

Project Sleep Narcolepsy Nerd Alert
Becoming a Narcolepsy Advocate (Season 1, Episode 3)
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.

Ana E. Lara is a poet and stay-at-home mom who is passionate about writing. She is a person with narcolepsy, who advocates for sleep health and serves on the board of directors for Project Sleep.

Matthew Horsnell is a father of three and science nerd living with type 1 narcolepsy with cataplexy. He is a Rising Voices of Narcolepsy trained speaker and a facilitator for Wake Up Narcolepsy online small groups.

In today's episode, Julie talks with guests Ana Lara and Matt Horsnell about how they each began their narcolepsy advocacy journeys and have a discussion about how to get into advocacy, the different types of advocacy that are out there— including self advocacy, public advocacy and legislative advocacy. Julie reminds us that people living with narcolepsy are likely already advocating for themselves in many areas of their lives, and there is no prerequisite to begin advocating for narcolepsy in whatever area you feel most drawn to.

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 “Becoming a Narcolepsy Advocate” (Season 1, Episode 3) 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: So you'd like to advocate for Narcolepsy but aren't sure where to start? In this episode we talk about the power of your story and break down narcolepsy advocacy into three categories: self advocacy, raising your voice publicly and legislative advocacy. I'm joined by two incredible advocates, Ana Lara and Matt Horsnell.

Julie: Hello everybody! We're really excited to talk about becoming a narcolepsy advocate. I'm Julie Flygare and I'm the President and CEO of Project Sleep. And I am joining you from Los Angeles. And we have some very special guests with us today. We have Ana— hi Ana, where are you joining us from?

Ana: I'm from Arizona. I'm in Glendale.

Julie: Okay. Hi, Matt.

Matt: Hey. I'm calling from Nashville.

Julie: Alright, well guys, we're so excited to have you here. Ana let's start with you. You could share a little bit about your journey as an advocate.

Ana: Yeah, I just— I kind of started sharing some pictures and things online, and— and I decided you know what, it's time to really educate myself— and I did it as a means to try to educate my family a little bit about narcolepsy. But what I found was just the connections to the community and, you know I started writing some poetry, and it just kind of took off from there. Little by little I started to meet more of you in the community and I started to feel kind of a sense of involvement and a sense of like, this is where I belong. And it just showed me to slowly kind of, open up and really live my life. You know, saying— This is me. These are the symptoms. No more hiding them or pretending that— you know, everything's okay. And it just gave me kind of an empowerment through, being educated, I guess I could say. And educating my family members and learning more about everybody else's story. I kind of, started to get involved with Project Sleep and taking pictures and stuff for World Narcolepsy Day which was really exciting and I got my family involved and, you know— they were— really happy to be involved. And you know it just, little by little it took off from there. And then I had a small publication, like a magazine kind of reach out and say, "Hey— you know, we've read your poetry and we're really excited about it." You know, "would you like to be a feature?" And I just kind of told them a little bit about my background and then I talked about my narcolepsy. So they got back to me and they said "Wow, we're really excited about your story and it really touched us." And they just said, you know, "Would you want to write about your story?" And so, of course, any opportunity to share my story. So I wrote my story and they published it in the magazine and everything just kind of happened organically, and— I'm very proud of this community, and— Project Sleep, and— all the love and everything you guys have shown me.

Julie: Thank you Ana. Her poetry is so beautiful. We just included a few here. And you're underrating yourself, my dear, when you said, like— a small publication. It's this gorgeous, gorgeous magazine— with such beautiful art and the design of it is just incredible. So being featured here is— pretty awesome, and we're just so super proud of you. So, let's just go ahead and have Matt introduce himself quickly as well.

Matt: Well first I just wanna thank Project Sleep and Julie and Ana just for having me on here. It's an absolute honor to share this moment with you guys and to be a part of Nerd Alert. In many ways I've punched my nerd card along the way. I started off with the social media when it comes to advocacy, and it was— it was reaching out. I was diagnosed in '07 and I was never— bashful— about doing a grassroots advocacy, so I was telling people that I would meet about it. I was trying to reduce stigma, really just kind of on a, on a personal level.

Matt: And I realized that I was going through some transition in my life right around 2015, 2016 and I wanted to change a lot about how I was approaching my condition. I wanted to take more ownership of it. I wanted to treat this condition as more of an asset in my life and look for the positives and tease those out. Narcolepsy sucks, a lot of times. It's— You struggle with it. But there's a lot of ways that it's helped shape and define who I am, as a dad— and as a man. And that's been about a paradigm shift.

Matt: So in 2016 I started to be a little more vocal on social media. I reached out to Julie on Twitter. Made some connections there, really just started opening up some conversation. I started participating in some early #NChat which is a Twitter interactive social media effort that's independent— kind of hosted by Mike Kyle, as the founder. And that was where I really started to build my network of support.

Matt: What I realized is that the support that I was receiving from this community was fueling me every single day. And so I really wanted to get more involved. So, I talked to Julie on a number of messages back and forth and I decided that— I really wanted to step up what I was doing. She was able to get me in touch with some Know Narcolepsy folks, which is an effort to raise awareness, and they do a lot of campaigns, maybe check them out. But— they had a great opportunity for me to share some of my kind of, words and wisdom. I sound smarter on those memes than I actually am, just to let you guys know, but its been a great opportunity. I did that in 2018— I also followed that up the next year, 2019, doing some legislative advocacy — with Julie. We went to Washington. And at that point I was hooked. I realized there was power in my voice and in my message. It was a way for me to really feel like I was taking ownership and helping shape the future of narcolepsy research in a way I— I never really knew was possible.

Matt: Later on in 2019 I was able to do the Rising Voices of Narcolepsy program. With that, just really gave me the speaking opportunities, the abilities to communicate— what living with narcolepsy is like. Using storytelling is my main method. I've been able to speak to Belmont's College of Pharmacy, sharing my story. I've also spoken with the pharmaceutical group. And that was all of course, before COVID, but— I've kind of changed how I'm doing things now, but — for me its the fundamentals, its the grassroots. Its the telling people one-on-one.

