Project Sleep Podcast
"Why Aren't Primary Care Doctors Asking About Sleep?"
(Sleep Insights Series Episode 6)

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.

Dr. Dennis Hwang MD is a pulmonology specialist in Fontana, CA and has over 23 years of experience in the medical field. He is a Primary Investigator for Sleep Vital Sign Study and a Kaiser Permanente Sleep Medicine physician.

Dr. Andrew Philip is a clinical health psychologist passionate about integrating care to better address patient and provider needs and enhancing care for underserved & often undervalued populations.

Dr. Michael Perlis is an Associate Professor of Psychiatry, Associate Professor of Nursing, and Director of Behavioral Sleep Medicine Program at the University of Pennsylvania. Dr. Perlis is also a member of Project Sleep's Expert Advisory Panel.

The Sleep Insight Series invites listeners to learn about this amazing adventure we take every night called sleep. Through these insightful discussions, we examine sleep, and our societies beliefs about sleep, from a variety of angles. We hope you'll learn some cool new facts and analogies that you can use to help us raise awareness about this under-appreciated one third of our lives. This is a written transcription of the podcast "Why Aren't Primary Care Doctors Asking About Sleep?" (Sleep Insights Series Episode 6) from Project Sleep. Transcription provided by Mirela Starlight.

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: Has your primary care doctor ever asked you about your sleep? If you're like most people, probably not. Today's podcast covers an important, but underrated discussion about what work is actually being done to develop better sleep disorder assessments for primary care doctors and screening tools so that more people get accurate diagnosis and treatment sooner. Today's guests include Dr. Dennis Hwang, a pulmonologist and primary investigator for Sleep Vital Signs study at Kaiser Permanente's sleep medicine and department of research and evaluation. We also have Dr. Michael Perlis, an associate professor of psychiatry and an associate professor of nursing and the director of behavioral sleep medicine at the University of Pennsylvania. Last, we'll hear from Dr. Andrew Philip, who's a clinical health psychologist and a leader working on healthcare transformation initiatives. He's passionate about integrating care to better address patient and provider needs and enhancing care for underserved and often undervalued populations.

Dr. Hwang: First, thanks for the invitation, I— I actually feel pretty blessed to be working in a health system in which there is a flexibility of being able to you know make diagnoses even if the numbers don't completely fit, even providing empiric treatment for you know diagnoses for somebody who I believe either has narcolepsy or idiopathic hypersomnia, and so forth. So, you know, these— a lot of these patients really need some— you know, immediate relief. And for a college student who has finals and so forth, even delaying a couple of months can very much be problematic. Part of that flexibility also includes the ability to introduce fun little projects, I think we kind of described this project as maybe kind of like a little fun cute little project, where we introduced a Sleep Vital Sign based on a simple two question survey for utilization in our primary care clinic. As a little bit of background, we developed a Sleep Vital Sign, two questions— with the goal of improving the recognition of patients with potential sleep disorders and to eventually track our longitudinal sleep related outcomes. Here are the two questions. Question one or sleep vital sign one is, how many days a week are you not satisfied with your sleep? And question number two is how many days a week is sleepiness a problem. Both of which are scored on a scale of 0-7.

Dr. Hwang: The idea here is that one question is more targeted towards sleep disruption and the sleep experience and the other question is more targeted towards consequences of poor sleep, namely sleepiness. Study aims, the first of which was to— essentially do something exploratory and see whether the Sleep Vital Sign actually matched scores of other standardized or standard validated sleep surveys, namely the STOP-BANG which is a screening tool for obstructive sleep apnea. The Insomnia Severity Index, that's a measurement for insomnia severity— the Epworth Sleepiness Scale as a reflection of sleepiness and the FOSQ-10 as a measurement of general sleep quality. Next we wanted to evaluate the utility of the Sleep Vital Sign in identifying patients with potential sleep disorders as a screening tool in a primary care setting. So we had, you know, give or take about 1,000 patients, and— I'll highlight some of the differences actually between men and women. Women tended to have a higher Sleep Vital Sign 1, which is a reflection of more sleep disruption or poor sleep experience, and their sleep latency was quite a bit higher, you know give or take about 15 minutes as opposed to 30 minutes. Men on the other hand, drank more caffeine and as expected, the next signs, the STOP-BANG scores were higher as well.

