

Project Sleep Narcolepsy Nerd Alert
Health Insurance 101 (Season 1, Episode 12)
Transcribed by Mirela Starlight

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Megan Donnell is a passionate advocate for those living with rare disorders, primarily children's growth and narcolepsy/idiopathic hypersomnia. She is the Division Consultant for Small for Gestational Age for the MAGIC Foundation and ICOSEP and has provided benefit education and advocacy webinars for MAGIC and Ascendis Pharmaceuticals. Megan holds a BA from The University of Richmond and an MBA from The University of Phoenix. With over 20 years of client service and account management experience, she works closely with clients as Vice President and Account Executive at Eastern Benefits Group. She lives on the South Shore of Massachusetts with her husband Jerry and has two children in college, one of whom is living with idiopathic hypersomnia.

In today's episode, Julie talks with an advocate and caretaker to someone with chronic illnesses who also has over 20 years of experience in the insurance field. The process of how to understand a health insurance policy and how to best navigate getting the services and medications one needs, including prior authorizations, pharmacy benefit managers, denial and appeals processes and more is discussed in depth.

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 "Health Insurance 101" (Season 1, Episode 12) 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've ever felt like navigating health insurance is a full time job, you're not alone. Today we speak to Megan Donnell, about health care coverage and resources. Megan Donnell is a passionate advocate for those living with rare disorders, and she also has over 20 years of professional experience working in the healthcare and insurance benefits industry. Meghan has two children in college, one of whom is living with idiopathic hypersomnia.

Julie: Welcome! We're so excited to have Megan Donnell here, and— just so grateful that she's willing to talk to us today on a topic that is— overwhelming, I think, for a lot of people. And can be rather scary, and filled with fear. So. I think one of the best ways to handle our fear about something is to become— educated, and empowered. And so we're just so grateful for Megan for sharing her expertise with us today. So, Megan do you want to take it away?

Megan: Sure. So, thank you for joining us. My name is Megan Donnell, I am a parent of a 19 year old who has several different diagnoses, which is why I work with the MAGIC foundation but, her most recent diagnosis was narcolepsy type 2, idiopathic hypersomnia. And she gave

me permission to share that information but— one of the things I do in my daily life, I work in employee benefits and health insurance— day in, day out— it's pretty much what I do all the time. I've done several presentations before, and thought it would be helpful, I'm hoping it will be helpful for you. To understand medical insurance a bit better, how to understand coverage, benefits, choosing a plan, you know, what happens when you get your famous denials, I'm sure many of you know what I'm talking about. And steps that might lead you to success, and then any resources. So, typically health insurance, in my world I work primarily with groups, so — group coverage, that's sponsored by an employer. Offered through your employer, you might actually be on a spouses employer plan— a domestic partner plan— that's not required, or mandatory, it's not always allowed, but that is a possibility for some people. And then maybe you're not working or you're not on a group plan, you prefer a private pay plan, which is direct with the insurance carrier. You might have coverage through the exchange, or The Marketplace. And that's, you know, under the ACA that The Marketplace was created— maybe you've purchased a plan through your state marketplace, the federal marketplace, maybe your plans subsidized or unsubsidized. And then, medicare and medicaid, we won't really address very much— medicare is typically age 65+, there are exceptions to that, of course. Younger individuals who have qualifying disabilities or conditions could qualify for medicare. Medicaid— and CHIP is just for kids— and medicaid is in each state, partially funded by the government, but then each state also governs that. So you do have varying levels of coverage and availability, based on where you live. And what your income and family size is.

Julie: Yeah, I think it's just important, to just note for everybody— it's not that medicare and medicaid aren't important, and— there could definitely be people in our audience that do have these insurance, but— Megan do you just want to explain quickly, you know, why we're going to focus a little bit more on the employer programs, today?

Megan: Of course. So, first of all, what I do is mostly group health insurance. I— know about medicare, medicaid— they really are very specialized, so— I'm not a specialist in those two areas. So we're going to focus on group health insurance, potentially which is— which is my area of expertise, but a lot of what we're going to talk about can be applied— to— the other plans, as well.

