The Strange Skin Disease No One Talks About (But Should) Transcript

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Introduction to Morgellons and the guest expert

And I remember early on, I get so much criticism from doctors, and I'd say, well, what do you think we should be doing for these people? And they would say, just let them wait till we find a cure.

That could be decades. So you're just basically saying, so sorry, you're absolutely miserable. Y'all are committing suicide in huge numbers. I just found out yesterday, one more of my patients committed suicide.

It's 54 years old. I'm not a psychiatrist. Psychiatrists may be used to this. I've seen too many suicides. And these are some very, very miserable people.

And when you add insult to injury of nobody believing them, their family deserting them, their friends deserting them, people diagnosing them as crazy, oh my God.

They lose their jobs. They lose everything. There's no wonder there's a high suicide rate for these people. This is Doctor Talks. Welcome back to Lime Bites, rebuilding immunity, reversing inflammation, and redefining recovery.

Today, we're diving into one of the most misunderstood and controversial conditions in medicine, Morgellons disease. Often dismissed as delusional or psychogenic, Morgellons is now being recognized by a growing number of clinicians as a physiological manifestation of chronic infections, including vector-borne diseases like Borrelia, Bartonella, and Babesia.

Our guest today, Dr. Ginger Savely, is one of the world's foremost experts on Morgellons and a leading clinician in the treatment of complex chronic vector-borne infections.

Based in Washington DC, Dr. Safely has dedicated over two decades to the care of patients suffering from Lyme disease, Morgellons, and other stealth infections.

She's the author of Morgellons, The Legitimization of a Disease, which is a groundbreaking book that brought scientific credibility and compassion to a condition long dismissed by mainstream medicine.

Her pioneering work has been instrumental in demonstrating that Morgellons is not psychiatric, but rather an infectious multi-system illness associated with immune dysregulation.

Today, we'll explore what Morgellons truly is, what's happening at the cellular and immunological level, and how it can be effectively treated. We'll also talk about the emotional and psychological impacts on patients who have been misunderstood for way too long.

We'll also talk about what healing looks like when both the infection and the person are finally seen for what they truly are.

What Morgellons looks like clinically

This is Lime Bites. Let true healing begin. Welcome, Dr. Savely. Thank you so much for joining us today. I'm happy to be here. Thank you for asking me.

My pleasure. So for our listeners that might not be familiar with Morgellons disease, how would you describe it clinically? The very unusual thing that these patients have is they have a sensation under the skin of crawling, biting, stinging, but that in itself isn't a terribly unique thing because other illnesses can cause that.

but they have spontaneous lesions that break out and most significantly filaments that come out of their skin that

can be black, white, blue. We've even seen orange, purple, red.

We've seen all the colors of these filaments that come out. They have other unusual things that come out of the body too that look like seeds and some of that look like fuzz balls.

And there's so many unusual things that come out of the body. The patients normally have also a lot of systemic symptoms, and those symptoms are very familiar to a Lyme audience, because they're the symptoms of Lyme and co-infections for most of these people.

But I'd say the distinctive feature is the filaments, because in my book, in fact, I compared this disease to a lot of other dermatopathies. There was only this one distinct feature that made it very distinguishable was the presence of these filaments.

Otherwise, any other symptom they have can be attributed to something else, you know. But that's pretty much diagnostic right there. So when they come in and I can see those, and you have to use magnification, very rarely can you see these with the naked eye.

and at least 60x magnification. And then you see these unusual fibers and just tangled up underneath the skin, the most unusual stuff. I mean, it's just, I've been looking at it for 25 years and I still, every day, I'm just amazed by what goes on with these folks.

They're very unhappy people. So I've had a few handfuls of Morgellons patients who've come to me not knowing what they had already. And almost every single one of them comes to me thinking that they have some sort of microscopic bug infestation.

Do you see that a lot too? I've had patients come in with bags filled with tissues where they think that they've captured the actual bug that was biting them and causing these sensations.

Yes. It's very, very typical, and I often have a very hard time dissuading them of the notion that they actually have some sort of ectoparasite, you know, something like mites or that type of thing.

I'm not saying that some of these people may not also have an infestation. I mean, who knows? Some of them may. But with Morgellons itself, it's not an ectoparasite.

We know that. We know it's not a worm. I mean, a certain amount of research has been done. So the thing that's confusing, and I easily understand why people think they have a worm or some sort of ectoparasite, is the sensations really confuse you because you feel biting.

You really feel it. You feel stinging. You feel crawling. All of these sensations, you are convinced you're infested with something by the sensations.

then you see these little black things.

Misconceptions about parasites and contagion

And you're like, oh, these are some kind of tiny little white. But when looked at under the microscope, well, under electron microscope even, they're just tiny curled up little fibers wound into a ball.