Dr. Hwang: So first we wanted to take a look to see whether the Sleep Vital Sign had a similar pattern with the Epworth Sleepiness Score. And what you can see here for both the vital sign 1 and for vital sign 2, as the Sleep Vital Sign score increases, the Epworth score increases as well. And so we found that that was a statistically significant pattern, or relationship, that we identified. Same thing for the Insomnia Severity Index, in fact the pattern is probably a bit more pronounced. Same thing for the FOSQ-10 for both the sleep vital sign 1 and sleep vital sign 2. And also for the STOP-BANG at least as it related to sleep vital sign 2 which is the question related to sleepiness. So overall what we found, you know, we felt pretty confident that the Sleep Vital Sign was measuring what we expect it to measure, being able to identify potential sleep disorders and sleep symptoms in people who truly are having some trouble with their sleep. So in regards to the part of the project as it relates to the implementation in a primary care setting as a screening tool, this was the protocol that we used. Step number one, the medical assistant would collect the Sleep Vital Sign, in addition to the blood pressure, heart rate, etcetera. Step number two, if either the Sleep Vital Sign 1 or 2 was at least four, meaning if they had problems at least four days, or at least half the week, then we would proceed to step number three. Step number three the medical assistant would provide an expanded questionnaire. A lot of what we were trying to do was to really simplify the process for the primary care clinic and the primary care physician. We know that the primary care clinics are

overwhelmed, they have a lot of responsibility. A physician has five, 10, you know maybe 20 minutes to assess a patient and then to manage them. And so we really wanted to streamline this for the primary care physician. And so the expanded questionnaire, in the algorithm there is a series of seven questions that are asked to the patient as it relates to whether they snore, whether they have problems falling asleep or staying asleep, whether they feel like they're not getting enough sleep, are they shift workers. Do they have restless legs, and do they take any medications for sleep or for depression, and whether they doze off regularly, in a way that impacts their ability to function during the daytime. Whether they answer yes or no to these seven questions, the primary care physician can follow this algorithmic tree to a recommendation, or various recommendations, for example should the patient be referred to sleep medicine for possible sleep disordered breathing, or for insomnia, or for hypersomnia evaluation for a patient who we think might be at risk for narcolepsy or idiopathic hypersomnia. So we really try to implement this as a way of truly simplifying this for the primary care physicians.

Dr. Hwang: Our results. Half the patients were randomized to the Sleep Vital Sign pathway and you can see that 18% of them were identified to have a potential sleep disorder, and referred to sleep medicine. Versus only 2% of the patients that were randomized to usual care. What we also found is really a critical result here, is that of the 83 patients that were identified to have a potential sleep disorder and referred to sleep medicine, only 19 of them actually showed up to their sleep medicine appointment. And so one of our key conclusions from this study is that an effective screening tool cannot be limited to just identifying patients who have a potential sleep disorder. It has to be partnered with some type of engagement strategy, you know for the patient to really understand and to become engaged with following up with their sleep evaluation. In conclusion, first we successfully implemented a novel Sleep Vital Sign, a two-question survey, in the primary care clinics, and number two we— where applying the Sleep Vital Sign increased the rate of identifying potential sleep disorders, it increased the referral rate to sleep medicine clinics. Number three, however most patients did not keep their sleep clinic appointments, indicating that engaging patients, and not merely identifying patients, is critical for successful sleep disorder screening strategies.

Dr. Perlis: Thank you for the invitation Julie, so we'll start with the premise that sleep health matters. I think we're preaching to the converted here, but sometimes I think we lose perspective a little bit, in that how much poor sleep is related to poor psychiatric and medical health. Poor sleep generally defined is related to a host of medical and psychiatric disorders, from heart disease to obesity to diabetes to PTSD, to depression. And depression is where this linkage in my mind is perhaps the strongest. And I think that there's clear and convincing data now that it is— a very much a reciprocal relationship. But I won't be surprised down the line to find out that many of these health-sleep links are more reciprocal than uni-directional.