Megan: Okay, this is the most important thing when we think about— how do I know what my plan covers? So first of all, medical insurance, it feels scary. This is not my first industry— I came from a different industry. When my daughter was very young, I realized I wanted to help others, because I spent so much time working through her health insurance— and switched to that. So I've been in this world, this industry, for over 15 years. And understanding what's covered, can be very difficult and confusing. You might get a summary of benefits and coverage— these are pretty generic, they're produced by the insurance company, but everybody who has a group plan is probably familiar with these by now. They're very standardized, they're landscaped, they typically have blue and white stripes. It was set so that you could sit down and talk to somebody in another state and you could put your plans right next to each other and compare. But it's not all of your information. It provides information on maybe co-pays, deductibles, out of pocket max.

Megan: Good to know, but a lot of times people need a lot more specific information, such as — pharmacy coverage, or— when does a deductible apply? Etcetera. And, you could ask for a certificate of coverage, those are not typically provided, certificates can be— 150-200 pages long. Those are typically also able to be downloaded, if you have insurance through carrier, if you go in and open— a login for yourself, which I strongly recommend— you're typically able to pull it down that way. And then, the most important thing that I learned is, for certain procedures, and medications, there's something called a medical policy. It may be called something different, like a— coverage policy, or a pharmacy policy— depending. It's not

always the same name, even your prescriptions though, still might be called a medical policy— on x,y,z. You could look online, after you've logged in— so the system recognizes what plan you're on, and pulls the correct information. Call member services— you could try to— ask at work, for assistance.

Megan: And then one thing that's really important that is something that everybody asks, and — something I see a lot is, oh— I have Cigna. Does your— does your Cigna plan cover X? And people reply with all sorts of answers, and people get confused— it really truly is dependent upon your own specific plan. So, just because you have a certain carrier— and even if your plan name is the same as your neighbor, you could have two totally different plans. There's a lot that goes into the backend of health insurance, it has to do with what state you're in— what state mandates have to be covered, if the plan's self funded— and these are things that are very specific and hard to tell— so I always encourage people, don't ask somebody else, ask your insurance carrier or find the information, documentation— for your plan alone.

Megan: So how do I find out if a specific prescription or a procedure is covered? So, again, the insurance companies typically have those medical policies in place for a wide variety of situations or medications that need prior authorization. And— part of the education process today, and— it's unfortunate— I have been doing this for a long time, for a family member— and, obviously some of you are doing this for yourselves, you might be here for a child— it's— very difficult for me to tell you that you have to take on more responsibility. The best way to have success though, with your medical insurance coverage, is to— try to take ownership of it. And understanding a lot of this and hopefully the— today at least is the first step to help you understand. Some of you may be pros, but some of you may be new, helping you understand the wording. To help avoid problems.

Megan: So the medical policy typically is— could be two pages, 18 pages, the first medical policy I pulled, you know, 18 years ago, for something my daughter needed, was 18 pages— and had three pages of footnotes. So, that medical policy could be short or long, but it's going to describe— in which situations it will help provide coverage, and pay for certain procedures and or medications. And I always recommend, before your doctor applies for any prescription medication, you want to know the medical policy of your particular insurance company and plan. And when you read through that medical policy, I literally sat down with a highlighter, and — I still do this today— even though I'm in the industry— 'cause they're long and confusing. And I would highlight what was important. And you need to pay attention to what diagnoses are covered. And what is not. And also pay attention to what brands might be covered, or types of classes of medications could be covered. And for which condition. And which brands may not be covered at all. So for example, for my daughter— the MAGIC foundation which is referenced, she has a growth disorder— when you read a medical policy it might say, for this diagnoses, only this brand of medication is covered. But for this diagnoses, we cover three brands. So, having that information to share with your provider ahead of time is really important because— when you think about the providers offices, they're stretched very thin— and they could be dealing with— thousands, tens of thousands of medical plans, with all of their patients. And they really don't know everybody's plan individually. It's really helpful for providers if you give them the information and show them what was highlighted or talk to them before hand, so that they know, okay— I'm not going to apply for this, I'm going to try for this medication brand first, because this is what it says would be covered. And therefore you— you may be able to prevent a denial, by sharing that information with the provider.