But from our naked eye, It's just a tiny black thing. We don't know what it is. And a lot of people just assume that's the cause of the pathogen, whereas it's just more waste product or whatever you want to call it that comes from these patients.

Right. And I think one of the most devastating things, besides the fact that most of them have been told that they're crazy, they are so afraid to pass whatever they think this infestation is on.

people around them or to their loved ones, and they're afraid to be intimate and just… It's good that you're bringing that up because I feel like this is another thing, probably you've just mentioned the two hardest things to dissuade them of is one, that they're infested with an ectoparasite, and two, that they're highly contagious.

I always try to explain to them like this. This is, whatever causes this, and we still don't know, we really don't, it has to get into the skin, under the skin, with some sort of a bite or a thorn or splinter or something.

So I said, just kind of think HIV, you know, it's got to be… body fluid to body fluid kind of thing. It's not going to be sitting next to somebody on the bus, you know, or hugging somebody.

It's possibly sexually transmitted. We're not 100% sure, but we know that the fibers, the filaments are in semen and in vaginal fluid, so who knows? But usually it's something getting under the skin.

So that's why we've seen so many with flea bites, tick bites, cactus or rose thorns, splinters, or people being around really filthy things like with a laceration.

You know, like a lot of gardeners and, you know, if they don't wear gloves and their hands are in the dirt, I've seen it happen with that too. So something is triggering this and I just, I've always felt that whatever pathogen is causing this is somehow manipulating the DNA of ourselves somehow to do unusual things, basically do the wrong thing at the wrong place at the wrong time.

So our body produces keratin, of course, we need our nails. And so the The cells here should be producing a lot of keratin, but you shouldn't be randomly just producing it out of cells all over your body.

And that's what we see happening here is that these shards of keratin or little skinny little thin filaments of keratin are just coming out in random places and it causes pain as they try to get their way.

You know, people always say it feels like somebody's poking me with a pin, but from the inside out. And so that's part of the misery, too, is all the pain that they have from that.

Right. And so you mentioned infections. So I know that you specialize in treating chronic vector-borne disease. What are the infections, including the vector-borne diseases, that you see most closely related to Morgellons?

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This year's meeting is jam-packed with leading industry experts discussing long COVID, mycotoxin illness, PANS Pandas, as well as Lyme and other vector-borne diseases.

This conference will arm you with the knowledge, clinical pearls, and practical solutions that you can implement immediately into your practice Monday morning that will literally change your patient's lives and get them on their path to true healing.

So join us at Pompano Beach or virtually from anywhere. Register now at LymeBytes.com. That's L-Y-M-E-B-Y-T-E-S dot com. Well, originally, I published a paper, actually, I was the first publication that ever mentioned the association between Lyme and this.

Links to Lyme, Bartonella, and immune dysfunction

And basically, I never for a minute was trying to suggest Lyme causes it. I was just saying, hey, look, this is

showing up a lot in the Lyme population.

And what's the connection there? Since then, two other studies have been done in Australia and in San Francisco, where they found that 6% of a certain Lyme population ended up with more jelons.

So we don't know whether the Lyme is immunosuppressive enough to make them more susceptible to whatever is causing this, or perhaps it's another co-infection whatever is causing this.

But I really don't see any indication at all that it's caused by Lyme disease. I mean, you know, just because Lyme is present, you know, obviously that doesn't mean it's the cause.

I've always seen a closer association with Bartonella just because Bartonella has so many skin manifestations, you know? And some of the skin manifestations of Bartonella are so similar to those in Morgellons patients, these red tracks that they get.

And when I treat a patient for Bartonella, that's when their Morgellons gets better. Now, once again, I'm always very careful to say this. I'm not saying Bartonella causes Morgellons.

I have no idea what causes it. But I noticed that there is, if I go after Bartonella and treat that, that's what helps these patients the most. So it presents an interesting question, you know, like what could be.

There's so much we don't know in terms of pathogens, right? I mean, we know so little right now. Even 10 years from now, 20 years from now, we'll look back and laugh at what we didn't know.

And so I don't even think we're close to being able to say yet what actually causes this. So you referenced this study that showed 6% of Lyme disease patients had more gallons.

Has anyone done a study to look at what percent of patients with more gallons have, whether it's Bartonella or Borrelia or a different vector borne infection?

And that was my first published study. And so I based it in two ways. I based it the diagnosis that I made on lab results, you know. And as you and I both know, plenty of times a person can be a poster child for Babesia and have a negative test, right?

