Project Sleep Narcolepsy Nerd Alert
Pregnancy and Narcolepsy (Season 1, Episode 11)
Transcribed by Mirela Starlight

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Katie Williamson is a person living with narcolepsy, trained Rising Voices of Narcolepsy speaker and web designer living in Missouri. Katie wants to help raise awareness of how life altering living with narcolepsy can be.

In today's episode, Julie and speaks with guests about the entire preconception, pregnancy and postpartum journey with narcolepsy, including Dr. Morse who shares the medical side of things, support group leaders who share their personal perspectives and other parents living with narcolepsy and raising families who have information and tips to share as well. Adoption and some of the adoption process is talked about, and medications in relation to breastfeeding is brought up with a small study.

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 "Pregnancy and Narcolepsy" (Season 1, Episode 11) 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: If you're interested in starting a family while living with narcolepsy, this podcast is for you. How might you manage medications or symptoms during pregnancy and, what about

adoption? I'm super excited about today's episode because we have an incredible panel with so much real life experience and insights to share, including people with narcolepsy, who have already walked this journey, alongside an amazing clinician, Dr. Anne Marie Morse. Diana Anderson lives with narcolepsy type 2 and is a mother of a four year old son. She also works full time in physician assistant education. Emily Barker is a scientist living with narcolepsy with cataplexy and is the mom of three boys. Emily is also a co-facilitator for the Wake Up Narcolepsy Pregnancy and Parenting Peer Support Group. Ashley Nutter is the mother of three children and a person living with narcolepsy with cataplexy. Ashley also has her Masters in Education Community Agency Counseling. Katie Williamson is the mother of one daughter and a web designer living with narcolepsy with cataplexy. Michelle Zagardo is a photographer and teacher living with narcolepsy with cataplexy and the mother of a six month old daughter. Dr. Anne Marie Morse is a board certified and fellowship trained pediatric neurologist, specializing in sleep medicine at Geisinger Health Systems in Pennsylvania.

Julie: Hello everybody! Just to go over the agenda today, we're going to be talking about pre-conception, pregnancy and postpartum, because— man, pregnancy is a long journey, I've learned a lot, already— in preparing for this. We are also going to be talking about adoption throughout that as well. I just wanted to start with this 'cause I feel like this is a question a lot of people ask— "If I have narcolepsy, could I have a child with narcolepsy?" So we asked Anne Marie to put together, kind of like, what we— know about that question right now.

Dr. Morse: Sure, and I think it's a very appropriate thing in regards to the conversation that we're having in regards to preconception. Because this is something that typically does weigh heavily on the minds of individuals who have narcolepsy and sometimes comes from not only the mom but the father as well, depending on who actually is the carrier of the risk gene and then whether or not they have narcolepsy. So when we're talking about narcolepsy, many times people will ask whether or not this is something that my child can inherit. And so when we're talking about inheritance we typically are talking about kind of, Mendelian inheritance. What does that mean? I have a certain characteristic, there's a gene that my child will get, and therefore they will have that characteristic. Now, although in narcolepsy there is a specific gene, this gene is really just a risk gene. Meaning that, 25% of the general population carries this gene, but they don't have narcolepsy. When you look at individuals who have narcolepsy type 1, about 95-99% of them will carry this gene, and then about 30-40% of individuals who have narcolepsy type 2 will carry this gene. What gene am I talking about? It's HLA-DQB1*0602.

Dr. Morse: So, because of this, most cases of narcolepsy are actually sporadic, meaning that they randomly occur. They tend not to be a familial pattern. However, we do recognize that when we do see it occurring in a familial pattern, that it tends to be a first degree relative who may be affected. And so when you look at this, the frequency of first degree relatives being affected, is about 2-5%. However, this relative risk, when studied, has varied across different ethnic populations, which we don't fully understand. And so when there was a study done in Hong Kong, it demonstrated that, this first degree relative risk was about 85 times as likely— versus when you're looking at the Czech or German or Japanese, those risks are lower with as low as seven times as likely in the Japanese. Again, this risk is related to likely this HLA inheritance, and again is not your traditional mendelian, I have it, my child has a 50% chance, etcetera, to have it. It really is just kind of stratifying those risks.

Julie: So I just have to ask, 'cause I thought I'd heard something like someone say that your chance of having a kid with narcolepsy if you have type 1 narcolepsy with cataplexy, and you have the HLA gene— would be like, one in 100? Is that—

Dr. Morse: Yep, that's about accurate.

Julie: Okay. And— I think we will talk a little bit more about that later, as well. And, and— our panelists, as far as how they've thought about that too. Or Ashley I remember you had a story about that.

Ashley: Yes, my— my son is— all over the place with his sleep habits, and has a lot of the symptoms that narcolepsy falls under— he has lots of night terrors, he gets paralyzed in his sleep, things like that— at such a young age. And I do think sometimes that he may be— genetically predispositioned to have it. But, at the same time, I'm confident that because I have it and because my husband and I are kind of on top of it, that he has the best support ever if he does kind of turn to narcolepsy and— we're just kind of keeping an eye on it. I was hoping that he wouldn't have it, but— you just never know.

Julie: Yeah, and you would be a great support system. I love that. So, Anne Marie— Dr. Morse, um— tell us a little about what people should think about as far as, you know— who should be on their team.

Dr. Morse: Sure, so when we're talking about, taking care of a family, who— there is a member that has narcolepsy, it is really important to make this a team dynamic. So very frequently, you'll hear me say in different types of settings that I always want the patient to be the captain of the ship, and I want to be the first mate. So in this particular scenario I'm going to use a sports illustration and say, we want the all-star team, to be able to help mom. And so mom really should be the captain of the team. So she's the one who should be really kind of calling the shots, but using the rest of the team to help be well informed about the decisions that would be important for her. Now with that mom's partner or other support person should also be intimately involved. Making sure they're equally well educated about risks and benefits that may impact the mother as well as the baby in terms of the journey. In terms of preconception, the actual pregnancy, and then postpartum. Thinking about not only that, that— immediate postpartum, but really the fact that you now have someone who you're going to be taking care of, for the next 18-21 years. The sleep doctor should be, very much heavily involved, in regards to educating mom, what are the options in regard to narcolepsy management. Including both detailed conversations about pharmaceutical uses as well as different behavioral strategies that can be applied or augmented during these periods. The obstetric doctor or equivalent pregnancy or birthing support should be involved. There should be very, very open communication between the primary provider managing your narcolepsy symptoms and the person who's primarily managing the pregnancy, to ensure that there's a very clear understanding of what the expectations are, and what is the reasoning behind the decisions of using or not using certain strategies to manage the narcolepsy.

Dr. Morse: Finally, in some pregnancies there may also be the involvement of another specialized obstetric doctor, called a maternal fetal medicine doctor. These sometimes are also referred to as the high risk doctor. These doctors are specialty trained to be able to take care of individuals who may have certain medical conditions or higher risk pregnancy conditions, that may impact the length of pregnancy, the health of the mother or the health of the infant. And so it is important to be able to incorporate all of those key stake holders in the conversation, to ensure that all of the concerns are being addressed— and that there's not a conflict of, interest or information, that's being presented to the patient. So that this way they can feel very secure, during your period of— considering pregnancy, becoming pregnant, and then the delivery.