Julie: Megan, so— when you are able to see the medical policy, is it usually that cut and dry? Like, that it's either covered or not covered?

Megan: No, thank you for asking. So, one thing that you see from medical policies, a lot of them are written in— staged— “We will cover x if this diagnosis happens, but also— this, this and this, or— two of the following.” So it’s not simply yes or no, and there’s one thing that’s really important, thank you for reminding me to bring this up— sometimes a medication may not be covered at all. You’ll go to look it up, and it says it’s simply not covered. And you and your provider know that you’ve tried all these alternatives, you can still ask for coverage for the medication, even though it states its not covered— as an exception basis. So, when you see a medication that is covered, but you need a prior authorization, that means— yes, we allow that medication if you meet our criteria and we approve it. If you don’t see it at all, there’s a slightly different process, but it’s very similar to a prior authorization and they may refer to it as a prior authorization— it’s sort of an exception prior authorization. So that is, don’t give up hope— if your providers willing to work with you. And it is a lot of, just so you’re aware, when— providers take the time to do the prior authorization, it can take them a significant amount of time to do so. So thats one thing where if you have all the information ahead of time you can help them out.

Megan: So something thats really important is how do you find the medical policy. Like finding Waldo sometimes, right? Trying to find the medical policy you need among all the documentation from the insurance company. The first thing I recommend is trying to search when you’re logged into your own account online, and go to the website for your insurance, log in as a member, use the search bar. Type in, “medical policy x,y,z” or— if it’s the brand name of a medication, or a class of a medication— try searching that way. You could try logging in, if you can’t find it when you’re logged in as yourself, log out— go to the insurance company’s main webpage— and sometimes they’ll have icons that says “member, provider, broker,” etcetera. Click provider, thats when I’m pretending to be a medical office— sometimes they lock those sites up. But other times they’ll put medical polices on there without you having to log in as a provider. So sometimes I’ll try the provider website. If I can’t do that I might call member services and ask for the medical policy to be provided to me. Could ask, if you have group insurance, you could ask human resources to help you get the policy. Especially if the plan is self funded, and you may not know if it’s self funded and I’ll just give a quick overview.

Megan: Fully insured plans are plans that are offered to the company from an insurance to a company or organization, from the insurance company and it’s purchased and they pay a fixed amount each month. A self funded plan is a little bit different— it looks, walks and talks like a regular insurance plan— they have providers, networks, etcetera— but the way that it’s structured with the funding, they can make changes and eliminate or add coverage. So, human resources may be able to best help you if you know your plan’s self funded and you can’t get access to it online. And sometimes you could do all these things, ask, and have difficulty obtaining this. I myself had to call for a medical policy recently and the member service rep was clearly very new, and had no idea what I was talking about, even though I explained it to her. So, expect sometimes that it’s like looking for a needle in a haystack, sometimes— sometimes it’s very easy, but once you find that policy, know the rules— and use them to your advantage.

Megan: So, common terminology, these are—three phrases that I think are very common, especially with prescription drugs. Prior authorization, step therapy and dispensing limitation. Prior authorization we’ve sort of covered, it requires the doctor or provider ordering a procedure or prescribing a medication. They need to show medical evidence and medical necessity why you need this particular medication, etcetera, etcetera. Usually prior authorizations are good for a year, I’ve seen some for less, for six months— I’ve also seen some for in perpetuity. You know, for 10 years. Be very cautious about reading— you typically get a written notification, when the prior authorization is approved— I actually put the end date in my calendar and then a reminder a month earlier, to remind my provider to start their

paperwork for the prior authorization, for myself, for my child. Step therapy requires that you might try a lower tier or a lower cost prescription drug before the higher cost brand is approved, and sometimes it's actually not a lower cost, but it's a preferred— because they might buy it in bulk, for example, an expensive medication, if they focus on one brand, sometimes like, they can negotiate— So it isn't always, but typically it's a lower tier, lower cost. Step therapy typically applies to things like— cholesterol meds, that's a very good example. And the new one which I'm not really fond of is, ADHD meds— those are very hard to titrate for kids, especially— dosing, and branching just happen frequently, and step therapy tries to have the provider pick from a group of medications on step one, before the member moves to step two.