So I also had a clinical diagnosis. So I set up a list of symptoms that qualified a person for a clinical diagnosis for each of these. So when I say that 40% of my patients had babesia, that doesn't necessarily mean they all 40% tested positive for it, but they either tested positive or had floored symptoms highly suggestive of it.

So anyway, that was the study where 97% of my Morgellons patients had Lyme disease. Lyme disease or a co-infection. Yeah. I first sort of associated with the Lyme because generally speaking, most providers are kind of a little more familiar with that.

The average provider really doesn't spend a lot of time thinking about Babesia or Bartonella, as we know. But yeah, but you know, and then some people argued with me and said, that should have been 100%. But no, because I have seen over the years, I've had numerous patients that had no Lyme symptoms whatsoever.

Tests were all negative, but they clearly had more Jones disease. But they always had something else suppressing their immune system. I had an AIDS patient once with it.

I've had several organ transplant people who are on immunosuppressant. I've had people with severe autoimmune disease where they had to live on very high dose immunosuppressants, have some of the worst cases of it.

But these were not tick-borne disease patients. Clearly, what they all have in common is they have immune challenges. All of these people have. And so that's what we need to discover more than anything.

When we don't know a pathogen, for an illness, hey, let's look at every other potential immune burden, right? find out what those are, play detective, look for all of those, and try to mediate those problems.

Hopefully then the immune system will be able to take over and do what it should be doing. And that tends to work, you know, most of the time. The only time it doesn't work is when I can't get a patient to really cooperate with me about the whole mold thing, because that's the other thing.

really found with all of these patients, there's a mold component. Once again, I'm not saying mold causes more gelatin. I got to be careful because, you know, I get quoted sometimes, so I really want to make sure.

I have no idea what caused more gelatin, but I do see a very close association with the mold. because it's just such a big immunosuppressant. And when I check HLA-DR type on these people, 24% of the population supposedly, according to the work of Dr.

Richie Shoemaker, has this HLA-DR haplotype that says they are mold-sensitive. And 100% of my more gelatinous patients have that HLA-DR type and they are all living in mold or recently we're living in mold and still toxic.

So that always seems to come into play, you know, and that has to be dealt with for them to get better. And some patients just don't want to go down that road, because it is a pain.

What if you find the house you're living in is so moldy, and you're like, oh my gosh, you know what? It's huge. It's so difficult. What are you going to do?

You're so sick, and you're going to pick up and move? It's just horrible to even think of. But I think, really, to get people well, we do have to consider every single burden on the immune system.

And unfortunately, that's a big one. It's a big one. It's huge. It is. And we've all of us that treat Lyme. I mean, you know, we started out when I started out specializing in Lyme and co-infections 25 years ago.

You know, in the background we were hearing Dr. Richie Shoemaker kind of go, mold, mold, and we were all like, eh. And then the years went by and we just realized, oh my God, this is huge.

This is why a lot of these people aren't getting better. And so it's the same with the Morgellons, you know, it's just, once again, it's just discover the immune burdens, try to take care of all the ones you can.

And my patients with PTSD, really hard to get those people well, really, really hard. And I do insist that they be actively working on that, going to therapy support groups, whatever, because those are some of my sickest people, for sure.

You know, just a little anecdote here. I just talked to a patient right before this. First time I talked to her, she was really out of it. And she's a more jealous patient.

So I just talked to her, and she just seemed great. You know, she seemed great. And her daughter was on the phone, too. She said, you know what? Her primary had given her an anti-psychotic, because he thought she was delusional.

And she felt awful because of the side effects of the anti-psychotic. And she's actually fine. She's healthy as can be, but she's one of my people who, she's fine systemically, but she's got all these more gelatinous symptoms.

So not all of these people are neatly fall into this have Lyme, have, you know, all of those sort of inflammatory symptoms, but they still have the lesions, they still have the fibers, you know, so.

Are you suffering from Lyme disease or another complex chronic illness and aren't sure who to trust when it comes to herbal supplements? Hi, I'm Dr. Mariah Hinchey, founder of Lyme Core Botanicals.

Mold exposure, PTSD, and other immune burdens

As a naturopathic physician specializing in complex chronic infection-driven illnesses like Lyme disease, I needed herbal medicine I could truly trust.

That's why I formulated Lyme Core Botanicals. where our herbal tinctures are handcrafted in small batches right here in Connecticut. We use the whole herb, never isolates, to preserve the full spectrum of medicinal compounds.

Every single step from sourcing to extraction is done with precision to ensure maximum purity, potency, and consistency. These are the same herbal formulas I used to heal myself and have used for years to help my patients and family members heal, too.

And now I'm making them available to practitioners and patients everywhere. Lyme Core Botanicals, herbal medicine you can trust from a doctor who lives this work.