Matt: I also am the owner of the longest hashtag in narcolepsy, it's #worldsstrongestpersonhavingnarcolepsywithcataplexy. And what that means, for me— yes there are times when I feel like I am the strongest person— but it's more about the mindset about what it takes to get up, to work out— every single day— even when I don't want to. To fight through those moments.

Matt: I'm also the facilitator for Wake Up Narcolepsy small groups where I'm able to help share my experiences with newly diagnosed folks or who've been diagnosed for a while and what I've learned just throughout all of this is that, by opening up, by shedding a few tears— and being vulnerable— that is my ultimate strength. And that vulnerability as a strength is something that I'm really trying to get the word out for— both the ladies, and the guys— to share their voice. And so that's the next step.

Julie: Awesome! Thank you Matt. I really love what you said about vulnerability, it reminds me of Brené Brown. We'll have to add her to the resource list. You know, being nerdy we need to have our resources reflect all these great things, so. Thank you, for— all of your intros! You guys probably are aware, I just like to put this in a timeline so that you understand that like, getting, possibly— where you see I am today— it was a very long journey.

Julie: So I was diagnosed the same year Matt was, in 2007. I think the first time I did a speaking engagement was with my own doctor at Harvard Med. School for a class. It was more him asking me questions and me giving responses than me presenting a formal presentation. I wouldn't have known how to do that at that time, for sure. 2009 is when I started my blog— 'cause blogs were a thing!— back in 2009. You guys, 2009— Instagram did not even exist. So— just saying. Blogs were cool. I was cool, I promise.

Julie: And so that was really when I first started reaching out, the same way Ana said how she was trying to— really, probably communicate with her own friends and family. That's the intention of my blog. And then I was so surprised by all the other people with narcolepsy around the world that found that. And that sense of community there, that I wasn't even really looking for— becoming such a big part of my own journey.

Julie: So, the first time I helped as a volunteer, I helped Narcolepsy Network coordinate an advocacy day for narcolepsy back in 2010 on Capitol Hill. Because their annual conference was taking place in Washington, D.C. that year. So I really didn't know what I was doing. I worked with some other volunteers and we kind of put together an advocacy day, but— it was kind of a one-off, in a way, 'cause we were— volunteers. And just trying to put something together.

Julie: In 2012 was when I published my book— Wide Awake and Dreaming. And the very next year I founded Project Sleep! And I also, that same year, I guess— [laughs] It all seems like a lot to do!— But I started Narcolepsy Not Alone— as a campaign— to raise awareness, and to reduce isolation for people. And that really took off and opened a lot of doors to meeting a lot of people around the world and across the country.

Julie: And in 2017 is when Project Sleep started the Rising Voices of Narcolepsy program. And that same year is when we started collaborating with the Sleep Research Society on sleep advocacy. So that was a really big year for us, to start that program.

Julie: And then— just in 2019 is when we launched the World Narcolepsy Day, as a coalition of organizations around the world. So— to see some of the impact of some of those later efforts is still so surreal, 'cause I remember that feeling, back— and I tried to find a message, I couldn't find it last night— when I first said to my dad, "I think some day I wanna do something, you know?" I didn't know how— [laughs] but, "I wanna do something to make a difference. This is so frustrating. And so angering. And so, how can I be part of the— the change, you know, that I wanna see." Couldn't find the message, but— I know it's, it does exist. And so, the— the whole thing— is a journey.

Julie: So, where to start, right? If you have that feeling, possibly— I've seen that on social media— some people responded to our posts about this, saying that, they're not really sure where to start. They want to be an advocate. So we have a really— first, broad message for you. How many of you have ever had to talk about narcolepsy to a friend, a family member, a doctor. [laughs] Has anyone ever had to deal with an insurance issue? Trying to get a medication— through some red tape?

Julie: 'Kay. If anyone— If you raised your hand, you are a narcolepsy advocate! [laughs] You are one! There's no certification, there's no— rules around what that means, and we just want you to feel empowered that— your experience matters, and because of that— and your story matters, and— having to deal with this every day makes you an expert and makes you an advocate.

Julie: So, there's really no one right path, but we're going to go over some of the things that we thought of today— and, it's such a broad topic that we could probably have— days and days of— conversations about all these. So, we are going to try to— get some good thoughts out there to start this conversation.

Julie: Really quickly, why advocate? I think these are absolutely essential. To remember, what is the change we're hoping to see? And for Project Sleep and especially in the narcolepsy space as we think about our efforts, what guides us is really the problems that we're trying to solve. And so these are some of those main problems and you're probably super familiar with these already but just to go over them quickly, is that— public understanding and awareness of narcolepsy is limited and often inaccurate. That is one of the main reasons that there are 8-15 year average delays between the time that someone's symptoms start and diagnosis. People with narcolepsy often face stigma and report feeling isolated. And that research is limited and urgently needed to better understand and treat narcolepsy.

Julie: So those are some of the main problems that we're trying to address through our efforts. And as you look at this list, some of these might be more important to you and your experience, closer to your heart, than others. So if you are trying to address possibly, something like, the fact that people feel isolated. One of— a great solution could be, getting involved in support groups. Like Matt was talking about Wake Up Narcolepsy's support groups. That's a way to make sure that people don't feel as isolated, right— to have the social connection.

Julie: If you're thinking about how to raise public awareness, you might take a different approach. If that's most important to you, that we change perceptions, that we get doctors understanding— you might think about more like, how do you present or share your story with medical experts, stuff like that.

Julie: If research is important to you, funding research. We have some ideas on how to help be part of that solution as well today. We thought kind of like, there are a lot of different areas of advocacy and we definitely want to acknowledge all of them today even though we can't go into— tons of detail on all of them. Here are some of the different areas that we thought of them. We want to— probably I'd start with self advocacy. I don't know if that's actually the exact right term, it's just the best I could come up with. It's somewhat advocating in your own life, or in your loved ones life if you are a parent or a loved one of a person with narcolepsy.

Julie: Advocacy that is dealing with your doctor, your insurance company, the pharmacy. Advocating for yourself for possibly— for reasonable accommodations, at school. Or, at— a job. Or going through the Social Security disability process. Or as I've learned most recently there's even a lot of advocating for yourself in getting a service animal. And there's also advocating with your friends and your family. So, there's a lot there. Like I said, we could have a whole, probably, conference— just about [laughs] that one bubble of advocacy. We're going to go over some tips in that area today but, we're not going to focus a huge part on that today.