Megan: So here's a tip for you— whenever you switch insurance companies, make sure that you are learning about these because one insurance company doesn't tell the other one, "Hey we approved this person for medication, for five years," and they don't follow the same policy and procedures. So it's important to remember that those don't transfer with you, and that the prior authorization and step therapy may apply to different medications for each insurance company. Dispensing limit's not common, but occasionally it happens, if the FDA— states that maybe something— has to be limited, for whatever reason— maybe eight doses in a month and a doctor provides 30 doses, the provider can still prescribe 30 but the insurance typically will only allow the dispensation of eight, until the provider does a prior authorization. A new prescription drug trend that has happened over the past few years, and— it applies, to— people— many of us look at those patient assistance programs— whether it's a co-pay assistance program, or a patient assistance program. In 2017, we started to see, in the industry — so, I work for a broker's office, and 2017 a lot of pharmacy benefit managers, PBM, they're called, that's the short name. They rolled out a new type of cost saving, co-share program called co-pay accumulators. And some states actually have legislation pending to make these programs illegal. So with those accumulator adjustments, patients can receive the same amount of money they were receiving before, from these programs— but the payments no longer were counting, towards the patients' deductibles and out of pocket maximums. So this was very confusing because the insurance company, not all of them keep pharmacy in house, so most of them work with these PBMS— pharmacy benefit administrators. CVS, Optim— there's so many of them out there— Express Scripts— and within the plan they can make their own prescription drug changes, each year. And even during the year. So this was one that was showing up and it was very— something that sort of, sprang out of nowhere, we were hearing about employees calling our office saying, why isn't this happening anymore? Why is— you know, I'm getting \$1000 a month for medication, how come it doesn't apply to my plan anymore? And— the reason is is they decided that they would stop doing that because it didn't actually meet the out of pocket definition, because it didn't come out of the employees pocket, to pay for the medication.

Megan: So one example is if if the prescription's \$1000 a month, and the first year of the plan, the first day of the plan you— you get a shipment, you want to use that patient assistance, that you get— of \$1000, great! You know— it simply in the past was applied over, and— nobody tracked where the \$1000 came from, only that the insurance company and the pharmacy benefit manager got paid the \$1000. Now they're saying it no longer counted because it didn't come directly out of your pocket. So this is something to be aware of, again some states do have legislation that's already passed, or pending— to make this illegal. But, it doesn't apply to self funded plans. If you're on a self funded plan, no matter what state you're in, they are not bound by those state or federal regulations, in many cases.

Megan: So the pharmacy benefit managers could also call them, just so you know, out of pocket protection program. True accumulation. Coupon adjustments. Benefit plan protection. So— we kind of covered how those work and which states, there's a list you can look at them,

because it does get update during the year. And the other thing that's new that we're actually utilizing at work, for one of our clients, is employers that are still funded could use their pharmacy benefit manager, and their insurance company, but then they can break out a piece of the program, and work with a company called Paydhealth. And I'm going to name the program because you might get a phone call, this might happen to you. So certain high cost medications that have any sort of coverage from a patient assistance program available, they get removed from the insurance plan coverage. So, let's just say my daughter's medication got removed—mhowever, she can get it covered, by Paydhealth providing her with case manager, helping her do all of the paperwork, we'd apply for the patient assistance program, and because she worked with Paydhealth, if there was not coverage, the insurance company and the self funded plan would then cover that medication. So I like to warn people because this is new— and we do have it work very successfully for the patients as well which is really great to see— one of my clients has done a full year, and over all the members who used to have to pay a high co-pay each month to get their medication, because they worked with Paydhealth, most of them got their medication covered for \$0 cost to the entire plan year. Which is great. But they did have to engage with Paydhealth, so I'm using that name because they were one of the first people to do it— they're the most popular, and if that happens to you— simply know they're not a scam, and do work with them, because if you don't— you might lose your coverage entirely.