Dr. Morse: So, when you're talking about the approach to this, I do think that it's so, so critical — to maintain patient empowerment, by encouraging shared decision making. This should not be a unilateral conversation where the provider is only dictating that, there's one option and that's it. Pregnancy is not a one size fit all. In fact, narcolepsy alone, we know is not a one size

fits all. So when we are adding in additional layers we really need to make sure we're tailoring these decisions, to the person in front of us. And so with that, some of the things that you can feel empowered with, when you're considering getting pregnant or having children, is really thinking about these questions to ask your doctor.

Dr. Morse: Number one, do my medications impact my birth control? Maybe perhaps you're not ready for pregnancy, and so you want to be sure that you're doing the right thing in protecting yourself from pregnancy. And there are certain medications that can reduce the efficacy of certain birth controls. What are the risks of medication that I'm on, if I do get pregnant? Does this risk differ by trimester? Recognizing that pregnancy is not a fixed state, and that there's different risks associated between the first trimester, second trimester or third trimester.

Dr. Morse: And what are the risks for my baby, during breast feeding? So after I deliver, do I still have to have concerns or considerations about the medications that I'm on, or is it something that I can just start quickly afterwards? What the doctor may ask you specifically is, do you want to be off your medications for your pregnancy? This is an important question that I hope many providers are asking. Because frequently, what we encounter when we look at this, is that we— the response typically, is saying, you need to be off medications. And so what needs to really occur is, do you want to be off medications, and can we discuss what the risk benefits are. It also is important when you're asking the patient about— do you want to be off medications, that you're asking them not only about— their narcolepsy symptoms, but physically and mentally, how do you think you'll be able to cope, once you're off medication?

Dr. Morse: Recognizing that when we're talking about pregnancy, we're not talking about a few weeks. Very frequently we may be talking about two to three years for a person. The pre-conception period sometimes can be as long as one plus years, depending on how quickly a person gets pregnant— the pregnancy itself is about 10 months or 40 weeks. And then the postpartum period when a person is breastfeeding, very frequently can be up to 12 months to two years long. And so recognizing that there can be significant implications by being off the medications, for those periods of time. And then, do you want to consider other medications or behavioral strategies to manage your symptoms? Perhaps you're on medications that really aren't the best choice, or best option available, but maybe there's other medications or lower doses of the current medication you're on, that may help in reducing the risk, or perceived risk, associated with it. That may allow you to have a more optimal journey during pregnancy than being off medications all together.

Julie: Well I feel like this is like one of those Instagram videos or TikTok videos where it says, this is how it should go— and now we want to hear how does it really go? [laughing]

Dr. Morse: [laughing] Yes— yeah.

Julie: This is our ideal, this is our hope for the future— [laughs] is what I'd say. Or, and thank you Anne Marie for putting these questions together, and we can't wait to have them in the toolkit as well. So now panelists, let's hear— preconception— how did this experience go? Were these questions, the kind of questions and conversations that you were having? Anyone eager to dive in?

Ashley: Yes. Especially because you mentioned the maternal fetal medicine specialist, because I have a lot of— complications, on top of having narcolepsy. So I have always seen a maternal fetal medicine specialist with— all of my pregnancies. And unfortunately I go, almost every single week, just to make sure other things are okay. And with that in mind, a lot of— talk about narcolepsy kind of gets put on the back burner. Because they're more focused on, just the

health of the baby— just my physical self, and— some of my other health issues, such as— thrombocytosis, which is blood clotting, and— cervical issues, and things like that. So— when it came to asking about, what to do, now that I'm pregnant, or— if anything's wrong, because I'd been on medication, for— a really long time, wasn't expecting it— I kind of got a lot of— you know, shrugged shoulders, and— kind of, doctors that would skip over that. And— perhaps they didn't know, perhaps they just didn't want to— add any more to my plate, because we had so many other things going on, but— those questions, are so great to have— and again like Julie said, I wish it kind of went that way.

Dr. Morse: And I wouldn't be surprised, if— if, one of the comments that may have been stated to you, and I don't know this to be facts, is— let's focus on your medical issues. And narcolepsy again I think we all recognize as this silent suffering. Even though there are very obvious symptoms to it. But, I would not be surprised if the comments are, let's focus on your medical issues— and, we'll take care of the— we'll worry about the narcolepsy later. And so, I just invite you to respond to that, if you feel comfortable, because I do think that that's unfortunately a very common thing, when women do get pregnant or are experiencing another medical issue— is that that becomes de-prioritized, and this optional consideration in terms of, how this affects me as an overall individual.

Ashley: That is exactly how it felt in there, I don't know if that was word for word, but— almost word for word. And I'm sitting there kind of like, this is a medical issue too, this— impacts my life daily, this is just as important as a lot of other things, but— unfortunately some people don't see it that way.

Julie: Lots to talk about, I know it. Michelle?

Michelle: Yeah— so I'll just outline a little bit of what Darrell and I went through. We used ovulation strips to test for ovulation so that I didn't have to stop medication pre-maturely. I had a goal of stopping my Xyrem, however— that was not successful, and I think that there was this idea that I had that it was virtuous to be unmedicated during pregnancy— but it was not realistic for me and I think what was virtuous was really doing the thing that was best for my family. So, I did try to stop Xyrem unsuccessfully, and made the decision with my husband and with my neurologist to go back on it. And Darrell was crucial in making this decision, because we both had to be okay with the risk that we were exposing our baby to. So he read papers, I read papers, we had a joint meeting with our— with my neurologist. And once we made that decision, we went to my obstetrician and told her, this is what we're doing. And, we didn't really leave any grey area for her to question it— I did work a little bit with a maternal fetal medicine doctor, not because of narcolepsy, but— you know, there were all hands on deck. And so, this was really important for the whole preconception period, 'cause it took us about a year to conceive— and doing that without medication would've been brutal for me.

Emily: I also can share a little. I love, Dr. Morse, that you are promoting a model like this— I think that definitely is the ideal and especially for the mom to be, to be the captain of the team. And— for the sleep doc to be— approaching this with questions rather than, merely advising to be off of meds. And that's what I was advised, and I kind of— was willing to accept that at the time. But like Michelle mentioned, it seemed so crazy to me, to— and we were seeing a fertility specialist, and had no idea how long conception would take, and to be off of meds, when— more than half of the days we may not have any idea whether pregnancy was a possibility— didn't feel like, didn't feel sustainable. And so, we decided— with the help of the neurologist that we were working with, to basically— I was taking Xyrem, and I would stay on Xyrem, and I did reduce my dose— when pregnancy was a possibility. And then at the time of a positive pregnancy test, is when I stopped taking Xyrem. That was our approach for all three of our children, and— I'll get into it more when we talk more about the experience of pregnancy

unmedicated, but it was interesting, how my experience was different, I think my symptoms changed, but also my environment changed so much. And so from pregnancy to pregnancy, my response to being unmedicated was— was definitely varied. And would change the way that I would go forward, were we to conceive again.

