which is so important.

Julie: And of course there's Narcolepsy Network. Project Sleep— you're here, you know about us. And Wake Up Narcolepsy. Wake Up Narcolepsy has a ton of support groups, very robust— different support groups going on weekly so definitely check those out in addition to other programming. The Narcolepsy 360 podcast—definitely check that out.

Julie: For international— our international friends, we have a list of the different patient groups on our website under the World Narcolepsy Day webpage.

Julie: So with that— any last words, Shannon, do you have anything else you want to add?

Shannon: No, I think this was— pretty great, thank you for doing all this. I think getting these toolkits out there are going to be amazing helps, for people to provide for school accommodations, work accommodations, things like that.

Julie: Well with that I guess, everyone, thank you for joining us and thank you again to Dr. Maski and Shannon for joining us today. Hope your brains feel— without the fogginess as much as possible— thanks everybody!

Access and download the Becoming a Narcolepsy Advocate toolkit here.

The Narcolepsy Nerd Alert series invites listeners to dive deeper into specific topics relevant to living with narcolepsy and are available in many formats to listen, watch or read.