Megan: How do you pick a plan? This is confusing. Before I got into this industry, I probably was going to pick whatever I had and didn't really think about it. Now I've learned that that's really— probably not my best option. Sometimes a deductible plan is better than a co-pay plan. You have to think about a couple different things. You want to think about what actually is the deductible, is the deductible capped per person, and per family. So for example, if you have more than one person enrolled in a family plan, how is the deductible going to apply to the individual family members and the family as a whole. It's important to know because it can be treated differently. Don't forget about your out of pocket max. You might have a co-pay program, with a really high out of pocket max. And you might have a deductible program with a very low out of pocket max. And you want to think about those things too. In comparison to also what you're paying, out of your paycheck, if this is a group insurance plan, versus what you're getting. And the other thing to think about too is, are you going to stay in network? Do you have out of network expenses? You know, do you need that PPO versus HMO? And that varies in different parts of the country, in Massachusetts, HMOs are very common and very typical, very uncommon for most people to pick a PPO. Because in our area we have access to a lot of specialists and most people typically would not find the need to utilize a PPO. But you may live in a location where you really do need the PPO. Versus a narrow or a limited network. So those are things to think about. And the other thing too is, at the end of each plan year, you can go on to your insurance company account, there should be a way for you to download a history of the whole year. So you actually know what your expenses were, and how many times you went to— a specialist, or a provider. And thinking ahead what services you're going to have in the future. Those are all things to think about when you— when you think about taking a plan. So just a quick overview again, think about the co-payments, the co-insurance, deductible, and out of pocket max, when you're making your decision.

Julie: When you make those kind of decisions as a very tired person, it seems pretty overwhelming and I guess I've always kind of had this thought, well I'll choose an expensive plan, because I'm assuming it's just going to kind of cover more. Is that generally— kind of true — or, no?

Megan: It's a really great question, thank you for asking. It is not always necessarily true. It might be, depending on the type of plan. For example, most companies— except for really large ones, are going to offer a single carrier. So most carriers want the company, they don't

want to split business with another carrier, they want the company to only offer plans, a plan or multiple plans, from them. So in most cases, unless it indicates that you're picking an HMO, the HMO network, for example at my job we have four plans to pick from— and it doesn't matter if I pick an HMO or a PPO— my in-network providers are exactly the same. My pharmacy benefits are exactly the same. But what varies is one plan is a PPO, so I would have the ability to go to any license provider out of network, and I may or may not need that, right. I might be okay with an HMO because— that's, I only need who's in the network, if my network is really large— I've got great doctors— they cover my medications— but those are things to think about, too is— as a tired person is sometimes, asking for help. Asking somebody to— go through this with you at work, often times we used to do open enrollment meetings in person— now I typically— very routinely, for all of my client companies, each year at open enrollment, I definitely do videos. So, I do a video just like I'm presenting now, and we provide it to the company and they share it with the employees and a lot of times people don't watch it. And I try to be very educational in these, so watching it— at home, in comfort— might be helpful for some people. You can start it, stop it, go back usually, and have somebody watch it with you to help you walk through this, is another good thing to do, potentially. And then human resources, may or may not at your company be very helpful. Every department's different, some people only have one person, some people have a whole bank of people— they may also be able to walk you through certain things.