Dr. Morse: And I think you highlight a really important point, that the preconception period can vary so much from person to person. And there's so many additional stressors and things that a person is experiencing, that can only layer on additional potential psychiatric comorbidity. Of depression and despair, anxiety— and then you have your uncontrolled symptoms of narcolepsy, that are going to make you feel even more helpless and vulnerable. And so there is innate dangers there— that add on, and then when you become pregnant, how much of that is maternal depression, postpartum depression— versus, I feel helpless and— in despair, because of the fact that I have a medical condition that's making it more difficult for me to be the mom I want to be. And, in that is I think a part of that conversation— because I think, some of the pieces I keep hearing is that there's almost like this feeling of guilt, of me putting me first. And, that should be abandoned— there's no other chronic medical or psychiatric disease where an obstetrician would say, you should feel guilty for wanting to take care of your medical self. We would be saying instead, we need to ensure mom is healthy, because mom's health is baby's health. And so I do think that that is a bit of flipping the paradigm, and again moving away from this stigma of invisibility, and really making sure that we're putting our patients first, and our persons first, right. So, I appreciate the stories that you guys are sharing with us.

Julie: Diana did you want to share a bit about your preconception?

Diana: Yeah, so, mine was I think a little bit different, in the fact that my husband and I had just gotten married and— about six months prior, and— you know, I was diagnosed a couple of months, before we decided to start trying to have a baby, and— the only thing that was really brought up during my sleep visit was— you know, oh, you're going to try to get pregnant, okay you need to stop modafinil, you know, a month before. So— that, you know I was kind of like, okay— so I can't take anything? And they were like, no. And so then— my OBGYN, they knew that I had narcolepsy, that that was a diagnosis on my chart, but— nothing was really said about it to me— and part of that is me not asking, but also, I didn't know really how to ask. I thought— I thought more so that, like my sleep specialist was supposed to take care of that— and every time that I had been to the OB, it was more so of like, okay your sleep doctor's controlling that, right? So it was, you know, even though I have a healthcare background, it was still— confusing, to know— who I was supposed to go to. And not that either of them were wrong, in any way— it was more of the lack of information that I had as a patient, as a whole. So I discontinued the modafinil, and then, it didn't take us very long to get pregnant, so — that's kind of my story. It's a little different from everybody else's, but— once again, it was just not having the information that I could've really benefited from, during those preconception visits.

Julie: Yeah, and I feel like Diana, you'd also said that— when we'd talked about this before, that— this idea sort of that you were still so new to the diagnosis, you know— and so the idea of going off, you're like, well, I've been— can you share that, like you're kind of like—

Diana: Yeah! I had just been diagnosed, so— I had been living with narcolepsy for 10 years, right— before I got diagnosed. So at that point, the medication, I was on it— I didn't notice a whole lot of a difference, so I was like, well— guess I'll just come off it. Like, I lived most of my life without it, so I'll just come off of it and everything will be fine, you know. It'll just be like normal. Not knowing that pregnancy is— a whole new ball game— uh— [laughs] you know, you hear about it, but until you experience it, it's like— "Oh-ho! That's what they're talking about." So, that was just— and my husband was just like, "Okay! If you think that's best." You

know, “You’re in the healthcare field.” And I’m like, well, I am, but— [laughing] still, you know, I’ve never been pregnant. So— [laughs] it was, it was definitely— not a hard decision for me to come off of the medication, because I didn’t at first notice a whole lot of difference, and then also it was so new to me that I just didn’t know.

Julie: So Katie, at this point in your journey, you know making a decision to go the adoption route, how did you make that decision? Tell us.

Katie: I’ve had— or I was diagnosed with narcolepsy at age 29, and like, it was a really fast onset, like Emily— and I was diagnosed fairly quickly. And I have narcolepsy with cataplexy. And I have very severe cataplexy. And— part of the— [laughs] nail in the coffin— was my cataplexy. I tried to do the Avadel study, and I had to go off my other meds, and I made it like, three days, and— my cataplexy is so severe that, I was falling— I couldn’t— basically, I couldn’t— function. So, just the thought of even if I stayed on my meds, I didn’t know like, what could happen with my cataplexy. And so that scared me— [laughing] because, it’s just so severe. So, basically that was a really big part of it, was just my cataplexy, and so— to be honest like, we didn’t even— like really go down the route. My husband’s sister is adopted, and we’ve always liked the idea of adoption, so— it was kind of like, we were okay with that. And my husband is a type 1 diabetic, and— so we also didn’t like the idea of, “What if our child is diabetic and had narcolepsy"— [laughing] so, that sounded like a— not a fun combo— so that was kind of how we made the decision.

Julie: Thank you so much for sharing.

Julie: On to the pregnancy, ‘cause there’s just so much to get to. Walk us through a little bit of this, Dr. Morse.

Dr. Morse: Sure, so one thing just in hearing Katie describe her journey of getting the decision, I think one person that I may have failed to potentially include or consider, especially nowadays — in that team, especially when there’s that heavy concern that you’re describing about what is the risk for my child— even though we can guess statistics— would be potentially considering to include a genetics counselor. Because they may be able to have more of those detailed conversations, about what the risks are— and then what are the avenues that may— potentially mitigate some of those risks. So, sometimes there’s options in regards to utilizing IVF with some genetic profiling, that could potentially help in alleviating some of those concerns. So that literally is just giving some additional thoughts on the fly, as I’m just hearing and thinking about some of my approaches in other genetically susceptible conditions. And so I just wanted to kind of share that.

Dr. Morse: So, when we’re talking about medications during pregnancy, I think first and foremost, it’s really important to highlight, how do we know what the potential risks are— during pregnancy. And so the majority of the data that we have, in fact doesn’t typically come from humans. It typically is coming from animal models. And the reason for that is because the data that we’re able to collect from humans, generally is based on observational data. What I mean is, a woman gets pregnant, she was on the medication, either intentionally, or— or, unintentionally, so she was on the medication maybe for another reason, narcolepsy, or potentially maybe if you’re talking about a stimulant, ADHD— and then they get pregnant. Or perhaps they did have one of these conversations with their doctor, and then we are able to follow them forward. There are some pharmaceutical companies who have made specific registries, for their drugs— so that they can collect that data forward. The reason why there’s not more stringent trials looking at this is because it’s unethical. We can’t randomize women who are getting pregnant, to continue your medication or not. That clearly would be an ethical red flag. So instead the approach typically is using animal models and applying these

medications in animal models and then seeing what happens in regards to— ability to get pregnant, the— the outcomes of the pregnancy, meaning are there any changes in the fetus, or any changes in the mother? And then what does the— the delivery, and baby look like, afterwards. And so some of the things that we're going to review here, are some of the outcomes that we've seen from those animal models.

Dr. Morse: And so when you're talking about sodium oxybate, or oxybate therapy in general— animal studies have not demonstrated any evidence of teratogenicity. What does that word mean? It means that it has not caused any major malformations in the fetal outcomes. Now, there's limited data from pregnant women exposed in the first trimester, and there is a suggestion that there is a possibility of there being increased risk of spontaneous abortion. Now with that said, there hasn't been very, very detailed studies looking at whether or not pregnancy itself in narcolepsy is any different. There have been some case control trials that have occurred, of looking at narcolepsy against individuals without narcolepsy, and seeing if there's any significant difference in signal. But again, these are still limited data sets. And then when looking at pregnant patients during second and third trimester, again there was no major malformation or toxicity seen with sodium oxybate. And I think Emily will be able to talk a little bit later too, about some of the great work she's done in the postpartum period in relationship — in terms of lactation.