Learn more at Lyme Core Botanicals. That's L-Y-M-E-C-O-R-E dot com. So can you elaborate a little bit more? I know you said, you know, we don't know exactly what causes it, but clearly there is a level of either immune confusion or dysfunction or imbalance at the heart of it.

Can you tell us what's happening more like at the cellular level, like with the skin or with the production of keratin? Like, do we have any idea of like what the pathophysiology that's kind of going awry is these fibers are being overproduced.

You're asking the million dollar question. And unfortunately, there's the minimal research, you know, research costs money. We can't ever get money, you know, and we've applied for grants to the NIH and they say we don't support diseases that don't exist, you know, that kind of thing.

So it's been all volunteer basically, all the research. And that's when they found that the filaments come out of the body are actually the body's own protein keratin.

And so it's just always been my assumption that something has gone haywire in the DNA of the cells to make them produce this enormous amount of keratin in places where it shouldn't be producing it.

And the sensation people feel of, they often talk about some things crawling underneath their skin. Well, we've seen those fibers do grow sideways under there too.

So there is a feeling that they're having under there. But no, I don't, everything about the pathophysiology is still a mystery. And there's just so much we don't know.

And it's very frustrating to me because we can't seem to get the people you know, CDC or NIH or anybody really interested in this. And so until we get some more research, we're just kind of, I'm just out here just trying to help people feel better.

You know, I mean, I don't claim to know more than anybody else about this. It's just I've been doing it more. I've seen a lot of these people, and I have learned a few things from them, from the patients, and from what we have tried over the years.

You know, that's basically all it is. experience with these patients, but I still feel like I'm in the dark about most things. It's very frustrating, you know, and I think that's why a lot of my colleagues, a lot of doctors don't want to touch this with a 10-foot pole, because there's something very, you know, it's very unsettling to be treating, just sort of throwing treatments out there, not even having any clue what the heck you're treating, you know, and But I've always had a lot of empathy for the misery these people go through.

And I just feel like, let's try something. And I remember early on, I get so much criticism from doctors. And I'd say, well, what do you think we should be doing for these people?

And they would say, just let them wait till we find a cure. And I said, That could be decades. So you're just basically saying, so sorry, you're absolutely miserable.

Y'all are committing suicide in huge numbers. I just found out yesterday, one more of my patients committed suicide. It's 54 years old. I'm not a psychiatrist.

Psychiatrists may be used to this. I've seen too many suicides. And these are some very, very miserable people. And when you add insult to injury of nobody believing them, their family deserting them, their friends deserting them, people diagnosing them as crazy, oh my God.

They lose their jobs. They lose everything. There's no wonder there's a high suicide rate with these people. Yeah, absolutely. And, you know, to your point of people not really wanting to learn about this disease or treat it, it's like, yeah, I mean, there's some of the most difficult patients to treat, you know, because it's misunderstood.

But B, because there's so much like trauma and so much gaslighting with these patients. They don't trust anybody. If they didn't have PTSD before, they do now.

Because, oh my gosh, these people have lost all faith in the medical care system. I mean, I can see why, you know? It's awful, the gaslighting they go through.

It's really incredible. And just cavalierly, given anti-psychotics, high primary care providers, not even referred to psychiatry. They don't even want to rule out anything physical.

They just immediately confer a psychiatric diagnosis, which is malpractice, really. Every patient that had come in to me were told that they were literally delusional.

Yep. They were diagnosed with delusional parasitosis. Right, exactly. That's the most common diagnosis these people get. Sometimes, you know, they might see a dermatologist that'll say, oh, you have you have perigo nodularis, which is one of those many, you know, I always kind of laugh about dermatology.

They have so many diagnoses that are really just basically a name for a symptom complex, you know? Hey, all these people have this, so let's give them a name, you know?

So I don't even really think of those as true diagnoses, you know, because they're just… let's call this a name. And a lot of people are misdiagnosed with that, with Perig or nondularis.

And there's a lot of different misdiagnoses. Some of them are just diagnosed with scabies and given medicine for that, even though You know, if the person diagnosing it knew anything about scabies, they would never call this scabies because it's not in that typical pattern that scabies would be.

But, you know, at least they're listening a little bit to people. That's one step better, right? So what other misdiagnosises do you commonly see? And how do you help clinicians?

Because we have a lot of clinicians that listen to this podcast. How do you help them differentiate between more gelins versus other dermatologic or psychiatric illnesses?

Okay, it's easy as pie. One thing, one thing, and that's just look for the fibers.

Pathophysiology and the lack of research

Look for them. If they're there, They have Morgellons disease. That's it. It's the distinctive diagnostic feature. And, you know, you can just diagnose all kind of other dermatologic diseases just looking at them across the room.

