Sawbones 369: The Parasite Delusion

Published 25th May 2021

Listen here on themcelroy.family

Clint: Sawbones is a show about medical history, and nothing the hosts say should be taken as medical advice or opinion. It's for fun. Can't you just have fun for an hour and not try to diagnose your mystery boil? We think you've earned it. Just sit back, relax and enjoy a moment of distraction from that weird growth. You're worth it.

[theme music plays]

Justin: Hello everybody, and welcome to Sawbones: a marital tour of misguided medicine. I'm your cohost, Justin McElroy [whispers] and I feel great.

Sydnee: And I'm Sydnee McElroy.

Justin: Friday, right?

Sydnee: Yeah?

Justin: Woo!

Sydnee: Feeling good? You happy?

Justin: Feeling good, feeling Friday. Got that sun outside.

Sydnee: Yeah, this warm weather is— yes. It is—

Justin: Energized. Got my D, got my C, that's coffee.

Sydnee: I'm growing plants outside again.

Justin: Yeah! You said they're starting to perk up a little bit, too. You were a little frustrated.

Sydnee: I know, I was so worried. I was so worried my herbs were not responding well at the beginning of the season and I thought— there was the frost where I didn't get them in and they got snowed on and oh, I thought they were done for.

Justin: Yeah.

Sydnee: But they're growing again so all is well. They just had to chill? I don't know.

Justin: If you think it would be—

Sydnee: [laughs] I don't know anything about that.

Justin: You might be thinking, "Oh man, I'd love to hear Sydnee do a gardening podcast, I bet that would be so relaxing," let me simulate the experience for you.

[shouts] "They're never gonna grow! It's never growing! It's never gonna grow! I enjoyed this so much last year. It's never growing, they're all dead, I'm a failure." Every day.

And then eventually, they perk up.

Sydnee: They're growing very well and I'm happy.

Justin: They're growing really well. It's a much more relaxing episode that week.

Sydnee: Fire and ice.

Justin: Fire and ice. [laughs] Fire and ice.

Sydnee: [laughs] That's life with me.

Justin: What are we talking about this week, Syd?

Justin: Justin, kind of building off of last week's episode where we talked about the TikTok trend of eating papaya seeds to rid yourself of parasites that most likely aren't there, and also it's probably ineffective, we mentioned that there is this sort of, kind of com— I don't wanna say it's a common belief, but it is definitely something that you find out there in the internets. A fear that you have parasites, and a lot of people who are willing to build off that fear by selling you products related to that…

Justin: [crosstalk]

Sydnee: Or whatever. Or just knowledge, like, a lot of it isn't even "here's some pills," it's just "join our community and we'll tell you some weird stuff you can eat at home."

Justin: Yeah.

Sydnee: A lot of it built on the idea that doctors lie and there's conspiracy and all that kinda stuff.

Justin: Sure.

Sydnee: And we mentioned briefly delusional parasitosis, which is the fixed belief that you are infested with some sort of parasite, worm, bug, something, but it is not actually, physically there.

Justin: Which is like weirdly— I don't know, maybe I'm— I'm a layman, so I might have a skewed perspective of this because I'm just drawing on the experience of hearing you talk about, like, your studies, but it seems like of all the delusions one could have in the entire world, it seems, like, strangely common. You know what I mean? Like, it's like, specifically like, this is one which pops up a lot. Which considering it's a delusion is weird, right? Like, you wouldn't think that it would just be like, there'd be a common theme.

Sydnee: It is really interesting because you can see— and I should say, I have a little bit more experience with this than probably your average family doctor just because I did extra training in my career in tropical medicine and global health, and I've taken some extra courses in parasitology and that kind of thing.

So, when you do that sort of medicine, sometimes these patients who have this condition can find you, and I was found by multiple people who were hoping that with my credentials and expertise I might be able to find the parasite that they were convinced that they had.