Julie: Then we have raising your voice publicly. So that is, kind of moving away from— your inner circle of your experience, to putting yourself forward— as a public voice, and that could be through speaking engagements, on social media— blogs, poetry— as Ana pointed out— speaking to media outlets, getting stories in magazines. So that's an area that we're going to talk about today.

Julie: And the third area we're going to talk about today is legislative advocacy. Which is another way and I like it because it's— I guess seemingly, sometimes it feels like it's going to the source of the problem sometimes, that it's working on a systems level— a systems level approach to making some change. But all of these are super important, and they all are hugely impactful and important. You can't address any problem just in one way. So, these are just some different approaches.

Julie: In the self advocacy area we've just put together, some of these— kind of like, key statements. When I had thought about my own personal experience— and hopefully, Matt and Ana you can add some other additional ones, but— when I thought about my experience of working with medical management, and— red tape, of getting things approved— and, that whole process. Some of the statements that came to mind for me, was realizing— this idea of, "Is there someone else I can speak to?" [laughs] Uh, that, if someone— if not getting through to someone, that that is— you know, important for any sort of customer service situation, I guess. But that's been helpful for me, to ask that sometimes. And then, "How should I proceed to resolve this issue?" Because, I sometimes think— has anyone ever felt like, other people in the system are dropping responsibility easily? They say, "Oh, well, that's someone else's job."

You know? And so I think this helps, again— people think from your perspective about— what's the next step. What's the next step for me to resolve this. And, "Oh— hm, I didn't really think what you have to do—" you know, so. That can be helpful. I know Matt you had this idea about making a list, did you want to talk about that?

Matt: Mm-hmm, yeah. So, "Can I ask a favor?" So, its a great intro. When you're trying to break the ice you might feel a little bit apprehensive about how do I bridge this gap. I love it when friends do, read or ask. This is where I love to offer them resources, whether it be Rising Voices of Narcolepsy presentations, Julie's book— it's a great way to hear from somebody else, 'cause sometimes just hearing it from a third party, hearing it from somebody on the internet— it can really help them comprehend— and they hear it in different words than what you've been saying over and over again, and that's just really critical.

Matt: "Thank you for thinking about me, but I can't at this time." That comes to— to the, "no," word. You know, learning how to say, "no," is invaluable. You know, its something I've struggled with over time but I have to realize that my condition does have— puts limitations. And I need to make sure that I'm prioritizing, and I'm balancing my schedule to make sure that — I'm getting my priorities taken care of.

Matt: "What do you know about narcolepsy?" That's a great way to— you know, when we think about advocacy— it's a conversation. It's a two way process. You're communicating with, you know— your family member, your doctor. It's not just you telling somebody, it's you seeing where they are and, and— understanding what their, you know, comprehension of narcolepsy is.

Julie: Do we have examples of that? It's from legislative advocacy.

Matt: I do.

Julie: Let's— let's do it now.

Matt: Yeah, it's great. I had just finished telling my story to a state representative— health legislative rep. And he was, kind of had this stoic presence— and it was tough getting a read on what he was thinking, what he was feeling. And so I told him about what narcolepsy means to me, and then Julie I think was picking up on some of those— mute responses— and then, so she said, "Well, what do you know about narcolepsy? What are your experiences with the condition?" and, "Can you tell us about your experiences?" And his response was, I don't want to say who it was in his family, but— "I have a close family member with narcolepsy." And— all the sudden, there was this connection— that wouldn't have existed had the question not been asked. I don't think he was going to come forward with that information— unless he was asked. And from that point on, that changed the trajectory of how we were approaching that particular legislative meeting.

Matt: You've got 15 minutes, or less— to spend with these key figures. And so you want to make sure that you're optimizing that and making sure that there's connection established. It was great for me to sit there and watch that interaction unfold both from how I had started off and then to see how things started to change after Julie asked that question, and— it was just a profound moment. It's like, okay— I need to make sure, too, that I'm not just telling— about my experience, that I'm engaging— in a conversation approach. And so that is something I'll never forget and it's definitely been incorporated into every legislative conversation that I've had after that and also the ones my grassroots efforts taught me. "What do you know— about narcolepsy?" And it gives me a chance, too, to reduce stigma too if they don't know anything about the condition.

Julie: Yeah. I think what I said was something like, “are you familiar with it?” you know, and he nodded. I was like, oh— like, from— I was kind of being a little bit, I don’t want to say snarky— but kind of like, I was like, “oh, from TV?” Expecting that he would be like, “Oh yeah I’ve seen Deuce Bigalow: Male Gigolo,” or some, you know— but he just nodded, saying he was familiar with it— so I said like, “Oh— from TV, or your personal life?” And then he revealed he had a family member. And so yeah, it was just a really— a reminder of like, that we’re not always talking at people but it can be a conversation, and that was— really, good— reminder of that. So then, oh yeah— how ‘bout the last one?

Matt: Yeah. So, “What questions do you have about narcolepsy and how it impacts me?” So again, you’re giving them an opportunity to ask questions, thoughts that have come up in their mind. For me, again, too often— when I was learning how to talk about it— it was focusing on me, talking from my perspective. But, it— this just gives me a chance to— put it all, a bridge— out there— let them meet me and we can begin to build on their knowledge, and what they need to know.

Julie: Cool. Thank you, Matt. Ana, are there any of these that you feel like you’ve used, in particular? Or— different questions, or— communication techniques?

Ana: Yeah, I think for myself, self advocacy is just— it’s become more of like, self care. Advocating for myself has become, like— something that I need, you know. So, for example, if I’m— going to hang out with friends and they know that I can’t— drive very far— then I say, oh, you know— “Can you meet me half way? Can I bring someone, so that they can they drive me.” Because, you know, as a mom— you don’t get a lot of moments to, you know— take care of yourself. And for me self advocacy has become— my own personal self care. And like they said, to be a little bit assertive. Like, these are my needs. That’s the only thing I wanted to add [laughs].