But you know, come on, dermatologists are supposed to look at these things with magnification. The other problem is most dermascopes that the dermatologists have in their lab coat are about 14x or something, and that's not

enough.

You really need a good 60x to see this stuff. And so even if they do think to actually look, which they rarely do, they usually diagnose it from across the room, they're probably not going to see what they need to be seeing.

Anyway, it's a frustrating thing that these patients go through because doctors don't even give them It's so disrespectful the way they're treated because they're not even really examined.

They say their symptoms and then they're just like, you know, psych. And how can that happen? I'm very disillusioned with my colleagues that do that. It's so upsetting.

These people are dear, wonderful people. Currently, I have a hundred of them, right? About a hundred. And, you know, we do an online support group and everything because I tell you, when you have a disease like this, there's nothing like the support.

You just need more. I mean, I think a lot of diseases, you need support from fellow sufferers, but boy, Morgellons is one where you really do because almost everyone, a lot of these people won't even tell their own spouse that they have it because they're just nervous about what they're going to think.

So it's a very, it's like, I feel like I kind of, I don't have a choice. I mean, I can't just turn the other way and ignore these people and not help them.

I mean, why would another doctor say to me that's irresponsible for me to treat with FDA approved drugs, by the way, but of course being used off label, that that's irresponsible?

Why is it not irresponsible to just ignore people's suffering? Or to throw them on a psych medication. Yeah, or throw them on a psych medicine, like this poor lady.

I just talked to her. She was like a different person. And her daughter said, yeah, because she stopped that psych med that they put her on. And so anyway, I'm disillusioned by the way these people are discounted.

and not helped. And so my goal has always been the two things to uncover all the burdens on the immune system, to help the immune system function at its best.

And then also, honestly, just trial and error of different things. And they're all FDA approved medications, it's just we're using them for a different reason.

And through the years, I've definitely found certain things that work better than others. And so I start with what statistically has helped the most people.

That doesn't work, we move on to the next thing. So there's a lot of things we try and different things work for different people. And I've always suspected that's because of their particular unique immune burdens.

So that's why I had a patient get so mad at me once because she'd been on antibiotics and wasn't helping. And then we put her on antifungals and she got completely well.

But the next 20 people I did that with would not get well on the antifungals. So that's the thing. People talk with each other. They'll say, this helped me.

And they don't understand, not everyone is you. There's not a one-size-fits-all. Exactly, exactly. And I mean, you know, we know, you know, you and I know that's true for tick-borne diseases in general, but I think with more gelins even more so, because I mean, I've had all kinds of different things work.

you know, for, for people, but it just, you never know who's going to respond to what. So it's always been like, okay, let's try this, let's try this.

And luckily I've done it enough where I've treated thousands of these people where I kind of have my own little statistical bank of information, like, okay, here's, here's.

Let's try this first, because that works for a lot of people, you know. So that's what goes. Let's talk through your treatment strategy. So I mean, I would imagine in the beginning, there's a lot of reassurance, right, that it's an infestation that's not going to transmit it.

And then I would imagine that you probably cast somewhat of a broad net looking for vector-borne diseases, you know, fungal burden, you know. toxins in every part of the environment.

Yeah, metal toxins, you know, sinus mold, just a little bit of everything. And a lot's going to depend on the individual, of course. You know, the patient I was just referring to was put on the antipsychotics.

She's as healthy as she can be, but she just has this skin stuff. So honestly, I'm not going to be inclined to put her on a lot of antibiotics. I mean, she's fine.

She did a very thorough eugenics panel and really unremarkable, and she doesn't have any of those symptoms. So actually what I'm doing with her is taking her through a parasite protocol, actually Dr.

Klingharts. where we basically just run through pretty much most of the anti-helminthics, anti-parasitics. And then when they're finished with that protocol, I'll ask them, was there one that helped you in particular?

And they always have one. Most commonly, Ivermectin, but runner-ups are albendazole and preziquantil. So sometimes it's those. And then they'll just go back on that one that was the most helpful to them.

But then the other thing I try, especially if I assume that the person has had a lot of mold exposure, I'll treat them with something like poziconazole or itchiconazole because I have some cases where, oh my gosh, that's helped them tremendously right there, even with their more gelatinous symptoms, you know?

Misdiagnosis, validation, and patient support

So, but if I feel like there's some tick-borne infections, if the people really are systemically ill, you know, I mean, some of these people can hardly get out of bed.

So, you know, they're just like our sickest Lyme patients. Then I'll start with a Bartonella treatment because that always works. And I just start the very, very basic.