So, I have cared for people with this, and I can attest to how, whatever your feelings are about if there is a parasite or not, it is a very difficult disorder for the person who has it. It's very challenging to treat if you're trying to help someone with it. It can really take over someone's life.

Justin: I can't imagine that sense of always being invaded, always being, you know, having something going on in your body against your will. That must be very troubling.

Sydnee: And it can be part of— this can be one feature of other psychiatric diagnoses. You know, you have an underlying psychiatric

conditions and part of that is this delusion, along with maybe some other delusions or hallucinations or things like that.

But what I really wanna focus on is what is also know as Ekbom's syndrome, which is just the isolated delusion that you are infested with parasites. Just that, that fixed— and by delusion, I mean a fixed belief that is not factual. So, it is not something that we could just talk you out of. It is very firmly implanted in your brain, this is something that is true. So, it is named for the Swedish neurologist Karl-Axel Ekbom, who actually, he is best known— which this is where you may have heard of Dr Ekbom—

Justin: Where I, a layman.

Sydnee: Where Justin may have heard of him. No, but he's best known for his description of restless leg syndrome.

Justin: Okay.

Sydnee: You've heard of that?

Justin: Sure, yeah, yeah, yeah.

Sydnee: Ekbom also is credited with being the primary physician to describe that condition and kind of the underlying, like, what it is. In fact, sometimes restless leg syndrome is called Willis-Ekbom syndrome, although I've ever heard anybody say that.

Justin: Okay. So not that common.

Sydnee: Yeah. But it can be known as that. If somebody says that, that's—

Justin: One might even wonder why you chose to relay that information. [laughs]

Sydnee: [laughs]

Justin: "You might it hear it called this. You won't, but you might."

Sydnee: Well, it's actually important to why…

Justin: Okay. [laughs]

Sydnee: It really does matter, I promise.

Justin: Okay.

Sydnee: I mean, kind of. Tangentially. It explains something.

Justin: Matters to Willis, I bet.

Sydnee: [laughs]

Justin: Whoever Willis is, I bet it matters to that cat.

Sydnee: [laughs] Um, it's interesting though, I was reading about this, and there aren't a lot of, I guess, eponyms in specifically in, um, psychiatry. And so, it's weird that this guy gets two. Ekbom got a couple of them. Not that restless leg syndrome is a psychiatric disorder, it's neurologic. But anyway, the point is, he got a couple eponyms.

However, *he* did not call it Ekbom's Syndrome, he was not that kinda guy. He called it dermato… zoen… wahn. Dermatozoenwahn. Which literally translates to "skin animal delusion", or delusional parasitosis would be the English that we would take from that.

Justin: Okay.

Sydnee: He didn't name it after himself, that came later. In this disorder, people are laboring under this fixed delusion that they have been infested with something. He dubbed, what he would call the pathognomonic feature— pathognomonic means like, the hallmark of something. If you see this, it is almost always indicative of this disorder, right? This symptom or sign. He said the pathognomonic feature is the quote, "matchbox sign". Do you have any guesses what the matchbox sign would be?

Justin: The sign that…

Sydnee: Why would he call it, what is it?

Justin: Ignites it? That strikes up against it and sets it aflame?

Sydnee: No. [laughs] He called the— the matchbox sign is when a patient brings you something to investigate, to look at closer.

Justin: Oh…

Sydnee: And back then, it would usually be carried in something like a matchbox, because they are usually tiny, like, flecks of things, particles, pieces. That name has changed over time because not a lot of people bring me matchboxes anymore.

Justin: Is it Ziploc now?

Sydnee: But at the time— yeah.

Justin: A Ziploc thing?

Sydnee: A Ziploc bag sign or a Tupperware sign.

Justin: I'm sure both of those brands are super stoked to be associated.

Sydnee: [laughs] But the idea is that it was very common for sufferers of this condition to collect bits of things from their body, put them in something like a matchbox and bring them to the doctor so that they could look at them under the microscope and see what this was that they had been infested with. Because— so, these patients all experienced a sensation of formication. For-mih-cation.