Dr. Perlis: So, sleep health matters. What's the problem? The problem is sleep health is generally not a focus for primary care. So why isn't it? First is, patients may not view sleep disorders as consequential. Patients often don't report their sleep concerns. I call this the "Don't ask, don't tell" policy. Patients often view their sleep concerns as secondary. And this one is perhaps our biggest stumbling block, because we have promoted this concept, even within the sleep community, for generations. So this is a big one of many problems. Clinicians often don't have training in sleep disorders, clinicians don't have an efficient way to assess for sleep disorders that fits with the work flow. Clinicians may not view assessment or treatment of sleep disorders as essential for care. Clinicians often have the view that sleep concerns are

secondary. So this is true of patients, it's also true of clinicians. And finally, even if all of this wasn't a problem, clinicians may not have clear pathways for treatment or for referral.

Dr. Perlis: So, what's a potential solution? A brief, comprehensive, sleep disorder screener. How brief is brief? Two is pretty brief. Plus seven, nine is pretty brief! So I think that that was a very good start. Again I'll emphasize that ours was a bit different. But back in the day in 2016, Dr. Karen Klingman decided to have a systematic look at what was available at the time, and what she found was published in this study, and it's basically as follows, but the problem that we identified in that effort was that none of the existing screeners are, or were, brief— and are or were comprehensive. The list of the questionnaires that purport to be global screeners and what you'll see is some are short, like 11 questions, some are not short, like 175 questions. But what all of them have in common is none of them tap more than six sleep disorders, and most don't do that. So there's a real question about, how comprehensive these things are. So arguably, what we want is something as I said, brief and comprehensive. And when I say comprehensive, the goal is to concurrently assess all 13 sleep disorders. We can argue, about are there 11 sleep disorders or are there 15. Is this representation not fair, because you collapsed RLS with PLMs. Is it not fair because you have two levels of not otherwise specified disorders for pathological sleepiness. Shouldn't it be 11. Maybe. Should it be 15? Maybe. Somewhere around 13 disorders is what we want to comprehensively assess.

Dr. Perlis: So a potential solution was— not really made for this in the first place. Potential solution came from our need to have a rapid screener for research purposes. What we wanted to stop doing was having one- or two-hour phone calls with each subject that volunteered for a study, to comprehensively assess whether they met the inclusion, and not the exclusion criteria, for our study. So originally the SDS-CL, the Sleep Disorders Checklist 25 was made for research. To be a rapid screener. And it really worked well, and that's— for me was the end of it. But thanks to Karen Klingman and Karl Leung was they kept saying, let me show this to a few clinicians. Let's see what they think of this. And more and more we found that people wanted copies. That this is a really good device, it's very quick, very comprehensive. It was tweaked over the years, at the top is some header information about age, sex, height, weight— work shift, whether— what the total sleep time is, what the time in bed is. The 25 symptom questions. And then they're scaled from 0-4 on a frequency/intensity basis. From 0, never— to 4, which is greater than five times a week that I have this symptom. It takes three to five minutes to complete. Frankly, it could be done in one or two minutes. Modal is three. It taps as we said before, all 13 sleep disorders. Interpretation is easy-peasy. The last two columns represent greater than three days a week symptomatic for each of these items, and so if you wish to follow up to assess, to diagnose or to refer, these are the areas you're going to focus on. Once they've completed this survey, there's a pop-up and it tells people how to access informational resources, through the NSF or through The American Academy— it tells them how to find a sleep disorders center, and if they're looking for providers in their city and their state, it links them to provider directories. It's also sent, if they choose to have it sent to them, by an e-mail.

Dr. Perlis: So, what are the next steps? We are pushing forward with something we call the sleep health screener project. The goal is to collaborate with industry sponsors, to create a public facing, open access website and a phone app. Where the screener can be taken online any time, a completed questionnaire can be saved, the report can be downloaded, the results are e-mailable, and access to provider information is given. So that's where we're at.

Julie: Thank you so much! This is just so fantastic just to see all the work that's been done in this area. Have you guys been able to track at all the follow up of people? Similar to what Dr. Hwang was talking about, whether people are actually following up with sleep appointments, or?