Dr. Morse: When you're talking about wake promoting agents— wake promoting agents, examples of that would be— modafinil, armodafinil, things like solriamfetol or pitolisant. Now most the wake promoting agents data that we have is really more so from modafinil, armodafinil. Because they're much older drugs that theres a ton more data on. And so intrauterine growth restoration and spontaneous abortion or miscarriage have been reported with modafinil and armodafinil, and then some animal studies have demonstrated this embryo fetal toxicity and mortality, meaning in utero death. Now with this said, when we look at the study designs again, when you're looking at animal model study designs, it is important to make the specific point, that the dosing that is used is sometimes— 10, 15, 20, 40 times the dosing that we would be using for humans. In terms of looking at it milligram per kilogram, so weight based dosing. And so, it is important to make those distinctions, and many times we're doing those very, very high doses— to again look for— is it possible? That there could be an adverse outcome in a birthing situation.

Dr. Morse: Stimulants can cause vasoconstriction— and so when you're thinking about vasoconstriction, meaning that the blood vessels tighten down— we always worry about how that may affect the placenta, which is the main source of oxygen and nutrition for the baby. And so if the blood vessels kind of constrict, that could compromise oxygen and nutrition going to the baby. And so when you're talking about stimulants, you are considering your methylphenidates and your amphetamines. When you're looking at methylphenidates, there is some published studies and post marketing reports that are basically insufficient to inform any major drug association with major birth defects, miscarriages or adverse pregnancy related outcomes. Based on the animal data, again— it, there is the potential that it could cause fetal harm— a similar consideration with amphetamines.

Julie: And Dr. Morse, I feel like, you know, I've heard you say something so beautiful about— thinking about risks and— benefits, and I know you've said it a little bit, but you know, you just shared some of what we know so far, but— in the broader picture, you know, like— what are some of the risks of not going off of medication?

Dr. Morse: Sure, so I think number one, as I mentioned earlier, there really aren't any other medical conditions, or psychiatric conditions where there's this mandate that all patients should be off medication. In fact when you look at ACOG which is the American College of

Obstetrics and Gynecology, very frequently when they're publishing their guidelines on disease states, they have not only recommendations on medications that potentially may be the least harmful during pregnancy, but generally are stating— you need to have a detailed counseling session with your women who are of reproductive age, about— when they want to get pregnant, not wanting to get pregnant, and then what does pregnancy look like. And really prioritizing over all wellness of the mother, and making sure we're not putting that secondary.

Dr. Morse: Now, when we're talking about women with narcolepsy, I think its extraordinarily important to really uncover what is the burden of disease— and so I think Katie had said it extraordinarily well— her fear, and her experience of when she was withdrawing from medications— put her at risk of self injury. You put that same situation in a woman who is pregnant, and there's innate risk of, if you fall while you're pregnant, you can cause placental abruption— which means that that breaks the placenta away from where it's supposed to be, compromising nutrition and oxygen to the baby, and really causing significant neonatal harm. And so, it is important for us to think about— if you have someone who has untreated narcolepsy, and they're having severe excessive daytime sleepiness, which is compromising their reaction time or psychomotor vigilance, or severe cataplexy, which is causing them to fall — automatic behaviors, doing things that they're unaware of, and putting themselves at risk— you are doing them a disservice. And you're doing that baby a disservice. And so, those risks are very real, not only during pregnancy, but then also in the postpartum period. Women universally— we experience excessive daytime sleepiness and sleep deprivation, related to pregnancy. And the reality is that, SIDS, sudden infant death syndrome— the highest risk period is with a parent who is sleep deprived. Who is falling asleep inappropriately, in situations that can put that baby at risk. And so falling asleep in a chair and the baby falling down— so these are the real, transparent conversations we need to have. Of not just, suck it up and deal with your sleepiness and cataplexy— and, this is an invisible illness. But really taking a look at, what is the burden of this disease? And how do we make sure we're alleviating that. So we're providing women the opportunity to truly enjoy pregnancy and not make these decisions of, is pregnancy right for me, or maybe I'll only do it once— because I think that's unfair. I think that's an innate bias, that we're implementing onto our patients, without even giving them the option to have a chance to choose.

Julie: Alright, again— that's how it's supposed to go! How did it go, guys? [laughing]

Emily: Well stated, Dr. Morse. You need to be educating clinicians, I hope. I hope that's a plan down the road. Yes, I— feel kind of like, well I mean I had had— I had had my diagnosis for years, but— what Diana said kind of resonated with me, just like— not realizing what my role should be, in advocating, or, I mean— opening that as an option, I guess. Being on medication. And, so— like I mentioned, I had three pregnancies, and went off medication at the time of conception. With my first, I was actually somewhat surprised, I thought that I would be going back to square one, and— I ended up feeling better than I thought that I would, and was able to— supplement a lot with naps and felt like I was able to manage that fairly well. With my second, my first two children were 20 months apart, and so I had— a young toddler, during pregnancy. And I mean— I hardly remember much about it— [laughs] I know it was exhausting for years, actually. Because I was off meds through— breastfeeding with those first two, as well. It was like, 36 months. And then, I will mention that— with my third I did the same thing, but I mean what Dr. Morse was saying, about risk for falls, and psychomotor vigilance, I mean there were times that my husband and I were like, "What are we doing?" I remember one particular instance when it, it's interesting how my cataplexy triggers also have changed with the new emotions of motherhood— and, were like, elation and laughter was always my biggest symptom, like— this makes my kids sound bad, I have wonderful children— [laughs] but, when they are a little bit defiant, and like, kind of— it surprises me, I think. It surprises me, and that gets my cataplexy. So I just remember one night when one of my children was not staying in

bed, and I— it was just like the last straw, I remember throwing down an envelope and then just like— collapsing to the floor! And it could've been an injury to my head, and— I was in the second or third trimester with my third. And that was the moment where I was like, if we did this again, I don't know that I could— I don't know that I should— be off meds, we need to make this more of a conversation. And similarly with the driving and drowsiness. It was a lot of stopping on my 20 minute commute, for naps— or, arriving and just like, immediately reclining — and taking a nap, and waking up and being, and like— wondering what route I had taken to work, you know. Like, I mean that's not safe for myself, it's not safe for other individuals on the road, or for the fetus. So, I just really appreciate this model that Dr. Morse is promoting, and I think that its more common in other disease states, like you say. So that's my experience.

Dr. Morse: And I think you highlight a lot, like so when this actually is studied, right— when we look, when we survey women— who have narcolepsy, and have experienced pregnancy, and we ask them what have they done? There are women who have stayed on their medication and in fact, when they've compared those women to women who took off their medication, there was no major differences in terms of the pregnancy outcomes, the modes of delivery, how the baby did, or anything else. Now, with that said— the common behavioral strategies that then are employed, contribute to other burdens in a quality of life. Right? So many of them were experiencing kind of, maybe sleep elongation. So they're having longer hours of sleep at night, or as you mentioned, increased napping through out the day.