Justin: For-*mih*-cation.

Sydnee: That is the sensation that bugs are crawling under your skin. And so, it can be like an itching, a crawling, that whole sensation. You may have experienced it, most of us have for some reason at some time.

Justin: Yep.

Sydnee: And because they were experiencing that sensation, the patients would often damage their own skin through scratching, picking, trying to remove the insects. So, a lot of these patients would present with the sensation of bugs crawling, the fixed belief that they had some sort of parasite, and then also a lot of skin wounds from self-injury, basically trying to remove the parasites.

After his initial case series, so he— and I'm going to get into some of the things that he wrote about in is first publication, which he published in 1938 and everybody sort of became aware of this, that is when it got the name Ekbom Syndrome. But because restless leg syndrome was also connected to Ekbom, there was a lot of confusion. That is why that matters.

Justin: Okay

Sydnee: So, eventually they dropped Ekbom syndrome for delusional parasitosis and just called it delusional parasitosis.

Justin: Got it.

Sydnee: In Ekbom's work he talked about previous case reports of this phenomenon. So, there had been, prior to 1938, scattered writings from different doctors here and there about like, "Hey, I had a patient, they had this thing, here's what I did." That kind of thing.

But it had not been united cohesively under one condition described. And that's what you do, like, especially back then when we were still trying to understand all these different diagnoses, you would need some sort of like, paper, like landmark paper that would take the time to collect all of the available information about that condition and unite it under one sort of theory. Does that make sense?

Justin: Mm-hmm.

Sydnee: And that's what he's doing in this case series that he published. The thought had been, up to that point in these isolated cases, that it was a psychiatric condition. That there was nothing actually happening physically in the patients' skin. It was, you know, something with the brain. One doctor claimed to have treated it successfully with just psychiat— like, psychoanalysis. You could talk the patient out of it.

Justin: Talk them out of it?

Sydnee: Yeah. A couple other doctors had claimed that opium fixed it.

Justin: As it does most things.

Sydnee: [laughs] Ekbom decided that he was going to— he worked first in a neurology clinic and then later in a psychiatric hospital, and so he saw patients with this and he decided to kind of form his own opinion based on cases he was personally caring for. In all of the cases he talks about in the paper, which I read, it's available online if you're interested to read his original work, in each case there are some things that are all in common, okay?

Everybody thinks that somehow a bug got to them and invaded them. A bug, a worm, a parasite, something. It either came from another person, there was one case of like, they had warders in their house and someone had stayed in their house that they thought was sick and then they found something in the sheets later and they thought, ”Okay, that’s how it got in me.”

They had to sleep in an unclean apartment, there was one that they thought their apartment was very damp and that was why they got it. Or they held some object that turned out to be infested.

Sometimes people would say they were outside and brushed against something, felt the immediate stinging sensation and bam, there you go. Everybody had sort of like a very fixed story as to when and how.

Justin: Traumatic usually, or just sort of… benign?

Sydnee: Mm-mm. Usually just benign, everyday, kind of happened. And then they, you know, obviously believe that they had been invaded at that point. It would start with that sort of sensation and then build into the finding of the parasite, finding of the bug. So, first you have the sensation and then you start finding them.

Either you’re seeing worms, you’re seeing small bugs, sometimes they would be described as like, little white globular kind of things, sometimes they were black or brown or crusty, sometimes literally big, round worms I saw come out of me, whether it be in my stool or I coughed them up or vomited them up or I dug them out of my skin. All of these things.

Many patients insisted this was a brand new organism. Science didn’t know about it, doctors didn’t know about it, that’s why they were having so much trouble getting somebody to figure it out is because they had discovered something that no one ever had before. That was pretty common. All of them had some sort of itching or discomfort, right?