Dr. Perlis: We have done several studies, in 100's if not 1000's at this point, some studies are more interested in symptom profiles across a given disorder, like Parkinsons, or Alzheimer's. In terms of, does it work— that's the critical question. If we put this out in the internet, will people hit on it? Yes, we're fairly certain of that. If you just google "why can't I," the most universal reply is sleep. And if the first link is us, they'll have the opportunity to screen. Now I happen to think, when patients seek information, they're more likely to act. As opposed to in the primary care office, they're handed let's say a tablet, "Here take this." They may be less likely to act. So when people are in help seeking mode, and they're going online to look for what the hell is wrong with my sleep, my hope is they will take hold of those recommendations, those referrals that we're giving. But that's an empirical question. But I also think it is a question that we can address, once we have it up and live. And you know even if it's not perfect, it's a damn sight better than what we have now. What we have now is don't ask, don't tell— if you do tell, people drill down on specific sleep disorders and ignore the rest. We don't want that to happen anymore. We want there to be an opportunity for all of the sleep symptoms to be assessed concurrently, so that we can get the big picture. Maybe it's not just idiopathic sleepiness, maybe the person also has nightmares— and bruxism, which is by the way likely. So we're hopeful, we've done an awful lot of work to get this to where it is, where it needs to go, is— industry support, to put a beautiful version up, for free— for everybody. And then to hope that we're giving back the information in ways that they'll make good use of.

Julie: Dr. Andrew Philip, so excited to hear you speak!

Dr. Philip: Great, thanks Julie. I have to admit, as I've been sitting here listening to these fascinating discussions, I'm wondering, "Have I been set up?" These are the exact kinds of things I'm wondering about, and asking about— and so, in fact to hear so many good answers is very encouraging. You know as you'll hear, I'm not necessarily a sleep expert, and neither is our organization. But it's kind of an area that we've stumbled into, and I see great potential. And so it's exciting to get to come to these kinds of forums and explore a little bit. So a little bit about PCDC or Primary Care Development Corporation. We're a national non-profit, we're based here in New York but we were founded in the 1990s really to address a fundamental need around health equity. There was a recognition in New York City that primary care— you know a sort of fundamental foundational entry point to services for good health, is not equally accessible. Especially in underserved, disinvested communities, in New York and all over the country. And so we were founded to change that. To invest capital, to actually build up the primary care infrastructure, to provide training and technical assistance, to actually enhance the delivery of quality primary care, which includes behavioral health, it includes things like basic sleep health, sexual and reproductive health and others— and to sort of transform the system through advocacy and also supporting research that really enhances equitable, accessible, high-quality primary care.

Dr. Philip: And kind of stemming from our days in the early '90s in New York to now national, we've done a pretty good job, I think. We're worked with thousands of health co-organizations, public health departments and others all over the country. We've invested now over actually— just recently 1.3 billion dollars into the primary care system, particularly in underserved communities. And really built the capacity of the primary care system to grow visits. How do we

make primary care better? How do we make it more accessible— and certainly sleep has become part of this. But I'll give you a couple of examples of the kinds of things we do. One aspect that actually touches sleep quite intimately is trauma and adverse childhood experiences. We know that traumatic experiences including things like discrimination and racism, they carry with folks through their experiences and certainly through their health and even their sleep. So some of the work that we do for example where we sort of connect the dots is we invest in innovative primary care models, for example— health centers. When Henry J. Austin, who we were sort of able to use our capital to basically rebuild and restructure their facility, to be safer and more welcoming to patients from all walks of life. While we did that though we also helped with consultation of how to design that space. We work in states like California, to work on large state-wide screening projects around childhood trauma and adverse childhood experiences. And really implement that at scale in primary care and I think that's part of what I'm going to sort of connect to sleep here. We do this with integrated care, physical and behavioral health integration and others but I'm just going to jump into it around sleep.