I start all these people on is just a sulfa drug and along with either clarithromycin or azithromycin. And that's just the first step. And if a lot of these people, even at their next follow-up, even those two things, they're already getting better.

And then we'll just augment that by adding first recampin, see if they tolerate that, then double the rifampin, see how that goes, and then we switch to rifibutin.

And basically, my patients always say the rifibutin is the one that, not to be scientific here, but kicks butt better than anything. And that's the one.

But it's also tough. Because what happens with the Morgellons people, just like with Lyme people, how they have a Herxheimer reaction, Morgellons patients, their form of Herxheimer reaction is a zillion things come out of their body.

And it's overwhelming. They just say, I can't even believe it, how much fibers and other things are coming out of my body. But I've always told them, hey, good, because that means we're on the right track.

Yeah. Every time we try something and it causes a mass exodus, we're on the right track. And that's what

eventually is going to help them. People always ask me, do you think it's good for these things to come out?

And I say, you know, I can only guess that it is good. Let's say it's good. Well, with our skin being our largest organ of detoxification, I mean, it makes sense too, right?

That we're pushing a lot of things out through our skin. Right. And so that's kind of always been the goal to get this stuff out of there. And for the topical lesions, and by the way, not every Morgellons patient has lesions.

I have about 10 to 15% that have the sensations, have the filaments, all that, but they never get a lesion. And sometimes those people are told, well, you don't have Morgellons because you don't have lesions.

No, that's not right. You don't have more gelins if you don't have fibers, because that's the distinctive feature. But some more gelins patients, lucky ones, don't get any lesions at all.

So far, listeners that don't know what you're describing, can you describe what you mean by lesions? What it looks like the most, and the very first time I ever saw it, the first patient who ever came in with this, it looks like somebody had a mosquito bite and they just scratched the heck out of it.

And so it's just this whole sort of abraded, ulcerated looking area, but the patient always says it appeared just like that. Because they're always accused when they go to the doctor, oh, well, you just scratched too hard on all those things.

And they'll always, they're all very emphatic about it. No, this just appeared looking like that. And some of the worst ones can even look like cigarette burns or something.

They can be different sizes. Some of them are very small. But, you know, these lesions usually do have those fibers inside of them. Just got a new picture.

Yes, I get so many photographs from patients where she's all excited because she just got some kind of a scope. And she didn't even know she had fibers, you know, because I was telling, well, you know, look for them because that's the distinctive feature.

So you might need to get a little lighted magnifier to look for them. And she was shocked. It was, I mean, she just had a mass of tangled black filaments all inside of this lesion.

And it's just- So that might be a good clinical thing for people to be on the lookout for if you see somebody, you know, that has these lesions that aren't at a ceiling right, or they're very, very scarred, you know, scarred up with these round cigarette burn looking lesions to look closer and to look with the proper scope and see if you saw any of these filaments in there.

You know, I've seen things though that are just so amazing. Like we used to have the conferences every year and the first year of COVID was when it got canceled and sort of never restarted after that.

But we'd have naysayers come there. We have some doctors would come that didn't believe. And we would show them, you know, we would come over, look at this patient, look at the scope, look in there.

Even showing it right to them, they didn't believe it. And we're like, how do you think all that stuff got in there? Oh, the patient put it in there. No.

Have you ever tried pulling one of these filaments out? You cannot remove it. I mean, how could anybody stick that in there like that? Or the other thing they love to say is, oh, those are just fibers from their clothes.

And then we'd say, well, do you notice the patient wearing anything black today? And beside the fact that these are underneath the outer layer of the skin, they're not just like something that got stuck on there.

I mean, it's just so very clear, but it's interesting. Some people just, they don't want to be introduced to a new paradigm, you know? It's just like, I'm happy believing what I believe, so don't upset that.

And it's always been fascinating to me. I mean, who wouldn't be fascinated by this illness? Oh my gosh, it's so fascinating. 25 years of looking at these people and dealing with these people, every day it still amazes me, every single day.

And how could somebody not be interested in that and just discount it so easily? It's just mind boggling to me. I don't get it. But it happens all the time.

But here's the good news. There's good news. The good news is that more and more doctors are becoming aware and are even telling people this is what they have.

But that's where it ends. They'll say, I know that's what you have. I'm not going to put it in your chart. I'm not going to treat it because I don't have a clue how to do it.

But that's what you have. you know, that's just getting that can be patient in the right direction. To you or to watch the documentary on more gelatin to find your book or some of the studies, you know, and then hopefully realize, you know, that a gig percent of this does have an underlying, you know, infectious cause or at very least an immune you know, issue going on, and then they start, you know, on that road to healing.

So that's big. It might not seem like much, and it actually isn't much considering how long we've been plugging away at this, trying to raise awareness and all, but it's different.