Julie: I feel like that is such a powerful point, and because often, many of us already have established patterns with people. You know, you have established patterns of how things go with certain friends and family. And I’ve noticed myself— especially if I don’t, like— some family that I’m not close to, in the physical, right— so then we spend vacations, or holidays together. And so, and then I’m noticing that my needs aren’t really being met, because it was never like— when is the time to then readdress, and say, “Oh, so now—“ [laughs] “things are going to be a little different.” [laughs]

Julie: And I remember, with my family having my niece, Zoey, who’s my— The most adorable niece in the whole world, I love her so much— But when it was her nap time, you know— it was Zoey’s nap time and I’d be like— because she’s a kid, and so understandable— but then trying to be like, oh it’s Zoey’s nap time, perfect! You know, that really works out well for me. And then I think, when— at what point to then say, well, it’s also like, Julie— needs a nap time — not because I’m a kid, but— because of my narcolepsy. It’s a really hard thing that I struggle with. So, I think it’s such an important point about finding that assertiveness. And changing those patterns with people.

Julie: Raising your voice publicly. There’s a lot here. I was curious from both Ana and Matt, did — do you, do you remember a certain day that you decided that you were going to become public about your narcolepsy, and disclose that, publicly— or, at what point in your life, generally. I’d love to hear your experience.

Ana: I’ll go first— [laughs] I think for me it was just, I kind of started trickling it into my social media and I liked the response that I got from some family members. You know, they were like

“Oh, I didn’t know that this is how it was for you.” And I think slowly I just feel like the things for me to share kind of just chose me. So, with the poetry I feel like, I just put it out there and I thought, oh we’ll see. These are my feelings. Here are some feelings. We’ll see what happens. But, the response that I got from the community, and from people saying just, “Wow. I feel this. This is how I feel. You just described, exactly— my emotions.” And that was really powerful for me and so I thought, you know— maybe I can keep doing this. You know— maybe if I express myself, I can make others feel like, you’re not alone. There are so many other people that feel just like this or feel just like you. But I would always try to incorporate different infographics from like, Project Sleep because I wanted to, you know— back up my feelings or my symptoms— with facts. So that people could go through, and read them— and say, oh okay, that’s what this is about. Or that’s what this means. Sort of like that.

Matt: For me it was— around one of the early sleep weeks after I started to make the cautious decision to become more vocal. So I think it was 2017 I started to notice the Sleep Week coming up. There’s different fundraising activities— this was a chance for me to share some infographics, like Ana was talking about. The Sleep In for Project Sleep was a huge jump into the deep end. Lets make a whole lot of noise— lets raise some money, let’s make a difference. And, if you didn’t know I had narcolepsy before that— you definitely did after ‘cause I had talked about it straight for a week.

Matt: That was probably one of the key changing points— I started to realize that while I was talking about my condition with people one-on-one, I was really living an isolated existence with it because I didn’t have that peer support that’s been essential. And so, using those Sleep Weeks to see who’s posting, who’s using the hashtags— those are great ways for me to increase my support network.

Matt: The World Narcolepsy Day was great, because I got to see so many people that hadn’t shared before taking that opportunity to post about their life with narcolepsy and that was a huge moment for so many people. And you know, Sleep Week, National Narcolepsy Awareness Day, those are great opportunities to come out, feel the support, feel the love, and just start talking about it. You don’t have to do it every day, but it’s a great way to put it out there, and just use your strengths and your skills to advocate for yourself.

Julie: Yeah! I think I remember, for me— I made a very conscious decision because— my dad had been an employment lawyer, and so he had really talked about being careful about when I disclosed— publicly— because of job stuff. And, so that was always kind of in one ear, right. And then I had this voice in me that I felt like I was like— suppressing, and like swallowing it back. Like, “Don’t say anything, don’t say anything about this.” And then, I just was like, “Wait — if I do talk, I could write a book— I could do some media work,” and once I switched it was like— no going back really. And it so, it did feel like, when I changed my thinking to think, “How can I be part of the solution, to reduce the stigma so that people don’t have to feel afraid to disclose in the future?” it just was a big moment.

Julie: You guys both started on social media. Like I said already, I started with a blog because that was the thing back in '09. I mean they still are a thing and I still recommend it as a great platform for yourself. It really is, you know, kind of like a personal website. It’s a really great platform for some people that are looking to take that next step. And you guys have both talked about leveraging your interests and skills and I think that’s super important.

Julie: Because we all are people that have so much more to us than just narcolepsy. And I find from a storytelling perspective, and a communications perspective— sometimes empathy

comes in realizing that you share other things with people. So, if someone loves poetry— but they don't have narcolepsy, you know they can engage with Ana on that track. Matt is in the gym or, you know, doing his workouts, and he can talk with people on that track. And and so— I guess for myself, I did call myself REM runner— and I have subsequently realized I don't love running— [laughs] but I have run a few marathons and everything, so that's kind of— I brought my running together with my narcolepsy— so if you can bring some of those other areas of your life to your advocacy, I think that's a really, really powerful— lens to to be creating a platform on.

Julie: I think, as we all kind of have said already, it's finding community, organizations, training, and awareness days. It was kind of the unexpected thing, right? You go to like tell your own story, and then you find that community, and I think that's part of a really big step for a lot of people, is learning about the organization. Seeing what they're doing— seeing how you can get more involved, what kind of trainings are out there, or programming— and those kind of awareness days that Matt mentioned.

Julie: You never know who you might reach. So I'll just share a quick anecdote about that— which is that one of the earliest things I ever did was— reach out to my high school, [laughs] to raise awareness— and see if I could get into the alumni magazine. Well actually they said, "How about the online portal? How about not the- not the fancy magazine. How about the online portal thing." I was like, "Ahhh— okay, sure," you know. So they wrote a really small paragraph, and then never made it into the magazine. But I didn't realize that one of my old classmates was working at Marie Claire as an editor, and she actually reached out to me and then asked if I might like to share my story with her from Marie Claire magazine. So— that's an example where — I probably maybe had tried to pitch myself to Marie Claire magazine on my own, but didn't really know what I was necessarily possibly doing. And so taking those small opportunities —like that high school online portal— [laughs] even though it wasn't my dream—[laughs] awareness opportunity, it reached something— it actually took about a year, I think, even longer — for that article to even come out. So it's a very long process—but I just think that also, when I blogged, I had people that never commented, never said anything— and then in person, later— years later they said, "Oh, I love that blog post you wrote!" and I never knew that they even read my blog.