Megan: So, now you've gone through all of this. You've looked up your medications, you're on your plan, you— your provider goes to write a prescription, and— you find out that it was denied. So, the thought process, or excuse me— the step process, is the following. The doctor generally initiates the coverage request with the insurance company. They can do a phone call or a fax. I am going to explain the difference to you because most doctors' offices it's not typically the provider who does this work. Usually it's somebody else in the office, not always, sometimes the providers do. But generally it's somebody in the office, and they're going to fax over— whatever the form is that they need to fill out, and any supporting documentation. I always recommend that if you know your provider is putting in for prior authorization, you're going to ask how they're going to contact the insurance company. You're going to ask if they're going to call it in, or fax it in. Fax is most common. What generally happens though is somebody will send over the fax to the insurance company, and the doctor forgot to reply, or the person filling out the paperwork— to question 14b part 2, they forgot to check a box— and it gets a denial. Or, they had to supply five pieces of information and they gave four. However the provider sends in the prior authorization, they get back. So, right, the doctors' offices get back a fax, stating there was a denial. People aren't generally checking the fax machine very quickly, or they might check it but drop it off and leave it, and it's a piece of paper on the providers desk, if they don't see it quickly— there is a timeframe, usually a day or two, and then they close it. It can be reopened, but that's why I recommend people, when this process is happening, understand how it's going to happen. The phone call is easiest because the provider literally picks up the phone, they call into the insurance company, and they may wait for a while, but they usually have a 10-15 minute conversation with the provider on the insurance company end, and in most cases— I tend to see that, that reach out— which is harder for the doctor— usually gets a better result, faster. If it is a fax, which is most common, again— your doctor would handle the second contact with the insurance company after the denial. The doctor would say, okay— I forgot this information, and here's some supporting information, and send more over. So they do that. And then if the doctors appeal is denied, you're typically going to get a notification in the mail, with instructions on how to file a second level appeal. Don't miss the deadline, absolutely not. Like, that's the biggest thing right there, is that's an automatic denial if you miss your deadline, typically.

Megan: Provide all the information they request, don't over-share if there's a way to— put that nicely, because sometimes if you include alternative diagnoses, and one of them's not covered

or— you know, there's a reason that gives them something else to look at and potentially deny on. So provide what they're asking for. Keep copies of all your information. Sometimes you can email the insurance company, when we with my current insurance company, and it doesn't help that I'm in a broker's office, nothing is different for me, I am just a person with the insurance like everybody else— my current insurance company, we are allowed to appeal via email and we actually get the person's name and their email at the insurance company. Or I could fax, or I could send it via paper. I tend to do both, two of the three, at least. I don't have a fax machine so I often will email, but also send a copy of the original documents and keep my own copies. Just because I think it's safer to do two things, just in case. One other thing you can do is request the summary plan document from your employer. This is not a common document, an SPD or an SPD Wrap, is what it's often called. Your employer might send out a link within every five years, saying, click this link— and it'll bring you to your SPD— most people have never looked at it or read it. But that is a— document that describes the legal process for the plan governance, and also includes information on appeals. That is if you have trouble doing the second level appeal at the insurance company. Also you can ask your employer if their insurance broker, which would be me— and this happens sometimes, probably a couple times a month— an HR person will say, hey— one of our employees is having trouble getting this covered, can you help cut some red tape? And what I can often do is, I can't get it approved, or get personal information, usually the person has to sign an authorization, but I can ask— what exactly is missing? What— you know, if the person's called into member services and doesn't understand the answer, or— doesn't get a clear answer, which is entirely possible— I might be able to get that clear answer, from my counterpart at the insurance company, and provide it back to them, so they can talk to their doctor. And again, brokers generally have no power at all. Except for trying to clarify the red tape, but definitely don't be afraid to ask for help. And then, there is a final appeal— after the internal appeals, that's typically external, and will be binding. In my state, you can pay \$25, I think, and file an external appeal with the state of Massachusetts, asking for a reversal of the denial. And I think this study came out— it was either last year or year and a half ago, showing that in our state in particular, there were about 60% of reversals. So you might get a denial, and when you go to that external appeal, you may actually get that overturned. So that's always a process to consider.

Julie: I feel like it's like, kind of frustrating— I mean it's just such a crazy process— and when you just think about, how— when you're— don't have treatment, to like, go through all this, just feels like— so, so frustrating, I guess. I just feel like I don't really have a question, but— I guess it's just good to know that if you keep with it, hopefully you will get a— approval, eventually.