Dr. Morse: But frequently, they'll also describe that they discontinued working or discontinued driving. And so now its shifting the burden from not just being on the individual, but also across the family unit, which of course is fair— but, how necessary is it in every single situation? And how are we taking away from the individual empowerment of feeling as though that they can be autonomous and independent. And I think thats really important because I feel as though as a provider, I very frequently encounter patients who are so worried about, "achieving the normal," and— I like to encourage them of that, I take care of doctors, and nurses, and teachers, and— police officers, who have narcolepsy. And you are going to be able to do all those great things. I have families who, they have kids, and they go on to do these great things — but then when rubber hits the road, we take it away from them. And as you described, for years at a time. And I do think that thats just, such an important thing, that we have to just continue to resonate with one another, and to utilize as a part of— as a patient— advocating for yourself to your provider, because if your provider's not asking the right questions, sometimes you can demand that. And sometimes it does take the patient demand— for provider habits to change. And sometimes our provider habits are based purely out of ignorance, of not recognizing we're not doing the job well.

Julie: So glad we're having this discussion, of course we'll have the toolkit after which will be very helpful with these questions. Michelle I feel like you had a really different experience, you want to share?

Michelle: Sure, so I was diagnosed with narcolepsy— five years ago, and we knew we wanted to have kids, we were also making a move to the New York city area, so I made it a priority to find a neurologist who specialized in pregnancy. Now I also am very aware that that is not the norm, that a provider like mine is not available to everybody. But we were able to take advantage of that, and he really spear headed my care throughout the entire period of preconception, pregnancy— preconception and pregnancy, really. And— collaborating with Darrell, and making sure that we were all on the same page, and I was able to take those decisions to my obstetrician, and she was able— and really just said like, here's what we've decided, you're welcome. You are not really even part of this conversation right now— not in a bad way, but in a way that, like— you know, this isn't— this isn't a threat to you or your

practice, or you don't have to worry about prescribing these meds, because— someone else is — is taking responsibility for that.

Julie: So, but you decided to stay on medicine?

Michelle: Oh— yes. Yes. Thank you for— yes. Yeah, so I stayed on Xyrem throughout the entirety of my pregnancy, and preconception. So at a slightly lower dose, but at a dose that was still therapeutic for me. And was able to manage my symptoms with naps, and between naps and Xyrem— and then I did want to add— on top of what Dr. Morse has talked about, in preparing for pregnancy, we also prepared for me to be working part time. And that is a privilege that I have that I know that a lot of people don't have. And was important, because I wouldn't have— I couldn't hold down a full time job, during pregnancy.

Julie: And Michelle, how did your preg— I know Emily said that the first one, she actually kind of— felt better than she— but, so— did your preg— did you feel like, you know— better, or?

Michelle: I felt really— I don't feel like my narcolepsy changed a lot during pregnancy. I felt like a superhuman after Hadley was born. Which we can talk about in a little bit. But I— I was, same— sort of sleep schedule, same sort of nap schedule— same cataplexy triggers. And, it was really not until Hadley was born that things really just changed, for the better. But— we'll see how long that lasts.

Julie: Ashley?

Ashley: Yes. Thank you for sharing, Michelle, and Emily. I really, um— have a lot of similarities with Emily's share, actually. This is actually my fourth pregnancy— my first pregnancy, unfortunately didn't make it. I had a miscarriage during class, of all things. Grad class. And I had to have a D&C, 'cause I was a little farther along in the pregnancy. And when I got pregnant with my son, I had intrauterine growth restriction, which doctor just mentioned, and— small for gestational age— had problems with my placenta— and the E2 was low, just all the things— so— being on any kind of medication was just like, out of the picture. But also similar to Michelle, with my first successful pregnancy, with my son I had just a burst of energy— I don't know where it came from, it just— took over and I was just able to manage taking care of him and having naps and to breastfeed, so. I had been off medication for so long, and my daughter came as a surprise and I was kind of thinking that, around that time that maybe I'll get back— on medication, because I was starting to get a little bit— out of whack, I have really bad cataplexy as well so I was really concerned about that, especially with driving, sometimes when it rained I would just— my mind would just go blank and I wouldn't even know where I was. And when I had my— when I found out I was pregnant with my daughter, I brought that up to my doctor about narcolepsy kind of, coming back a little bit— being a little bit stronger, they were really hesitant about putting me on any medication because of everything that had happened with my first pregnancy. Because I already had a lot of the really extreme side effects without even being on medication. So I did that, I ended up having a seizure with her, right after she was born. And other kind of small, eyebrow seizures, but— also they weren't really sure the cause of it, because as some of us know, cataplexy can kind of look like— a seizure sometimes. It can kind of, seem like someone's like, having a fit, but they could really just be having cataplectic episode.

Ashley: Still no rule on what happened there, but— it did kind of, take me back a little bit and she definitely slowed me down. Caused me to— only breastfeed for a year, I breastfed for 18 months with my son, 'cause I wasn't on any medication with her. I stuck it out for a year. I don't know if I'll be able to do that again, without any medication— it was quite difficult. Just napping in between, sleeping in the car with the recline, it was just— really difficult and— I was

really excited to get back on medication, um— again, when I was done breastfeeding her, after a year, I was like I'm— through with it, I'm done— but, after I got back on medication for some reason, I don't know— probably not because of the medication, my cataplexy just was really terrible and I had to stop working. It really affected my writing, my just— ability to— just be present and I was in my residency for counseling at that time, so it was really kind of a bummer for me. And I started doing other things, I'll talk later about my empower project, Hot Nerd Club. Then all the sudden, I was pregnant again! [laughing] After being on medication for so long, and— there were some concerns, because of the first pregnancy that— medication might not be the best route, but— or may have affected the baby, but— so far, so good. I'm still not on any medication right now 'cause they don't recommend it with everything that happened with me. But it's been really encouraging to hear about the stories from you all, about being on medication and I'm looking forward to hearing about breastfeeding with medication, and all of those things, so— that's been my journey so far. We're just waiting on, to see what happens with this one.

Julie: Katie, do you want to share about the adoption process and talking about narcolepsy? How did that go? [laughing] As usual, you know, interacting with any— [laughs] group of people that might not be familiar with narcolepsy is always interesting, so.

Katie: Yeah! So, first off, the adoption process for everyone is going to look different. My husband and I decided to do a local infant adoption, within the state of Missouri. Obviously you can adopt internationally. And then you can also adopt out of state, as well. So there's a lot of different agencies. You know, it's— you learn a lot, like now looking back at the whole process, like we really like the adoption agency that we worked with, and— like looking back, I feel like we made the right decision. Because, it took a long time, it took over two years— and the pandemic didn't help— move things along— because we started our process, to adopt, like we looked at agencies and then started filling out all of the paperwork in— I guess, in— it was like, [laughing] like, January of 2018. So, maybe 2019— I don't know. It took a long time, basically.