Julie: So I feel like you guys also had some other stories along those lines of, not really knowing who might be— who you might be reaching.

Matt: Yeah just with sharing my story I decided to use— some of my artwork. I know I sent some to Julie. I basically glue some of the rocks and fossils together and create these, kind of— sometimes odd, sometimes dark, but just representations of where my mind is at night as I, you know, fading off. And I was able to send one to Neil deGrasse Tyson, astrophysicist. I was able to use my narcolepsy story as kind of the way to get in touch with the social media guy, and tell him a little bit about narcolepsy. It ended up making it's way all the way to Dr. Tyson's desk— and I got a picture of it for Christmas, sitting on his desk— and that was one of the coolest things ever. But I was able to share it with somebody. I'm sure Dr. Tyson, you know, he knows a little bit about everything— so he probably knew some about narcolepsy— but that was a great opportunity. And also, through a Project Sleep event I was able to meet Isaiah Thomas— which was really cool and I got a chance to talk with him, so you don't really know where it's going to take you— who you're going to run into, that has somebody living with narcolepsy.

Ana: For me with poetry I've just, I've actually had a few messages from other people, you know, just kind of, around— the world, saying like, "Oh wow. I didn't know that people made poetry about narcolepsy," and to me I was like, "Oh wow, well there's, you know— I know a lot of other poets who write about narcolepsy."

Ana: It was really eye-opening to see these people connecting through my poetry. And I even had one person from, I think— France, and she said, "Oh, I don't know any other people with narcolepsy, you know— in my country." And I said, "Well I know someone," you know, so I just— I kind of connected those two people, and it— for me it's like, "oh wow," you know. I feel like I'm doing something. But it's it's really neat to see those connections— and, building those relationships with the community and people.

Julie: And I think, you guys have touched on this as well— which is also, I think Matt you just said it kind of beautifully earlier, and I just want to highlight again about— you said, "You don't have to do this every day." But consistency is really powerful, I think, over time. And also relationship building, and trust. I do see a lot of people come in with a lot of interest, and they seem really gung-ho— but, that fades. And I think that consistency over time, sort of like, it's the tortoise versus the hare. Or, you know, the slow but steady. And we don't have to make a job of this every day, by any means. But over time, that that can really build up— and lead to stuff that you never imagined, as opposed to just— really, really strong, you know posting ten times a day!— but only doing that for a little bit of time, and then thinking it's too overwhelming. So— and that relationship building is just part of what we talked about before, with just remembering that, really, a lot of this is person by person. That's how I've built my network— of friends, or community— is really a lot of just, person by person.

Julie: So I guess we've talked a while here. I think we have a cool little quote, "Social change can only move at the speed of trust." I've seen a few different quotes like this, and— they hit me so hard. Because— I just think that, often, it's forgotten how much social change— advocacy, is really about relationships, and trust— and showing up for each other— and knowing each other, as humans. So, just a quick reminder about that.

Julie: If it's not right for you to disclose, I completely understand that. And, we did talk about— some ideas— Matt, you had a great example about, you know, there are other ways to be sharing—

Matt: Yeah, no— that's a great point. There's a couple people that I know that— they're concerned about possible impacts with an employer, and so they use an alternate social media account to do their their awareness for narcolepsy. So they're not having to put their name and their face attached to particular messages. And they do a great job of using infographics and storytelling— about their experiences, without having to "go public".

Matt: And I think you hit on a great point. It's about finding the right balance for you and at the right time— and so, you know, if you can't do it now, just put a little file in your brain that it's— you know, something that you want to revisit later. Because it does— it has to be the right time — or you do lose interest. And you do— people run into the problems with employers all the time and that's a reason to both keep it close to your vest, but also to raise more awareness. That just underscores the importance of what we're doing to reduce stigma, and change people's perspective about what could be accomplished living with this condition.

So there's ways you can work around that, you know, not having your face out there. Having, you know, some valuable messages getting across without without using your name.

Julie: Yeah— I mean, for Rising Voices we ask if people would like to use just their first name, or a pseudonym— and they can do that through their efforts. They probably would still have, if they're a speaker— people can see their face, [laughs] but, yeah. It's doing what's right for you. And— stigma of narcolepsy is real— which leads to discrimination, and that is a real part of the journey for people, so— and also there can be other factors in people's lives that are, you know— stigmatized aspects of someone's identity. Sexual orientation, race, ethnicity— all those things can be other sources of stigma, so when you bring a medical condition together with some of those things as well— that can be a lot. [laughs] And so I think that, you know— it's important to just, really recognize that it's okay. This isn't for everybody, to be— out there on social media, showing their face, and sharing their personal experience. There's a lot of considerations of safety, employment, stuff like that.

Julie: We have a little bit more in this area. So I think there is a lot of people who really do love sharing facts. It's very easy to simply, you know— put up an infographic, and— I definitely think that is really great— in certain situations— but I just think this is kind of an interesting thing to understand, as well. To be aware of the Information Deficit Model, which is a term that was coined in the 1980s that at the time described a widely held belief— much of the public skepticism about science was rooted in lack of knowledge. Sort of the thinking that like, “If only the public knew more— they would be more likely to embrace scientific information.” So it's kind of this, people are missing information— so if only we give them the info— if only we tell them, “Narcolepsy is a neurological condition, affecting one in 2000 people— and, it's a lack of hypocretin in the brain,” that all at once that's going to make people, “Oh my god! I had no idea — now I care! I'm, you know, much more understanding now!”

Julie: That that might not always be the case, that facts don't always necessarily help people embrace information— or increase empathy. So yeah, research has shown that that doesn't always change people's views. So, that's why we try to emphasize story sharing— and emphasize that especially in our Rising Voices Program. Because it truly is an evidence-based approach, meaning there's research that shows that you know, by sharing your story— and stories— that you are able to foster empathy, and be more empowered yourself— inspire people to take action, and reduce stigma. And create role models for other people. It's a really powerful approach. We're not going to get into it too much more today, but, the stories we tell become the world we live in. And I just think that's a really really powerful thing to remember.