Megan: Yes. And I absolutely— I'm trying to be factual, but I'm also an empathetic parent, like I've gone through this, so. For anybody watching this, I completely understand your frustration and I work in the industry and I— I switched into this industry because of my daughter, who now has— you know, has joined your group of people. As well as her other groups of people. Medically. It's frustrating as a parent, it's frustrating as an individual, you know, my daughter is fortunate, you know— because I do work in insurance and so I can certainly understand a lot with her and help her. Especially when she starts getting her own insurance, when she gets older. But a lot of people don't have that assistance, and— I'm not trying to frustrate anybody, and I can certainly— feel your frustration, I've gone through more prior authorization, denial, appeal procedures— than I care to count. And I just try to, when we created this, the goal— is to help people avoid this. Like pulling that medical policy up front, sometimes, really does make a difference. Because I work with probably a couple thousand families across the globe, and those that have— insurance here in the U.S., you know, I— I cringe sometimes, because they're like, my provider didn't know my policy, and they put the wrong diagnosis down, and now I'm declined forever— because they never cover that diagnoses— and if they'd just used the other diagnosis, which is— if a child has two, right— it would've been covered. Or, the

medicine's covered, but they put the wrong brand down, cause they only cover x brand, for this. So that medical policy, hopefully, can help you— get to a point where you avoid these denials and the frustration. But again, I sincerely empathize and I hope that it's educational, versus, I am telling you that you do have to put more on your plate, and that's also difficult for me, 'cause watching my daughter add stuff to her plate is hard.

Julie: Yes, it is— Thank you, thank you for— I just, it's just so much! [laughing]

Megan: It— it is! And, this industry changes every day, and the one thing I tell people that I didn't do yet that is really important, too, is— if you have a junk mail thrower-outer, in your family, and you view your insurance company as junk— prevent them, or yourself, from ever throwing anything out that you get in the mail from a pharm— you know, your pharmacy coverage. Because if you get a letter, it's most likely not a love note, you know, saying— hey, we love you, thanks for being a member. Typically it's— “hey, in three months we're no longer covering this medication, here are your options, have your provider contact us.” Or— it's a denial letter, or— it's happy news, you won your appeal and your prior authorization is good for a year. So, one thing I do that I had forgotten to mention is, open every single piece of mail you get from your insurance company. The other thing too is, I don't think I put it in here, is— you can ask, for a case manager, to help you as well, at the insurance company. And sometimes they're helpful, sometimes they're not. I've very politely asked to switch case managers before, from their manager, just saying— my personality just didn't work with them— I didn't put anything on them, I was very polite about it— just got somebody else. And sometimes they can help you understand it and walk through stuff as well. So that's important. If, outside of your insurance company, you get that denial— you could find it, in each state there are sometimes organizations that will help you at the state level— such as your attorney general, the division of insurance, these are different by state— legal counsel, you see cases where people have gone to the media, your state rep or senator— they have people, literally, that work in their office, who's job is to try and help constituents. And then medicare has a completely separate appeals process, if you are on medicare.

Megan: Steps to success— the basics are always be engaged, ask questions— if you have insurance at work, go to those open enrollment events and ask questions— you don't have to ask them in front of the group, you can hang back and ask afterwards. You don't certainly ever have to ask anything personal in front of a group situation. You could follow up with somebody afterwards, from the insurance company, or the broker's office, who ever presented. Always open every piece of mail. Never assume benefits are the same each year. Always check to see if your current prescriptions are going to continue to be covered the same way, even if you're told there's no changes. Insurance is really complicated. I have groups that go through no changes, so literally renewing what we call as-is, the plan carrier's the same, the plan design is the same, but the pharmacy and the backend, that PBM company— their plug in might be a little bit different. And that's not something even sometimes that we know, because we don't get notified— oh, there's 12 people on this plan that got letters stating that they need to change medications. So always ask if there are any pharmacy benefit changes, as well. If you're offered a case manager from the insurance company, accept. Some insurance companies, a diagnosis will trigger it— one of those ICD-10 codes that comes over to them, you're automatically picked, you know, to do that— and then sometimes you can call in and ask. So, if they don't work well for you, ask for a new one. If you're told you need to participate in a program, ask if it's mandatory— and ask if you choose not to, what's going to happen to you. Typically if there's a mandatory mail order, mandatory case management for asthma, or whatever it might be— so those are things, pay attention if you get those type of notifications or communications.