Justin: We had much less refined tools back then for looking for this kinda stuff too, so it makes more sense that something could escape our perception.

Sydnee: Yes. And it was in, you know, we’re still sort of constantly making these discoveries at this point.

Justin: Sure.

Sydnee: So, um, so it fit with that. And then they had all taken measures to remove these parasites somehow. Either by, well, one patient burned her skin with matches.

Justin: Ugh!

Sydnee: To kill them and remove them. Others would just scratch with their fingers or like a kitchen spoon, some sort of object. Apply caustic substances to their skin, like a lot of them would put bleach or something like that to try to kill them. They all suffered from wounds related to their treatments, and all were completely, completely convinced of this. There was no talking the patients that he saw out of this delusion.

Now, what's interesting is unlike his predecessors, who felt that this was purely a psychiatric condition, he sort of was of the opinion that while it is not a parasite, he did not feel in any way, he never was able to find any sort of parasite on them through any of his, you know, he would look under a microscope at all the things they would bring in and nothing was ever a parasite, but he did feel that there was some sort of sensation that they were truly experiencing. That whatever it is, itching, crawling, burning sensation, was absolutely real and they were misinterpreting it.

Justin: So not completely neurological, or psychiatric.

Sydnee: Yes, not completely psychiatric. Now, he did say though, that what is interesting— what he said is, you know, if you did have itching that you couldn't control, most people probably would not believe it to be an infestation of a parasite, or if they did think they had a parasite, if they went to doctor, the doctor checked them out and did these tests and all this and then said, "No, it's not a parasite," he felt that most patients would say, "Okay, I accept that as the truth,"

So, there is something different about these patients who are convinced despite medical evidence to the contrary, right?

Justin: Gotcha, right.

Sydnee: That is different.

Justin: They're willing to hold onto that belief despite all evidence to the contrary.

Sydnee: Yes. But he says at the end of his paper, treatment is still kind of a mystery. He found that opium was not routinely helpful. He tried things like bromide and phenobarbital, which he didn't feel helped much. One patient said that opium, by the way, made the bugs calmer. So the sensations were less because it chilled them out. [laughs] But they were still there.

Topical, like, itch relief creams basically were somewhat helpful for the symptoms to patients, but it didn't do anything for the belief that they had a parasite. One patient was helped by moving to a new apartment, because they felt like it was not infested. So, that helped them a great deal.

And over the years since this description, the disease, despite Ekbom's sort of assertion that "I do think there is something maybe that we don't know about in their skin that's causing itching, or in their brain or their nerves or something that's causing itching," um, along with the psychiatric, you know, component, it was largely seen as a psychiatric condition. There are other causes for the sensation of itching, but basically this fixed belief is psychiatric in nature.

There are some cases that we would eventually discover were associated with like, amphetamine use. This is a common side-effect of people who use methamphetamines, especially if you're abusing methamphetamines, I should say.

Justin: I feel like that's something you see depicted in pop culture a lot, like, somebody who is afflicted like that scratching themselves and trying to claw at themselves.

Sydnee: Yes. Well, and it is that sensation. So, they experience that sensation and so they can scratch or pick at their skin because of that sensation, trying to relieve it, and they may develop a belief as well that they have some sort of parasite in their skin.

And I have seen that too, although it is not necessarily as fixed, because in a lot of those patients, if they stop using methamphetamines, eventually that will go away. The sensation goes away, the belief goes away. So, it's sort of a different thing.

I wanna talk about, though, in 2002 when a new wrinkle is introduced to this whole idea.

Justin: Alrighty. I could use a break, because I have become extremely itchy by listening to you. [laughs]

Sydnee: [laughs] That is a side-effect. But before we do that, let's go to the billing department.

Justin: Let's go!

[ad break]

Justin: Now Syd, you said you discovered a new wrinkle in this, in this particular mystery.

Sydnee: Well, *I* didn't discover a new wrinkle. Something else happened. [laughs]

Justin: Okay.