Julie: We're just going to quickly, very quickly go over a few health communications best practices as you are out there sharing your story. Project Sleep recommends using people first language— and using a balanced, first-hand perspective that respects autonomy of different people's experiences with narcolepsy. Every single person I've met with narcolepsy has a different experience— and that's what's so wonderful about something like [Rising Voices](#) where we're elevating different stories, because— there's no one person that can represent the whole condition just by sharing their experience.

Julie: And even how we share about narcolepsy, it's important to remember that we're sharing our experience— and not representing everyone. And how do we balance that. Really quickly about people first language— you know, disease-only language would be saying something like “a narcoleptic,” or “narcoleptics.” Disease-first language is putting the disease before the

person, so that would be "a narcoleptic person" or "narcoleptic people." And people-first language is putting the person before the condition— so, "a person with narcolepsy" or "people with narcolepsy."

Julie: So what is behind this people first language? I just want to remind people that this is not a matter of political correctness. It is based on a scientifically established phenomenon— in which condition first language subconsciously propagates stigma— and dehumanization, in the audience's mind. So this has been studied. And it's actually been studied around the world, including different languages. And really shown that— people's perceptions of groups— will be different, depending on whether you're saying something like, "disabled people" versus, "people with disabilities," "the mentally ill" versus "people with mental illness," or "epileptics" versus "people with epilepsy." There's also been a lot done in diabetes, "a diabetic" versus, "a person with diabetes," and so this has been a cultural change over I'd say, I don't know— the last 20 or so years— as this research has really come to light and shown that— how they kind of research this is that they'll give a certain a group of people questions, like— "How comfortable would you be working with an epileptic?" and then a whole different group of people get the same questions, but, "How comfortable would you be working with a person with epilepsy?" And so they can actually show— by doing big groups, and, you know— all the data analysis stuff— that goes into it— that people would feel more comfortable and be able to feel less social distance— from people if you use person-first language.

Julie: A balanced first-hand perspective is really important— and so this is referring, when you're referring to a broader group. So when you're saying something like, well, you know, "people with narcolepsy," it's important to use neutral language that respects diversity and personal autonomy. So, you might not want to say something that's— kind of, non-neutral. So, a non-neutral term might be— that, "Everyone with narcolepsy is suffering." You can personally say, "I feel that I am suffering," but suffering is a very personal— to your experience, term— and shouldn't be assumed that you know how other people are feeling, in those kinds of terms.

Julie: So we say that— that's why we use words like narcolepsy is a "serious neurological condition," as as opposed to saying something like "a disabling." For some people it will be true, and they can define it for themselves that way when they're talking about their experience— but when we're talking about a broader group, we just stay a little bit more neutral. Avoiding stereotypes and generalizations, like "everyone," or "no one," or "always," or "never." Those are red flags to me. I always think, if anyone tells you anything is absolute— they're probably not true. So really, emphasize trying to to be a little bit more— careful, as far as saying, "often," "sometimes," those kind of terms.

Julie: Speak from your experience. So— I think a lot of people expect us to be able to represent the whole group— of people with narcolepsy. So you might find that someone asks you a question, like, "Do you drive?" Well— do they want to know if I, Julie Flygare, drive— or do they want to know if people with narcolepsy drive? So— the way you can probably handle that is like, "For me, I am able to drive. I track very carefully the timing of when I do that— to make sure that I'm well medicated and well awake. For people with narcolepsy, that varies. Some people drive, some people choose not to." So that's how you can— answer to both your experience, but also— remind people always, that— there's a variety of experiences out there. So those are some key phrases around speaking from your experience.

Julie: And just as we transition to legislative advocacy, just want to share this quote from [Ebony](#), who's one of our Rising Voices speaker, and she spoke at a congressional briefing, back in 2019— when we were in person, and doing things like that. And— she said, “I'm sharing my story because representation matters.” And I think that for her, that was a really powerful point of realizing that, if she didn't see other people that— looked like her, to be— someone that could have narcolepsy— that she might not know that she could, you know, have something like that. So thinking about the next generation, and how important it is to— represent different experiences.

Julie: Legislative Advocacy. This is just one other additional way to make progress, and I think it's especially powerful when conducted consistently, over time, and with expert guidance. So, that's not me— that's actually, we work with experts in Washington, D.C.— the [Health + Medicine Council](#) and they are in this stuff every day and they represent a lot of different patient advocacy organizations, professional societies, and universities. And so they really know how all this stuff works. Way better than I do. But I think that's important to understand— it's consistent over time, and it's with expert guidance— bringing those things together.

Julie: For Project Sleep, we focus our advocacy on sleep health and sleep disorders, which we're really really proud of. And these are some of our guiding principles, or the areas where— we're trying to make sure our advocacy is working on. Advancing sleep research, accelerating treatment options, ensuring access to healthcare— hugely important. Furthering education, awareness, and training. And addressing social justice and sleep health disparities. That has been a new area that we've added to our legislative agenda and really working hard on this past year and we're really excited about it.

Julie: So as we think about advocacy, when to advocate, when to get involved— there are some really key opportunities— and we do do stuff throughout the year. You know, Congress is responsible for creating the budget for the federal government in the U.S. So that includes creating the budgets for institutions and agencies that are relevant to priorities that I just talked about— that includes the [NIH](#), the [CDC](#), which does a lot of awareness work, the Department of Defense which actually does fund some sleep research. The [FDA](#), all of that. When they are working on that budget process, so when they're deciding how much money to— give [NIH](#), basically, to fund for medical research— that is an opportunity when they also can— make some suggestions to [NIH](#)— about things that are important, what they're hearing from their constituents. So that's why this appropriations process or this budget process is a key opportunity, to have our priorities heard— and be part of that process. So, in late February, early March— when they're starting that process, for next year— so they're just working, they're like, you know, like any sort of a company— like they're planning their budget for next year— and they're just at the beginning stages. And so that's an important time to get our voice in there, and say, what we hope— for [NIH](#) research, and for the [CDC](#) to be funding, and DoD and stuff like that. Okay?