Megan: And we talked about knowing your coverage, before your doctor applies for certain services— share that medical policy with your provider, set yourself up for success the best you can— so that you can try and hopefully prevent denials later. And then, document, document, document. Always. Buy a notebook— I keep notes on paper, I know a lot of people use their phones, if you can figure out a way to successfully do so electronically, whatever works for you. Every time you speak to— insurance company, broker, you know somebody at work, document the day— the time— who you talked to, what they said— you know, “Oh yeah this is going to be covered, absolutely no problem,” and later on, it’s not— you can go back and say well, you know— Joe the rep that I spoke to on this date at this time, said it was going to be covered. You might be able to negotiate with them. Some companies will say nope, they made a mistake, they’re new, etcetera, but— and in other cases I’ve seen things get covered because they have a recording of that phone call, and they were told it would be covered.

Megan: Again, documentation and keep copies of all your appeal documents, and follow any deadline and appeal instructions. And one thing, if you ever get to the point of an appeal— where, you are doing the appeal, you may or may not want to share a personal note as well, besides the medical reasons you need to get coverage for something. The last medication we needed to get covered for my daughter, she wrote a letter. She was old enough, she was 17, turning 18— and she wrote a letter about how her life was affected by narcolepsy, idiopathic hypersomnia, and— what that meant, for four years of high school, that she slept on a couch. She couldn’t go out you know, on the weekend with friends, of course with COVID in here, too, but— you know, it affected her in so many ways. She wrote, this is what my life is like. “I live on a couch, asleep, 15 hours a day.” And that’s— that’s something that, I think, worked for our benefit— we did get the coverage. But when you go for personal notes, I just want to caution you, you want to be very medically factual, “This medication I need it because I failed on x,y,z, I had severe side effects,” blah blah blah— but personally, you know— this is happening, and “This medication that I need to get covered, is so different than any other and it helps me in that way.” You want to be careful of— try to, I’ve seen people— do this before, and sometimes it doesn’t work out well, is— “I want it so you have to give it to me. And that’s your job is to give me what I’m asking for.” I try to encourage people to use a different way of presenting that appeal. If you do include personal feelings in that. And that can be very important when expressed properly.

Megan: And then, additional resources, I’ve found that the Patient Advocate Foundation can be very good, they’re at patientadvocate.org, [Health Law Advocates](http://HealthLawAdvocates.com), they do have a guide— I think they recently updated it, this should be the most recent link, but if not you google health law advocates guide to an appeal, and their new link should come up. They do change it occasionally. And then again in each state you could have your state rep, senator, attorney general, or division of insurance to go to.

Julie: In the narcolepsy community, you know for some of the treatments, there are specific— patient assistance programs, set up through Jazz— [JazzCares](http://JazzCares.com), is the name of their program. And also [Wakix For You](http://WakixForYou.com), through Harmony Bio Sciences. So, you know often people will come to Project Sleep sort of with some questions, about their insurance issues, and— it is, as you’ve seen today, it’s such a complex thing, and— and— we’re not, really in the position to understand all of it, or— help individuals, and— usually the best resource is to call the specific patient assistance program. So just wanted to remind people about those.

Megan: A website I wanted to include for everybody, and this can be shared with— other family members, or friends, anybody you know who needs this— needymeds.org, popped up a couple of years ago— they consolidate a great number of links and resources on to one website. Education, webinars, how you can save on your medications, locate patient assistance programs, maybe you know people that have different diagnoses that have different

medications— needymeds.org is a great place for them to go as well, and utilize to help find assistance.

Julie: Always like to remind people about the patient organizations that are out there, and specifically [The Hypersomnia Foundation](#) has a wonderful section of their website, that deals with insurance and disability, so we wanted to make sure to highlight that resource, in particular. But of course, there are different organizations as well— [Narcolepsy Network](#), [Wake Up Narcolepsy](#), and around the world as well. Today we're addressing the situation in the U.S., and every country is very different as well.

Access the toolkit for this episode [here](#).

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