Dr. Philip: So we sort of got to this place about a year and a half ago, as part of our federal— actually a subcontract we have through the federal government, the national council for behavioral health and specifically through SAMSHA which is the Substances Abuse and Mental Health Services Administration. We do projects around integrated care. A learning series for healthcare providers and stakeholders around sort of, how to innovate to really bring together the head and the body, and treat them within the same place within primary care. And so, this past year we offered this year long series on sleep talks. Really identifying this as a core opportunity where there's an intersection between behavioral health or even mental health, and physical health. As much of the presenters here have been speaking about today. And we— I think we were pretty successful. We engaged over 2,000 audience members from all around the country, including policy makers, researchers, clinicians and leaders. And really across all sides of the spectrum, from sleep medical specialists, to behavioral health folks, students, and others. And our series spanned a number of topics. So we talked about addressing sleep and acknowledging sleep disparities in places like health centers— we actually had a few NIH funded researchers come on and talk about some of the research you heard today, in terms of disparities and how that impacts sleep, but also how sleep can then impact the outcomes of experiencing things like discrimination, which is fascinating. We talked about sort of, clinically, how do you address sleep, how do you assess for it, how do you intervene, both on a behavioral and a medical component. And I think importantly and as you've done here today, we had sessions that were really dedicated to hearing the perspectives of patients. Children, adults, family members, people with lived experience who've gone through the process that I think were really nicely outlined today of— what the sort of journey is to really get care for sleep.

Dr. Philip: And then sort of this final discussion on— actually about us as healthcare providers, and what about us, and all this. And you know I'll just sort of share this quote from Eugena, one of our presenters, a sleep advocate herself— and someone who shared her personal healthcare journey, saying, professionals really just don't ask. They don't talk about sleep. They'll ask you about all these other things, she lists out here, vision, how your body pain is, but she said you know it needs to be on the radar. If our medical professionals aren't asking about it, how do they expect us to feel and really know to worry about it. And so she is really you know saying I think the words that we're all saying, which is— especially in primary care, if it's not being asked about, you know that's quite a problem. So yeah I think Dr. Perlis really laid this out nicely, right. So what's the problem— primary care— it's all the things he just outlined, I totally agree. It's sort of the patient awareness, it's the provider time and sort of awareness, having those pathways— and to Dr. Hwang's point, also the engagement. Primary care is essential access point for all

care, for behavioral health, for physical health, even for sleep health. But you know as you already know, visits are short. Like 20 minutes is probably the highest number I've seen and a lot of that is often actually eaten up by interacting with the electronic medical record and things other than sort of the patients' needs. And in fact, and this might get to the policy piece a little bit— although we hear or are talking a lot about primary care and the great opportunities of primary care, primary care is essentially the least reimbursed health-per-service we've got, of the major sort of access points. We're talking about pennies on the dollar, of our national health care spend, goes to supporting primary care. It's just 5-7%, versus the sort of behemoth which is like hospital based care and other forms of care, things that happen later in clinically speaking like a disease process, right. This is sort of not an emphasis on prevention and early intervention and emphasizing good health. So, that's already a problem, right. So there's not a whole lot of resource in primary care despite the fact a lot of us are talking about it. Also, there are a lot of demands in primary care, on the providers. And providers including the whole team.

Dr. Philip: The US Preventative Services Task Force, the USPSTF, these are outlined you know gold standards and what kinds of things you should be asking for and screening for and you know we're often disappointing them because we're only screening for like less than half of all those things they want us to be screening for. In primary care, we are an ecosystem of testing and of innovation. There is always new screeners, there's a colon-rectal cancer screen, there's breast cancer screening, there's depression screening, there's suicide screening. There is a screening for diabetes, different levels of diabetes based on the types of medications you take and your diagnoses, cholesterol and a whole number of other things and these are all sort of required— and then we see an influence of payment. And so in fact the things that we ask questions about, the things that we screen for, practically, when you go into a primary care office— they're certainly influenced by best practice, but they're heavily influenced by what is required and what is paid for. And that is a really important distinction, I think, to make. So with that all in mind, physicians tend not to really ask these questions very much as a reality, really. Less than half the amount of time for example that they ask about exercise or someone's diet, which are important, but— as we see here sleep is very important. And we have patients who, again, are asking about this. So what do we do? I thought Dr. Hwang's presentation on these two sort of questions, I'm like yes! This is actually what we've been asking for and what I've been asking for. And so in fact, Julie and I got set up, actually through a meeting that was originally put on by Dr. Marishka Brown at the NIH because this question came up, and I actually asked Dr. Brown this question a few months ago, coincidentally of, what is one key question that we can ask about sleep health and primary care, because we have only a few minutes, we have very little reimbursement and sort of money to play around with, and we have very pressed patients and providers who don't always appreciate the importance of sleep. But I do think and sort of in primary care there's a good understanding that a sort of core question or key question or maybe two questions is very important. Julie, you put out a paper on this as well, where you laid out two questions. My conversation with Dr. Brown she suggested perhaps asking about excessive daytime sleepiness may be a good core question. And so it's encouraging to see that there's so much research attention being paid to this.