Sydnee: In 2002, this— I mean, cause this— like, at this point this is something that we know happens, we know, as I'll get into, is incredibly difficult for the patient who's experiencing it, and is a very challenging disorder to try and help someone treat or cure, overcome.

In 2002, a woman named Mary Leitao became convinced that her young son had a new, unknown, undescribed medical condition. He had some sores around his mouth and she found what she thought was some sort of multi-colored thread-like object in them. Hair-like, thread-like, something like that. And she took him to the doctor, the doctor couldn't find anything in particular wrong, so she took him to more doctors.

He saw lots of doctors. Specialists, dermatologists, infectious disease specialists. And basically she became convinced that there was some sort of condition that involved these hair-like particles causing sores in the skin of her son, and then her theory was probably other people, that was new to science, had never been found before and the doctors were either just not listening or involved in some sort of conspiracy as to why they weren't recognizing it.

Justin: Mm… this is a good start, Syd. A lot of bad stuff starts this way.

Sydnee: She examined the fibers herself under a microscope, like a toy microscope they had at the house, and she felt like these are new to science, these are something that nobody's ever seen before.

The doctors that her son were seeing eventually would diagnose Munchhausen's by Proxy, believing that there was no actual— or at least *this* was not the medical condition that her son was experiencing, and that she was seeing symptoms that weren't there, believing things or creating things, something was happening in order for this. But there was not a medical condition. The primary problem was a psychiatric condition on the part of her.

She of course disagreed with this. She decided that if the doctors wouldn't listen to her, she was going to have sort of build a community to agree with her and to fight for this cause. So, first you have to name it, right? You've discovered a new disease. You feel that it is up to you to bring it to public awareness. So, she called it Morgellons. Have you heard of Morgellons?

Justin: No, never.

Sydnee: I heard of Morgellons originally from someone I saw who was convinced they had it, and their— that introduced me to the world of the internet, where it exists and the papers, if you can use that word, that have been published about it.

The word Morgellons, the name for the condition, the root of that is really interesting, where this comes from. Where did she find this name? Why? It's a reference to a document called "A letter to a friend upon occasion of the death of his intimate friend". It was written in 1656, so a really long time ago.

Justin: Really long.

Sydnee: By Sir Thomas Brown, who was a philosopher and a physician. And he's writing a letter to his friend, because his friend's friend just died of tuberculosis, right? And he sends him this very lengthy— you can read it, it's all available— he sends him this very lengthy letter where he sort of, first of all, he's describing the death by tuberculosis, and it's been sort of debated, is he actually describing the death of the young man or he is just describing like, what we know so far, what tuberculosis is like, kind of from the perspective of a physician.

Either way, he talks about that case, and then he sort of muses about different medical conditions and kind of where we are in that knowledge, and then just like, generally about the human condition. It becomes this

sort of expansive, thoughtful, you know, letter where he's really just sort of talking about life and humanity. And he gives advice towards the end about living a good life and making the most of your life and that kind of thing.

So, it's this long, expansive, thoughtful, personal document that he didn't publish at the time, by the way. It would be found and published after his death, later. So, it wasn't really even something that he was trying to like —

Justin: Get the word out about?

Sydnee: Get the word out about. But in this letter, he talks about an odd condition that is isolated to this one French province where children— and I mean, it's literally two sentences— children develop hairs on their backs and then they get convulsions and coughs. And he named it Morgellons. It's, I mean, literally, you can find it, it's like two sentences. And based on that, she named this condition Morgellons.

Justin: Great. Great. Great.

Sydnee: Thinking that this may be connected in some way.

Justin: Sure, perfect, yeah.

Sydnee: As you may already guess, nobody believes this is connected to whatever Sir Thomas Brown was writing about in 1656. There is no— I mean, not even proponents of Morgellons, people who believe that Morgellons is an actual parasitic disease, *they* don't believe that is the same thing, whatever the heck Thomas Brown was talking about. But that is where this name comes from, that is why it is called Morgellons, that is the strange history of the name.