It's different. When I first started doing this, I'd get calls every day from doctors yelling at me. and saying, you know, you're buying into these people's delusions, you know, blah, blah, blah, all this.

And now the only calls I get are doctors saying, I know that's what this patient has, what should I do? And that's a huge difference. I get emails from around the world, almost every day, doctors from Singapore, you name it, South Africa, saying, I've got this patient, I'm sure that's what they have, what should I do?

And thank God we've got, you know, something's happening here because we just, but we just need the people who give the funding for research to pay attention.

Is there still a conference? Like, is there somewhere that medical professionals can currently go to, you know, to learn? I think they are planning planning to restart the conferences.

Both patients and providers came to those. Unfortunately, it was more patients. We always wanted more providers to come. But even the fact all those patients came, oh my God, it was so healing for them.

You know, just to see, you know, be there in a room full of people, and they all have the same thing. And that goes a long way toward making you feel not crazy, because when you see that there are so many people dealing with what you're dealing with.

But yeah, I'd love to get the word out more to doctors. It's getting out there slowly but surely, and patients are responsible for it a lot. They'll find a kind of a sympathetic doctor that they know will listen, and they'll teach them about it.

They'll tell them. And dentists, they're one of the first-line people that needs to know about this, because one of the biggest symptoms of Morgellons is happening in the teeth.

The teeth are just crumbling out of people's heads. They're just hollowing out. I've had dentists call me and say, what the heck is going on? I don't know if this thing is leaching calcium or what, but people often end up going to their dentist first.

And I was almost going to speak at a dental conference about this. I was so excited about it. And then they changed their mind and decided, ah, this really doesn't have anything to do with dentistry.

That's the point I wanted to make to you. It does. Do you know what the link is? Do you have a hypothesis? No, I mean, all I can get, see, I wish if we had research money, what I would love to do is also do bone densitometry on all these people.

to see if there is some sort of calcium leaching going on with this thing. There's so much research we could be doing, but I'm sort of busy taking care of people.

I don't really have the time for that kind of research, and that runs into money. You know, a lot of these people would have to pay out of pocket for something like abundance.

I don't know. There's just so many ideas I'm always having about things we should be looking at and things we should be studying. But what I want the most is some really serious researchers.

I'm working really hard with somebody else to try to raise some funds so that then we can actually have serious scientists present proposals and we can give grants, you know, specifically for looking at this thing and what the heck's going on with it.

And we already have some people on the sidelines, really highly respected researchers that I think are, you know, kind of waiting for us to have this funding so that we can really get some of that work done.

But we've always been really low on funding, you know, that's a problem. Yeah. You know, it's funny, I interviewed Kevin Ellis, who's the bone coach, and we had like a really great conversation on the Healing Lime Summit about, you know, the role that Borrelia plays in causing osteopenia and osteoporosis by you know, through, you know, remodeling of bone and how Borrelia affects like the osteoblasts and the osteoclasts and, you know, through inflammation and immune dysregulation.

And so I'm just, I'm wondering if you know, if you're seeing Lyme and other vector borne diseases in that high of a percentage of Morgellons patients, you know, I wonder if part of the dental piece, you know, has to do with, you know, the breakdown of the bone, you know, as well as, you know, spirochetes living there, like, you know, in sort of like the socket of where the tooth goes into the bone, you know, and what role it would play there.

Well, you know, when they've done research just basically what bacteria is present in the lesions, again, that doesn't mean it's a causative pathogen, but they've consistently seen trypanema denticola, which I think is so weird because, you know, that belongs in the mouth.

Treatment approaches and response patterns

And they're seeing it in these Mordelen's lesions. So that's another very puzzling thing. They've also seen Bartonella. They've seen the Lyme Spirochete.

You know, they've seen a lot of different pathogens when they look. Well, and that's also a Spirochete, right? Right. Yeah. So for our listeners that aren't making the connection, so Australia is a spirochete.

Right. Kind of the same, similar pathophysiology. Yeah. Yeah. So it's easy to really want to jump on the bandwagon of thinking, oh, this is it. But I'm very careful about kind of standing back and going, wait a minute.

because I've seen a lot of that with this illness where people just find one thing to be true and then they just kind of go with it. And I think we have to be very careful and stand back and really, really do some very good research before we jump to any conclusions about, you know, what's going on here.

There's a lot of, on the internet, you'll see all sorts of conspiracy theories, of course, so many. and some sound more crazy than others. I often point out to people, like for example, and I say this in my book, you know, people

who swear it's chemtrails, people have been having Mordellans way longer than the chemtrails.