Julie: So, if you're bearing with me, the way that we advance that— the way that we say, here are our priorities, please keep these in consideration when you're creating this budget and this — big packet of advice, sort of— that goes along, comments that go along with that, when they hand it over— to the institutes and agencies, is through this congressional sign-on letter. And — it outlines these different priorities that we have, and in mid-February of 2019, we first asked you guys to say, “Okay we have this letter, it's for your representative to sign on to, hopefully.” And so we had probably over 100 or 200 patient advocates— along with sleep researchers, and

different people in the sleep community, reaching out to their representatives at the House— U.S. House of Representatives, and asking them to sign on to this letter. So we got 31 in 2019, and we were really pleased with that. Our goal was 20— and our our health experts in D.C. said that this was actually really— a good, good— strong response. I guess it's hard to know sometimes if we don't know like, well what's normal, right? I didn't know— I thought 20 seemed good. They said that 31 representatives signed onto a letter is something that you might see more, from— an organization that brings in like, 700 advocates to Capitol Hill— you know, they're thinking, like— major, major organizations— not like a small— really small non-profit. So, the passion of this community is incredible! That we got so many people reaching out to the representatives' office— which led to 31 of them signing on to the letter.

Julie: It was bipartisan, so it had people from both Republicans and Democrats, signed on to that letter. And then in 2020 we were hoping to just at least get over 31— and we actually got 41 representatives signed on. So we can't always get every representative signed on, and that's part of the process, in a way— is just, asking them, though. They won't be aware of this opportunity— unless you bring it to them, as their constituent.

Julie: So— what does the letter really mean? Does it really do anything? I mean it sounds great to have like 41 or 31. But I just want to— really show, your impact is real. Just like your narcolepsy is real! [laughs] Your impact— through this— is real. And sometimes it's not always— easy to— explain. But we've had some major, tangible success points. Of moving things forward. Because, like everything else— progress is— slow and steady. But we've had a huge win this past year. We have been advocating for the last few years, through that letter— for the CDC to establish a Chronic Disease Education and Awareness Program. To award grant opportunities to organizations to do awareness work. For example, a project could be to raise awareness about narcolepsy or sleep disorders, with— physicians, or with the public. This opportunity didn't really exist. So— creating this new opportunity, was— important. It was important for the sleep community, and for other conditions as well. So, through our work and through some other organizations' work as well, we actually got this program established. It was established at \$1.5 million program— which isn't very big if you kind of look at the budget for— something like the CDC, but it is a starting point.

Julie: So we're really, really proud of the work, that that congressional sign-on letter led to the actual establishment of a new program. That can help raise awareness about chronic diseases. Like narcolepsy, but also other ones— that are hugely misunderstood, and people are not aware of. Also, narcolepsy researchers have credited our advocacy for helping them to secure NIH grants. I know that two narcolepsy researchers have— said, really specifically, that they feel, that— our work— and in our letter every year we make sure that NIH knows that— we really want to see sleep disorders research. That sleep— sleep research has been going up at NIH, but sleep disorders research was kind of lagging. And reminding them that the community is making— wants to make sure that they are making advancements— not only understanding sleep in general, which is important— but also for people living with sleep disorders.

Julie: Believe that Project Sleep is the only organization in our space that has been watching the federal funding of narcolepsy research this carefully. This is a lot of— work, to even be able to tell you— how much funding is specifically going into narcolepsy research. So in 2008 that was 4.1 million dollars, was spent on funding narcolepsy research. So that is—

research that different institutes are doing. That's Harvard, that's Stanford, that's— money going out to— some of the leading institutions, funding their research.

Julie: And then in— 2009, it was 4.5 million. And at the time— this is when I first looked into this, this seemed about steady. This seemed about regular, you know— that every year, it was about four to five million. That they were in that range. Well, I didn't look at it again because like I said it is kind of a big project to kind of figure out this information. The next time we looked at it was when we were establishing our Sleep Advocacy program— which I mentioned back was in 2017, when we started working with the Sleep Research Society, and getting involved— much more, formally— in sleep advocacy again. That year, it was down to 2.5 million dollars. So that's a huge drop. And when you have so little— research, being funded— that's not good. To see narcolepsy research going down like that. And that seemed at the time to be kind of, like, what was happening. So that's when we really started the letter efforts. We actually did a letter in 2017 that was specifically asking NIH what they were doing about narcolepsy research. And, so after that— we're happy to say that in 2018— there was five million dollars, dedicated to narcolepsy and idiopathic hypersomnia research. And— in 2019, we were at 6 million. So, the trend is looking up— and it looks like our advocacy is really making an impact in that area.

Julie: It's necessarily, not something that we— talk about a lot— but I'm really glad that we have some of this information together now, and we can be talking about it and tracking it. This is really because of you guys— it's every person that reached out to their representative— which can be done by email, but we also— part of our efforts has been bringing some small groups to Capitol Hill. A lot of the work that we do in person is setting the groundwork for the online campaign for the letter. So it's getting all that set up— and then we do this big online campaign which involves everybody, from everywhere.

Julie: Matt, I know that you've been part of our advocacy in many ways. Is there anything from the congressional sign-on letter experience that you remember, specifically, about how that goes— that you might want to share with people if they're new?

Matt: Yeah— it's a relatively simple process. I mean Project Sleep gives you everything you need, from the letter— to a template. You add in a couple sentences of your story, letting them know that, you know, you're a constituent from their district. The Health Medicine Wellness council of Washington will actually get you your legislative's contact information, so you don't have to go and find who the hell's legislative assistant is from your representative— which is really, you know, it— just makes that process— all the easier. It's not just— people with narcolepsy, who can do this. If you have family members— who live in an adjacent district, or— live in a different state— they can, you know, use this opportunity to say, you know, "Dear representative, I'm speaking to you on behalf of my, you know, family member— or my friend— who lives with narcolepsy. This is something important to my heart," and I know that that's one way to kind of— expand, you know, the number of sign-ons.

Matt: I just want to think about how important— and how huge it was, that— during the COVID crisis we increased the participation— from 31 to 41— because that hit right when we were trying to get these letters going. That just underscores the importance and value of each person's efforts. And, you know, even if your legislator didn't sign-on this year, they might sign-on next year. The work that you're doing, it's planting for future harvests. It's not just an immediate turnaround. And so don't get discouraged. Now the good thing is, is sleep is a

bipartisan issue. We all sleep. We're not asking for exorbitant increase in funding. This is— consistent with what's already out there, and we're just asking that sleep and sleep research get their piece of the pie. And— a quick story, tell who you are— why this is important to you, and then just use that template and send it off. You can follow up.