Dr. Philip: However I will say this is not yet widely heard about or known in primary care. And when I say primary care I'm also talking about, not only large health systems but also small, solo practices or group practices. In fact in places like California which I'll talk about in a moment, a great deal of particularly underserved and vulnerable communities, they really rely on small practices, sometimes single provider practices, to understand the needs of their community and to get care. And they're often sort of the last ones to catch on 'cause they just don't have the luxury of participating in even wonderful forums like this all the time. But one thing that really

encourages me and made me think is— you know I mentioned earlier ACES aware, this is a California based initiative, funded by the office of the surgeon general and through their Medicaid funding, Medical in California. And they took this issue of ACES, which is adverse childhood experiences— this is essentially stuff like having a parent who is incarcerated, spending a night as a child not knowing where your next meal may come from, not having access to things you need— that kind of stuff. It turns out the more of these things you're exposed to as a child, the more barriers and challenges you're going to have in achieving and enjoying good health, among other things. California's acknowledged this. And similarly they said, well, nobody's screening for this. Nobody's asking about these things, and so it's hard to do anything about it. What they did however, is— two things, they took a whole bunch of money, like billions of dollars, and decided, we are going to get behind screening in primary care for adverse childhood experiences, on things including childhood trauma. And we are going to one, create state-wide initiatives, to train healthcare providers how to screen for, how to ask for questions around adverse childhood experiences, and two we're going to tie a special reimbursement incentive, we're going to pay providers per screener to incent them— incentivize them to ask these core questions. And then we're also going to support them in thinking about engagement and follow up through some of the points I brought up earlier. Basically they've had a many fold increase now in screening in the state around ACEs. These adverse childhood experiences. And this is just in the span of less than a year since this initiative was started. And what this tells me, and this is not a one-to-one comparison and there's definitely flaws in how this has been rolled out and there's problems still, but it makes me think that if we can get the right partnerships together, if we can get a reimbursement perspective tied into this, if we can get academic perspectives to sort of let us know what these key questions are, then we can get the right sort of industry standards as others have mentioned, we might actually be able to make some progress here to the points that everyone is making.

Dr. Philip: So you know our plans are to make these connections. We're sort of one of many voices of primary care, but there's these practical issues that we need to wade through. And I think a big part of it is really acknowledging the need for proper reimbursement and regulation, that's kind of what my call to action will be as we engage in the translation of this, we talk about translational research and how do we get information from researchers through clinicians and the community— but also how do we get that connected at a policy level, how do we get the conversations going which I'm very interested in, with— health plans with Medicare, Medicaid and others— to make sure that there's some bite behind the bark of we need to do this screening. 'Cause we have to make it practical, and we have to acknowledge all of the other things that are going on in primary care. But I'm very excited and very encouraged by this discussion. You can view our whole series, it's free, it's online, at pcdc.org/sleep. You can also find my discussion with Dr. Brown and others around sleep and we'd love to have partners in this work and I think we have some here.

Julie: Thank you so much! I think this is just such an important piece of the puzzle that was missing for me for a long time. In understanding, you know, one of the things you said— the things we screen for are heavily influenced by what's required and paid for. And that discussion of getting the reimbursement and the payers thinking about this, and possibly following a model, like ACEs Aware just really gets me excited. Alright guys, thank you!

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