She formed a foundation for this to raise awareness, to raise money, to get research into this condition. A lot of internet groups spun off from this. As soon as this was sort of put out there, a lot of people found her and said, "I have it too," or "my child has it," or my friend has it or my neighbor has it. Obviously not isolated to children, lots of different, you know, all over the globe, lots of different ages…

Justin: [sings] Tale as old as time…

Sydnee: Found this and joined her in her quest to get more research done.

Justin: Hmm.

Sydnee: Enough lobbying was one that Congress asked the CDC to form a team and investigate.

Justin: This real thing.

Sydnee: Morgellons.

Justin: [sighs] Yeah.

Sydnee: And they did. They did. They put together a large, multi-disciplinary team to take samples from these patients, analyze them, take their histories, take their stories and try to figure out, is this really a medical condition that for whatever reason doctors have decided to ignore, neglect, conspire against? Or is this maybe not and it's actually a collection of different symptoms, disorders, whatever that maybe are difficult to diagnose or for whatever reason people haven't figured out yet, and then we're just sort of collecting under this, like a basket that we're just tossing them all in even though they have nothing to do with each other.

Justin: Yeah.

Sydnee: The report was published in 2012 and basically it found no evidence of any sort of new organisms, any sort of parasitic infestation, infection, anything like that.

Justin: Big zilcho.

Sydnee: Nothing. They analyzed fibers from over 100 different patients and most of them were just cotton. Like, from clothes and things like that. There are— it's the things you would imagine would leave fibers on your skin.

Justin: And that study put an end to it, and that's why everybody deleted their Facebook groups and moved on with their lives.

Sydnee: No. [laughs] That's not the end of the story. I will say that the — I think that the foundation is not in operation currently. There was that

movie that came out within the last— remember we almost watched it? Under Their Skin, Under Our Skin…

Justin: Oh yeah. Oh God.

Sydnee: It's a documentary that talks about this. Anyway, there is still an active community that believes in this, even though the report from the CDC was pretty definitive that this is not… Morgellons is not a unique parasitic infection but another— a specific form of delusional parasitosis.

Especially, the differentiating factor between Morgellons and the general term delusional parasitosis, people who have Morgellons believe that these fibers are inanimate objects that are in them somehow. I mean, in terms of like, where people think they come from, you get wildly different explanations. For some people, it is aliens. For some people it is some sort of parasite, it could be a conspiracy—

Justin: You led with aliens.

Sydnee: —theories, like the government. Chemicals. 5G. Radiation. I mean, all these kinds of things.

Justin: Hey, if it's 5G, that's wild if it popped up in 2002. I'm gonna go ahead and put the 5G thing to bed right now. Reading the headlines, it does look like aliens are a thing that's happening right now, so maybe the aliens?

Sydnee: I've heard people say things like nanoparticles that are implanted from things like insects that the government have deployed. Drones. I mean, you get lots of from the very mundane, sort of like, "I think that there is a worm in my skin," to much larger conspiracy theory-based— I mean, it really depends on who you're talking to. You get a wider array of explanations from the patients themselves.

Justin: But that's the fun of make-pretend is that there's no bound— there don't have to be any boundaries on it, because the only limit is your imagination.

Sydnee: Well, but I think— I think this is one of those times, though, where you really have to remember where the— the damage has been done not by these people, who I think a lot of them, unfortunately, have an undiagnosed, untreated psychiatric condition in the sense that they have delusional parasitosis, and instead of seeking care from a

psychiatrist, because of the delusion, they're not gonna go to a psychiatrist or somebody who can help them with behavioral health.

They're gonna go to a dermatologist or an infectious disease specialist or a parasitologist or somebody like that, and then unfortunately what they'll eventually find is one of these… charlatans, who will feed into that delusion and claim that they also believe it, whether they do or not.