Katie: So with the agency that we worked with, you submit an application and then you do a home study, which— and I also didn't mention, there's also private adoption, which you still need to have a home study, and so that's like the big piece of the puzzle. And each state does it differently, but basically— a home study is something where a social worker will come into your home, and give you the green light, to say yes, you can. Like, this home should be a safe and stable home to bring a child into. And so, you give them— like, they do background checks, and— fingerprinting, and— you know, all sorts of different things. And— like you have to have a medical exam, by a primary care physician, and so— when I was filling out my paperwork I said I had narcolepsy, and— no one was that concerned about it, but they weren't familiar with it— and so, their question was, well are you going to be okay to parent? And this was the agency that I worked with, and so they just had me go— my sleep medicine doctor wrote a note, basically— and it was pretty short and sweet, like, [laughing] "You can parent with narcolepsy." And so we just submitted that, and that was fine. And then when it came down to, actually— so, we met our daughter's birth mother, and we didn't— that never came into the discussion. I don't remember in— you have to make a profile, like I might've— said that I have narcolepsy? But I didn't call it out. So— we didn't make a big deal about it. But um, yeah— it's definitely a big process, and— I mean it didn't, it didn't hold us back at all. It was just making sure that whatever paperwork I needed— and my sleep doctor was wonderful, but she was kind of like, what do you need? Like, 'cause she'd never had to do it before. So, now they have something on file. [laughing]

Julie: Yeah, and we'll have to connect people with you if they have questions.

Katie: [laughing] Yeah, exactly. Exactly.

Julie: Thank you Katie. Diana did you want to share about your pregnancy?

Katie: Sure. So, mine— you know, I came off of the medication. We got pregnant relatively quickly, within a couple months. And I stayed unmedicated throughout the pregnancy. I worked in surgery at the time, and— it gave me, I would say that, you know I was still able to do my job full time, however— after our morning cases, before afternoon clinic, I would sometimes go into my office, which just conveniently had an exam table, in my office, with a computer, so— I would go in there during lunch and— take a snoozer. And then I would come out for afternoon clinic and I would feel refreshed for a short period of time— and the surgeon I was working with at the time, he was very accommodating for that.

Katie: In the operating room, you know, it's— to me, it is a job where I— I don't have cataplexy, so— as far as the excessive daytime sleepiness, like when you are operating on someone, um — you just— I never had that where I had a sudden sleep attack, I think my adrenaline was just going too much, you know, knowing that that patient's, you know, life was in my hands, and, or — in our hands, and so I just kind of— got through it. But afterwards I really felt the effects of the— just, you know, done for the rest of the day [laughs] just so tired. I would say the one thing was, was brain fog, so like everybody has— they call pregnancy brain, right. Where everybody is kind of— [laughs] oh, I forget that— "Oh, it's pregnancy brain," but I had that, I feel like— to the tenth power, [laughs] or maybe twentieth power, if that's a thing? And um, you know— aside from that, I just, I slept a lot. On any opportunity I could get to sleep, I slept, during pregnancy. I was never asked, at all by my OB like, how's your narcolepsy doing? It was 'cause, you know they didn't have a choice, and so— you know, and— I guess the sleep specialist was just kind of like, okay well we'll see when you're ready to get back on medication, so— yeah, it was a little bit different than everybody else's, but, like I said I— I don't have the cataplexy, so I think that that is a little bit different.

Julie: Well said.

Julie: Let's move on to postpartum, and Emily we're going to have you kick it off with some of your amazing research!

Emily: I'd just like to share a little bit of how I became involved with the research, just 'cause it's funny how— paths come together, but, um— so, I studied chemistry for both my undergraduate and graduate degrees, so— as a chemist I was familiar with the pharmacology of sodium oxybate which was the main medication that I was taking, as advised, and I think— I don't want to like, put blame on my doctors— it will be great if doctors ask more questions, but — I do like, take responsibility for the decisions that we made, and said, "We want to minimize risk, we're going to try to cope without medications." And so I did stay off, during— breastfeeding for my first two children but, kind of always had this question because, I mean we who take Xyrem know it's not in the bloodstream for long. Like you wake up and you are awake. And, it was just unknown how that pattern was in the breastmilk. It's funny, I actually worked in a lab where we studied these small hydrocarbon molecules and I had a lab mate who worked on gamma hydroxy butyrate, which is— oxybate, so— I knew we had all the tools, but— I was raising a family, and engaged in grad school, and I'm like— I want to do this, eventually. So it was at my first patient conference that I attended with Narcolepsy Network, where there was a Jazz booth, and I approached them and said, "I'd really like to do this research," not knowing what they would say— and they connected me with one of their medical affairs people, who were at the conference and she was just like, glowing— she was like, "You want to do what?!" And so, she knew a clinician at Brown university, a Dr. Katie Sharkey, who had also expressed interest in a similar study. We were able to become connected which has ended up being, uh— led to more fruitful collaborations. And so I'm

going to share some of the research that we did, and our findings, for sodium oxybate excretion in breast milk.

Emily: So, specific for sodium oxybate, this is just an overview of how our study was designed and I don't want to slog through a lot of data, but, it's a small study. There's so little research in this area. It would be wonderful if future studies looked at larger populations. We had two participants and studied a total of three pregnancies. Both women had narcolepsy with cataplexy, diagnosed in young adulthood. We were able to test in both women, in all three of the pregnancies, one low dose and then a higher dose. So we're ranging anywhere from 2.25 grams twice a night to four and a half grams twice per night. And then we had women collect their milk every four hours following their dosing. We intentionally made our sample collection you know, when we imagined women would be breastfeeding, and we didn't anticipate that women would want to breastfeed from zero to four hours, while they're on their sodium oxybate, and— extremely sedated. And we quantified oxybate by a method called gas chromatography mass spectrometry. So this is how our dosing and collection went. S.O., sodium oxybate dose, so this is for— one woman, who basically did two consecutive nights, the first night was on three grams of sodium oxybate, second night was on four and a half grams. And so, we collected prior to her taking her first dose, and then collected at four hours after that, before she took her second dose. 'Cause we really wanted to see, like, what's the likelihood of exposure. Most women would wonder, can I breastfeed between doses? And then, following the second dose, we sampled every four hours, until that evening, when she took her higher dose. And then did the same thing for night two, and continued into the following morning.

Emily: So some of our overall findings, sodium oxybate is excreted in human milk. Increased sodium oxybate dose does result in increased concentrations in the milk. Sodium oxybate levels are elevated over baseline, in between night time doses, and four hours following the second dose— but those levels appear to return to baseline by six hours following the second dose of sodium oxybate. And so six hours was the earliest time point that we observed a return to baseline, and that was corroborated by findings of Busardò, who published a study in one additional patient and they— I'm not sure how they achieved this, but they were collecting milk like, every 30 minutes— and that, the pharmacokinetics in breastmilk was very similar to in blood, as far as the timeframe for— for being cleared from the breastmilk. And they observed return to baseline at five hours. So we never, we never captured a measurement that early— but with the studies together, it appears that, it's likely that sodium oxybate levels return to baseline, you know, anywhere from five, six, seven hours after that second dose.