Matt: Yeah, I found it helpful to follow up with an email— if you haven't heard back, in you know — a week, 10 days. And then also if you still haven't heard back, you can make some phone calls. And ask to speak to that person. Just leave some messages. Your voice matters. You already have all the tools. It's just a matter of putting it in an email, maybe two— and then, if you are like me, just— make phone calls— and, make sure they know who you are— in a polite way.

Julie: Yeah I think that follow-up is really important. I've heard that, you know, if you just send one email— and they think you'll just go away— “Ah, well!” you know? I mean, some offices will write you back and say, “Great— yep, I checked with the representative, and we're happy to sign on.” If that happens, wonderful. But I've heard that others, you know, “Maybe we'll just see if you go away,” [laughs] and when you follow up in, you know— three to five days, or maybe a week— and you check in, you let them know that you're not just gonna let it drop, and that you are, you know— looking for results. And that is a really powerful point, I've heard. So thank you, Matt— for being consistent, even calling. I don't, you know— I don't like making phone calls myself, I much prefer email— so anyone that's willing to make a phone call, extra bonus points of amazingness and advocacy. So— but it all can be done via email for the most part, and— it is so important everyone does that— and it's just one opportunity throughout the year.

Julie: And, so— there are other things we'll do throughout the year— especially, in making sure that we're advocating, for— healthcare coverage, for people. A lot of issues can be divisive, but — sleep affects everyone. And— Dane, our representative at [Health + Medicine Council](#) has said, “Our only opposition is lack of awareness.” And so, even if— your representative doesn't sign on, just imagine you've just informed a few new people that narcolepsy exists.

Julie: Here are some of the patient organizations— we had this last time, but I think you just want to reiterate it, because— each one of these groups is doing a lot— in different areas of advocacy. [The Hypersomnia Foundation](#) put out a really great broadcast about Social Security disability— and so I think that's one of their— of many— they have many great things, resources, but— I found that, you know, recently I was very excited to see that they were taking some leadership in that area, specifically. So if you have questions about Social Security disability advocacy, I would check out The Hypersomnia Foundation.

Julie: [Narcolepsy Network](#) has some of the best resources I've seen about educational accommodation awareness, and— how to get accommodations when you're in school. Project Sleep, what do we have? Our [Rising Voices](#) and our advocacy program. [Wake Up Narcolepsy](#) has the really fantastic support groups that Matt talked about, you know, as far as making sure that people don't feel alone. And also just really want to highlight Wake Up Narcolepsy's work, in— privately funding narcolepsy research. So they are raising a lot of money to privately fund narcolepsy research. Which is another avenue that's important. So they are helping to fund some of the same researchers that we're also hoping can get really big NIH grants. And so their work in that area is exemplary as well.

Julie: There are tons of international organizations, so please check out our [World Narcolepsy Day](#) webpage for that whole listing. And a lot of them are doing really interesting, different advocacy. The group in Brazil has really been working to establish narcolepsy as something — in their country, that they can get accommodations for. So we're really proud of all the different people doing advocacy around the world.

Julie: For raising your voice, some of the resources I just want to mention, Rebecca Fuoco wrote this beautiful, two-page, very, very short [article](#) that is available for free— called “People-Centered Language Recommendations for the Sleep Research Community”. So at the same time that Project Sleep is hoping to bring some of these best practices, around— language choice, to— patient advocates, we're also hoping to bring that to the research community as well. So that they can learn some of those best practices— so she published this short, two-page paper that's just— super eloquent in explaining some of these things. And I highly recommend that for everybody.

Julie: [The Stanford Social Impact Review](#) put out a beautiful podcast called “[Storytelling and Social Change](#)” and I think that's just a really powerful— there's different panelists talking about different ways of using storytelling— through the media, through virtual reality (VR), and through movies— and working with filmmakers, so— that's just a podcast, I just love. Getting nerdy, guys.

Julie: Please consider the [Rising Voices of Narcolepsy](#) training program, for people with narcolepsy and idiopathic hypersomnia— to be trained on some of these best practices, and more. And two of the programs that we built [Rising Voices](#) from are called the [Health Story Collaborative](#)— and they have a beautiful website, about storytelling— and opportunities to get involved in what they're doing— and [The OpEd Project](#) is a project for women, to make sure that women are authoring op-eds. I forget, there's some high percentage of op-eds— that are written by men— so this project is really focused on helping women, to learn how to write op-eds— to make sure that the voices of women are part of our national discourse. So, those are some of the trainings that we base [Rising Voices](#) on.

Julie: And then for legislative advocacy, please check our website. Make sure you're getting our alerts— through our e-updates. And we started the [Sleep Advocacy Forum](#) and there are some beautiful videos. So if you want to learn more about what NIH is funding for different sleep disorders— and, what FDA is doing in patient-centered drug development— or, what's happening in sleep, race, and health disparities— these videos are a really great resource for you. And they're on our different social— they're on [Facebook](#), they're on [Instagram](#)— and on [Youtube](#).

Julie: Okay! So! Thank you guys, so much for being here— and we'll have a toolkit that we'll put out— And huge shout out to Taylor who has been helping us to turn these broadcasts into a toolkit. It's a big project, so we're really grateful to be working with Taylor on that. Thank you to Matt and Ana for joining today. Any closing words, guys?

Matt: Just, the power of your voice— that's where your strength lies. You already have your voice, you have your story— and these are some great ways to amplify it— and do what's right for you. So thank you just for taking the time to learn about this. Congressional advocacy has meant so much to me— and, social advocacy as well, but there's so much— that we can do to make change.

Julie: Thank you Matt.

Ana: I just want to say to, you know, remind everybody that— advocacy is, you evolve with it. So, you know you can start somewhere small like, just posting your story— which is a very personal choice, of course— just sharing a few things, or advocating with yourself, and your family— and it evolves from there.

Julie: I loved what you said earlier Ana about how— advocacy kind of chose you, or it trickled in — to your social media. I think that's so beautiful. So, here's to more trickling in, and thank you guys for being so active and for taking this time today. With that, we'll go ahead and say — goodbye!

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.