Maybe they do, maybe they don't. But will sell them things and give them things and have them come back from appointments and pay them to treat them for something.

I mean, that is unfortunately— it's the same thing we've talked about with chronic Lyme disease and— which is not an actual condition, there is post-Lyme disease treatment syndrome, but there is not a chronic form of Lyme disease, but there are these quote-unquote "Lyme literate physicians"…

Justin: Ugh.

Sydnee: Who will—

Justin: Ugh!

Sydnee: Who will endorse that as real, even though it's not, and will treat you with antibiotics for years, even though that is completely not evidence-based and will not help you in any way and may harm you.

You'll find the same thing with Morgellons and other delusional parasitosis-type flavors of it, so to speak. But people who suffer from this, it's very similar to these early cases from Ekbom. They believe that this organism is new, they believe that, you know, nobody is gonna be able to tell them about it because…

Justin: It's new.

Sydnee: It's new, and—

Justin: Can you address how you, like, keep a therapeutic relationship with a patient like this, where you cannot grant them the thing that you would need as a basis of trust, which would be "This is real, we're working on it together." Like, how do you treat someone while not acknowledge— or not validating what they think is their chief complaint?

Sydnee: The— okay, so the recommendations on how to treat this I have found in my practice are not, um, very successful. And I don't know, I used to think it was just me, maybe I'm very bad at this, but I had other physicians that I worked with who had way more years of experience in this area and had as little success as I did, so maybe it's just that difficult. Or maybe I'm bad at it, I don't know.

But the recommendations are that you— I mean, you can't agree. Like, that is not the way, for something like this, to agree that there is a parasite there that you know factually isn't.

And I mean, don't get me wrong. I always take the time to— first of all, there are lots of other things that can cause the sensation of bugs crawling in your skin, formication or itching. So, investigate all those things. There are a lot of lab tests and diagnostic studies that you may need to do in addition to a very detailed history and physical examination.

I did take the time to look at things under the microscope. I don't think there's anything wrong with that. Like, I will take the time. You took the time to put this in a Tupperware and bring it to me. I will look at it for you. Because then I am able to confidently walk in the room and say, "This is a piece of cotton." Or "This is a scab. This is just a scab that you've picked off of you, it is not a bug." And I can feel very confident saying those things.

There are some recommendations that you should, you could treat with some sort of antiparasitic. I never did that because I feel like that violates informed consent. I don't believe you have a parasite, so why am I giving you a drug that I don't think you need? I have a lot of problems with that, so I could not—

Justin: It's like magic feather territory, right?

Sydnee: Yes. So, that is not something that I feel comfortable with. I do think that treatments for the skin and itching are totally fine because you are experiencing those sensations, so like, here are some medicines for the itching, treat the wounds, make sure there's no infections. There are often skin infections on top of that, so treat those, talk about proper wound care, talk about the importance of, you know, if you're having these sensations, you're still digging at your skin and scratching at your skin or putting bleach on your skin, please stop those things, and talking about those dangers.

So like, helping to stop the self-harm behaviors in that way, that was an area I focused a lot on. And then the other thing that they recommend is to just continue to insist, you know, I really think an antipsychotic medication would help you with these symptoms.

And hopefully, eventually, patients will agree to take one. And there have been case reports that suggest that if a patient will start routinely taking one of those medications that address psychosis, including delusions and hallucinations, that there is success there in some patients. I haven't found widespread numbers that everybody gets better, but like, there is some success there.

And I think it's a multi-disciplinary approach. You need a doctor that you know and trust to work with, if you need to work in conjunction with a psychiatrist or a psychologist, a counselor, somebody like that and the dermatologist who they first go to, or for me it's the family doctor they first go to or the infectious disease specialist they first go to. Working together in sort of a multi-disciplinary team could be really helpful.

Because then you're not just— because the hardest thing is a lot of these patients just get passed on from person to person, like, "No, it's not that. Leave."