Emily: And so what are the implications of this? How does this help somebody who's wanting to go back on sodium oxybate, and breastfeed their infant? Breastfeeding women receiving sodium oxybate therapy may be able to schedule their nursing to avoid potential GHB exposure to the infant through the milk. And so, if you're taking your second dose at 3 a.m., by eight or 9 a.m., that may be cleared from the milk. Like I said this is a small study and there are still some questions that remain, you know like— because your body's making milk all that time, would it be necessary for instance, to express that milk, and not use it— if you really wanted to avoid exposing the infant. And so those are some of the discussion points in our paper that maybe a woman would want to discard her morning milk and then resume breastfeeding at the next— at the next feeding. But all of these things can be a discussion with your physician and your OB, and I think it will be wonderful if there's more work within this area but our feeling was that, any data in an area where there's nothing— has got to be helpful. So, I mentioned Dr. Sharkey, who was wonderful to work with and then at Case Western Reserve, where I'm based, I had great support for doing the quantification of oxybate in milk.

Julie: That's so much information! So exciting. But Diana, before you head out, tell us a little bit about— you know, how your experience was, postpartum.

Diana: After Logan was born, I was breastfeeding, and, um— you know, it was— it was quite the battle, because at the time he was allergic to dairy, and we didn't know that he was allergic to dairy, and so— he was basically not sleeping. You know, 'cause I was breastfeeding him, I didn't know— the allergy at the time, he was spitting up a lot, not sleeping, fussing a lot. And I was not on medication, I was advised to continue to not take medication during lactation as well. So, one night I remember my husband and I switched off at night, and so it was my turn to kind of just, hold Logan in the living room and, and feed him— and then pump. And so, it was exhausting, it was like two or three in the morning, and— I remember just breastfeeding him sitting on the couch, holding him. And then my husband comes out, I guess, of the room— I don't know how much longer later, but he woke me up and Logan had kind of like, drifted out of my arm, and— his head was like, kind of off my arm, into the pillows of the couch. And thank god he was okay, but I just felt absolutely terrible. I thought how could I let my guard down like this? How could I do that? To a human. And, um— you know, it could've ended very, very badly and it didn't, and— you know, that— that kind of was a realization at that point, and I said this is it. I said, you know what, I said he's having trouble with feedings anyway— and, you know, he can get nutrition from formula— I just don't feel safe doing this anymore. And that was kind of the eye opener for me. He could've been smothered. And I just, I couldn't do it anymore. So I stopped breastfeeding, as a result. And got back on medication, so that I could — be awake, and— and be there for him. Obviously my symptoms of narcolepsy did improve once I got back on some medication, but it was a very scary experience.

Julie: Thank you for sharing that, Diana. I know it must be really tough to share that, but it's just so important 'cause that's the reality, I think. Of what so many people probably go through, right— so.

Diana: Yeah. And thats part of why I'm doing this— I don't want— I don't want anybody to have to feel that way, and have to go through that. So I think this, like, once again I hope that all of the pregnant women that have narcolepsy and even if they don't have narcolepsy, if they — they tune into this and, and just listen. I mean it's just so full of information. So, thank you— for letting me be involved in this, and I'm sorry that I have to hop off for another engagement.

Julie: Alright, thanks Diana.

Diana: Bye everybody, thank you.

Julie: Before we get to some of the support resources that are out there— can people share a little bit about their postpartum experience? Ashley?

Ashley: Sure. So, with postpartum with my son it was pretty— it was pretty good, I did have a scare kind of similar to Diana— one night where he kind of rolled off me into the bed in between my husband and I, but— we were able to catch it quickly and it kind of like, caught me. But that was really the only scare. I overproduced so like I— pumped, like 20 ounces every three hours. If people know what breastfeeding's like, it's like just— it's just a lot of milk. I ended up donating some of it because it was just so— so, so much. I did not have that with my daughter. And she refused to anything but breastmilk. She had acid reflux real bad and it was really the only thing she could keep down, so I had to exclusively pump with her as I had so many issues after— my seizure. And having another toddler while dealing with her, it was— it was quite challenging. I was really kind of happy and inspired when Emily shared about the study and how long medications last inside the breastmilk, because— I think that's really helpful to know. That would've been really useful with my daughter, who was a little bit harder

to breastfeed. I could go really long stretches during the day where I didn't have to pump or anything, and then just do it like— every six hours. With my son, because it was every three hours I would get engorged— I probably would have to modify that a little bit, but again that's — why we're here and all this great information. Hoping that my postpartum with this is kind of similar to Michelle and I get that burst of energy that I had with my son where things were just A-okay, that's what I'm— that's what I'm hoping for, I'm sending good vibes that way, and— hoping that it rubs off, but uh— yeah, that was pretty much it.

Michelle: I'm going to go ahead because I have two creatures who are quiet right now— Ashley, I'm sending you all of the hormones. I really hope that you have what I have, so— I was able to stop Xyrem immediately after Hadley was born. And breastfeed really easily, I was an overproducer like Ashley, and— which came with some challenges, and it was really nice to be able to not have to worry about Xyrem at all. There are three things that I want to tell you guys, that really helped us, during pregnancy and preparing for postpartum and I think that really set us up for success. The first thing is therapy— Darrell and I started couples counseling when we were eight months pregnant, with a counselor who specialized in postpartum and chronic illness. Now I understand that that combination might not be available to you, but it helped us to know that somebody else was on our team— and that when Darrell became sleep deprived, which he had never experienced before, we would have somebody who we could, you know, call on if we needed help with communication— I remember having a little bit of resentment towards him initially that, you know Hadley was only feeding from me, he would give a bottle, but— every now and then, but— you know, there were constant demands for me. We were able to talk that out really easily and move through it and come up with ways for him to support me. So that was the first thing.

Michelle: The second thing is having a lactation consultant who we knew about and we had met with before Hadley was born, and who helped us in our journey after she was born. And then the last thing is that we got rid of about 70% of the things in our house, before Hadley was born. And the reason for this is because— I'm responsible for most of the things in our house, and I knew that I was not going to have the time, energy or attention to really take care of those things after Hadley was born, and I wanted to prioritize time with her and with Darrell. And so if you follow me on Instagram you know that my house is immaculate, almost all the time, and the reason for that is because there is nothing in it. We have, Hadley has toys— she's not without— but, you know, all of her clothes can fit in one small basket from Target, all of her toys can fit in one small basket from Target. We're obviously going to experience growing pains as we, you know, get— as she gets older, as grandparents want to give her things but, starting from that baseline really helped us not have to worry about taking care of— everything— in addition to having to manage sleepiness.

Julie: Such important points. Anne Marie, I know you're going to have to possibly hop off soon — is there any last advice that you might want to share?

Dr. Morse: I think that one of the big take home pieces would be— you've heard from multiple women who have done this journey, and they've done it successfully— in both approaches, of through adoption as well as through having their own children and— and some of them successfully even with more than one. And so you can see that they're— in each of these journeys, they've been personalized— and they do describe areas where they— felt as though more knowledge would've been more power. So I do hope that you take some of the information and utilize that in your own journey. And— feel empowered and activated, in your own patient journey, to make sure that you are demanding the care that you feel you deserve— and although that sometimes sounds— unappealing, because it sounds like, you're being a mean patient— the reality is, is that you're the one who is experiencing this journey, and all of us, in the provider side— are here really to support you. And if we're not doing the right level of

care, or not answering the questions that you need answered, then— it is up to you, to be able to feel comfortable and confident to ask these questions. And so I'm very hopeful that this information has been helpful to people, whether it's you as a woman who's planning on getting pregnant, or as a partner— for your spouse, or significant other— because I do think all of the questions and a lot of the comments that have been made today, can only lead to— more successful steps forward. And then, the other piece that I would say is just, as a field— I would make the plea that, can we do better. Can we do better communicating, can we do better studying this. Can we be— do better, in empowering our patients to be able to have the lives that they— want. And I think that we still have a lot of steps forward, but I think if we're able to lock elbows, arm in arm, moving forward, I think those steps are going to be ones that we can get through more quickly.

Julie: Thank you, Dr. Morse! You're the best! [laughing] We're so grateful for you. And so, Katie, did you want to share at all about— what's it like, to— have a new one in your life, and— dealing with your narcolepsy and how that has been?

Katie: Yeah. So, we [laughing] so— Michelle spent nine months preparing, and actually Michelle and I had, like, talked before and Michelle like made a bunch of meals— I was very impressed— by her. But we didn't know when we were going to have a child come into our lives— and with the doctor in like a perfect scenario, I guess— you'd have three months notice. We had, like six hours notice. [laughing] We got a call on a Saturday morning and we went to the hospital that, like, afternoon. And met our baby, and— she was in the NICU for— um, a week. And that ended up being a blessing, because— she was a little baby, and so they wanted to make sure she was eating okay, and gaining weight. And it ended up being a blessing in disguise. And we learned so much in the NICU, so we were really grateful for that, and— then I could like, get some things ready, and really when you have a baby come into your house, you don't need that much for them— at least for an infant— you know, and my husband and I had been like, talking about this— and, for two years— but, until you actually know it's going to happen, it's really hard to prepare, I guess.

Katie: And so we had talked about it, my husbands awesome and we both work from home, and we're really lucky with that, and— so he got up at night and fed her because she was all formula fed, um— so he would get up in the middle of the night to feed her, and— I'm kind of a morning person, and so— he would feed in the middle of the night and I would feed her in the morning, and our schedules just— like kind of worked out, and I mean, he was sleep deprived for a little bit, but we're also really lucky because— I don't know, two and a half months in, she's basically slept through the night, every time. Like she sleeps 12 hours, so— [laughing] she's a good baby. Most of the time. [laughing] Yeah, so she's been sleeping through the night, so I mean— I definitely— get tired, and, 'cause I'm hanging out with her most of the time, during the day— and sometimes I'm like, oh— I am so tired, and I am— and I do have to have my husband, like— hey, you need to like hang out with her, 'cause I have to go take a nap. And — I feel like my cataplexy hasn't been— too terrible, but Emily, like you said, I definitely feel like, it could like change, too. Like my triggers— [laughing] down the road, definitely, um— could see how that could happen. So I mean— overall, it's been— I actually maybe would say it's been better than expected.

Julie: That's a good thing—

Katie: So I guess, in a sense, like just jumping into everything— like without overthinking it too much has been— good, so.

Julie: Yeah. Well let's hope that she stays a good sleeper.

Julie: So I think we should move to talk about some of the support resources that are out there, 'cause this is not the only thing that you can do. And I know we're getting late and I'm super sorry, but I knew this was going to be a long conversation, but it's an important one, so. Emily, do you want to share a little bit about the support group?

Emily: I will try not to be— longwinded, and all of this will be in the toolkit materials, but— if you like this format, of like, sharing— talking— asking questions about experiences, then you might be interested in this Pregnancy and Parenting with Narcolepsy online support group. So we run under Wake Up Narcolepsy, through a partnership with Heypeers. So you can find us at heypeers.com and subscribe to Wake Up Narcolepsy, where you'll find our meetings. We meet on Tuesdays, at 8 p.m., eastern time. However we're not meeting all of the time— we have, I co-facilitate with another wonderful young mother, and we take turns, and basically we'll meet for six weeks, and then we take a three week break, and then six weeks on and a three week break. And so we've been running for over three years, a lot of the women have been with us for a while. I feel like it's really a beautiful experience, Michelle can attest— she's been with us for a while. And there's always, you know, core people who are there frequently and I think it makes it a really welcoming environment for first timers who come often, but— I gain so much more than I give to this group, by attending from week to week.

Julie: Thank you so much Emily, for all that you've been doing— this kind of work is absolutely invaluable and so super important, so— I just can't thank you enough for— helping to lead this group. And we will definitely continue to be sharing about it. Here's some additional resources, as well. The Hypersomnia Foundation has incredible information about parenthood and pregnancy, along with also a whole section of their website about birth control, menstruation and menopause, so please check out the Hypersomnia foundation's resources. Emily you mentioned this Facebook group called Pregnant People with Narcolepsy and Mothers, so that's a great resource, and also you'd mentioned this NIH's LactMed, which helps to give information about drugs and medication and lactation.

Emily: Yeah, that's— Yeah, you just plug in your medication and it digests all of the research for you. So it could be a great resource to go through yourself, and take to your doctor, for whatever meds you're taking.

Julie: And of course your wonderful paper, about the levels— and so just a reminder, everybody, we have these great organizations— and in the U.S., and wonderful organizations around the world— and we will of course include that in the toolkit— but in closing today I just want to ask, those of you that are still with us— if you have one closing piece of advice, one thing that you would say to someone that is thinking about— taking your journey, either with pregnancy or with adoption and narcolepsy, what would be your one piece of advice?

Ashley: I would say, just to be kind and patient with yourself during the process, 'cause every pregnancy is just so different. And everyone experiences pregnancy in their own way. And I think we brushed the surface of mom guilt, but I feel like that just kind of, carries on with you from preconception to postpartum, to— teenage years, and— having this neurological condition that won't go away, doesn't make it easier so, try to take it easy on yourself and, accept help from others. I think thats a big one as well.

Michelle: I think what I would say is that, I hope that this Nerd Alert has given you hope, if you want to be a parent. And that if you're committed to becoming a parent there are a lot of ways to do it. And ways to do it, and take your health into consideration. And that there's an awesome community of people here, to support you— whatever your journey looks like.

Katie: And to kind of piggy back on what Michelle said, I just thought, if adoption sounds like a good path for your family, just explore it and go for it, don't be afraid. It can take time, so— just go for it.

Emily: Yeah, similar— I was going to say, it can be done! I think that was kind of why I became more involved, after we grew our family and went through a lot of the challenges and found ways to make it a little easier, and I would be in settings where I could tell there were many women who still had that as a big question mark. Like, can I really do this? Could we really grow our family? Reaching out, if you'd like, to get more support— you'll get a better feeling for the richness that can come! And how, with growing your family, and that there are strategies to make it feasible and even enjoyable. Even with the limitations of narcolepsy.

Julie: Thank you guys, so much! And thank you for giving so much of your time, especially— as parents, and moms— and thank you to everyone for tuning in, and we just can't wait to hear more stories and continue to connect on this topic, so. We'll see you again soon!

Access the toolkit for this episode here.

Narcolepsy Nerd Alert episodes are available in many formats to listen, watch or read.