Like, you know? "Your derm condition is that you're picking at your skin. Stop it. Go home." You have to engage with, this is difficult, this is gonna require a lot more help.

"I need to gain your trust that I am trying to help you, and maybe the help doesn't look like how you think it should look, but I promise you if we work together we can together come up with a plan."

Without ever, like— I mean, I would never endorse just going along with the delusion, I think that's wrong. I mean, you're lying. You shouldn't lie.

Justin: You don't have to sound so accusatory. I wasn't suggesting that you do that.

Sydnee: No, but it's tough. It's a tough— it's incredibly tough and every time I think, like, "oh it's so tough to treat," it is exponentially harder for the person who's suffering from it. And so, that's why like— and of course, I should mention, it has been tied over time to chronic Lyme and tick-borne illness. There are a lot of doctors—

Justin: It's all connected.

Sydnee: Not a lot of doctors. There are people in this area— some of them are doctors, some of them are just advocates— who insist it's all connected.

Justin: It's all connected. I have a chart. Look over here at my cork board.

Sydnee: [laughs]

Justin: You see? It's all connected.

Sydnee: And these are the people that make me mad. Not the patients. The patients are suffering. Nobody would choose this. Nobody would choose to believe they are infected with a parasite that no one can see or treat or cure, and they're constantly damaging their skin in an attempt to remove it. Nobody would ever choose that, right?

Justin: Right.

Sydnee: I get mad at the people who see that suffering and see the opportunity to make a buck. Or to make a name for themselves. Those are the people I get mad at, not the patients. The patients are suffering.

Justin: Yes.

Sydnee: And maybe, you know, I think that there is at least this to be said. There is no parasite here. There is no Morgellons organism. There is not magical hair-like thing that's causing this, there is no thread worm thing that's causing this. There's none of these worms that people think. None of that is true in these cases. No.

But they might be itchy! Maybe Ekbom was right, maybe they are itchy and we just need to work a little harder to figure that piece of it out, too. Obviously, there is a psychiatric component for many of these patients, but there's also people who are itchy.

Justin: Some people— guys, some people are itchy. I don't know how else to say it.

Sydnee: Do you know why the itch sensation exists? Why do we feel itchy?

Justin: Isn't it to get rid of dead skin cells?

Sydnee: It's to tell us if there's a bug on us.

Justin: Oh yeah. Makes sense, that's a better answer than mine, in context.

Sydnee: So, we evolved to recognize that when we get sensation, formication or itch or whatever, when we get that sensation our animal brain says, "Bug!"

Justin: "Bug! Get it!"

Sydnee: "Get it!" So isn't it normal that people would have that sensation and think, "Bug! Get it!"

Justin: Yeah.

Sydnee: Now, obviously there's a problem when despite all evidence, you continue…

Justin: [laughs] "Trust me! Bug!"

Sydnee: … to believe, bug. But like, that all fits. So, it's hard. It's hard, but you can't just write people off because they're difficult. You just gotta work harder and work with them. But you can still throw as many verbal, not literal, but verbal rocks as you want at the people who will take advantage of those who are suffering and desperate and feel tossed aside.

Justin: You know who I never hope feel tossed aside?

Sydnee: Who?

Justin: Our listeners.

Sydnee: Oh, me too.

Justin: Who were so supportive of us during the Maximum Fun Drive, and we so appreciate them. And we really appreciate you for listening. It's awful swell of you.

Sydnee: Thank you.

Justin: I think we're gonna take next week off, but we will be back with you in two weeks after that, and I'm excited about it for one— oh! Thanks to The Taxpayers for the use of their song "Medicines" as the intro and outro of our program. And thanks to you for listening. We sure appreciate it.

Sydnee: Thank you.

Justin: And until next time, my name is Justin McElroy.

Sydnee: I'm Sydnee McElroy.

Justin: And as always, don't drill a hole in your head.

[theme music plays]