So, you know, and there's a lot of the things that they're blaming and that because I do have I have this one patient who'd had it for 30 years when he came to me, and his father had had it.

And so that was going back to people having it in the late 1950s. So the thing is, I think it's been around, it's just been all these people have been very quiet about it, because they're always, they're crazy.

And this one patient who'd had it for a long time, he said back in the 70s, he went to Mexico to some small village and they totally recognized it. And they called it something like cactus man disease.

And so he felt validated because of that, because they just sort of with their country medicine, whatever, they, well, it didn't really help him, but at least they recognized that this was a thing that people get.

Right. And I think just not being ostracized and I guess having comfort in knowing that you're not alone and that other people have this and it's a thing, you know, goes a long way to somewhat soothe the psychiatric piece of it.

I don't mean psychiatric in the primary. I mean more of… Yes, of course. Of course. I mean, that's why every time I see a patient for the first time, They'll tell me later, they say, you know, I left that first visit feeling about 50% better.

Just because I was listened to, validated, you know, that just took this huge burden off of me and I already felt better just, you know, doing that. And so, gosh, come on, fellow medical providers, that's a pretty easy thing for you to do to make people feel really good.

It doesn't require prescription, it doesn't require them buying supplements or anything. I mean, my goodness, just my validation for crying out loud. I mean, you know, these people have something and you can't just discount them and call them crazy.

I mean, stop and look. you'll see amazing things if you really take the time to look. I couldn't agree more. Tell me what the typical trajectory is for recovery with your patients.

Yeah. Well, what I've always noticed is the longer they've had it, the longer it takes to get well. Usually if they've just started symptoms within the year before they come to me, We're in good shape with those people, relatively recent.

And also it has a lot to do with the age of the patient. My older patients have a much tougher time. Usually if I get a patient in their 20s with this, I feel real confident that we can get rid of it.

So if they're in their 20s, they've had it for less than a year. I feel very confident about that. But if I get a 65-year-old who's had it for 20 years, I got to admit, they're tough.

But we can always get them better. And that's why I do always tell them on the first visit, you will get better. Because I know they will. I know they will get better.

I'm not promising they'll be 100%, but they will get better. And I'm not lying when I say that. And people sometimes tell me, you're giving them false hope.

Well, first of all, I think that's an oxymoron. I don't think there's any such thing as false hope. Hello. But anyway, no, I can't tell you how many people tell me once they're well, the fact that you looked me in the eye and said I would get better.

that did more to healing me than anything because people need to believe it. They need to believe that they are going to get better and they will get better.

It's just how much better I can never really promise. You can kind of tell though by just the age and the general

status of the person how their general health and a lot of other factors and everything like that.

So we do get some totally well. More commonly, I'd say I get people 90% better where they have the occasional fiber or filament fiber and maybe even the occasional lesion, but it's not enough to overwhelm their lives.

They can carry on. They feel better systemically, they can go back to work, they can do everything. It's just, there's that little nagging thing, you know, they have like this little symptom, but it's not enough anymore for them to get freaked out about it.

They just, they're able to just sort of go, oh, you know, just observe it and not have it, you know, ruin their life. And so in that sense, OK, it's not 100% gone.

It's definitely not. But if we can get people back to living their lives, then that's really what we really hope for. But I have had quite a few, especially the younger ones, get completely well and not have a single symptom of it for many years after that.

So that's wonderful. And I think that's so important for any of our listeners have more jellens or who now are going, holy cow, I think I have more jellens.

I've found some answers from listening to this. It goes such a long way, you know, and such a long way to helping people to kind of like restore the balance in their nervous system, right, which is crucial to fixing the immune system and being able to heal the body when people are stuck in fight or flight and they're running from doctor to doctor to doctor to doctor.

you know, being gaslit and being dismissed and feeling like nobody's helping them, I feel like the body gets into such a state, you know, that it's like you could give them the best treatment, but unless they know that you believe them and that you can and you will help them, you get the best treatment in the world and you might not see hardly any improvement.

I think what you're talking about here is the most important thing, and it goes along with the art of medicine, which is kind of slipping away through the years.

But I just think that relationship is so important that people feel safe. They feel safe They feel heard. They feel like this is a place where I can be me, say everything that's on my mind, that nobody's going to judge me.

There's no judgment here. And that's, to me, really not a difficult thing to provide for people. Maybe it is for some people. For me, it's not. And it just goes such a long way in helping people.

So I my hope for everybody who has this or has an illness is to find somebody that can be that person for you you need to have somebody really have faith in and that you can just sort of Put yourself in their hands because it's a lot to have to be out there every day searching the internet It's so much stress, you know, and I try to get people away from that.

Just just don't do that anymore You know I gotcha. I've been doing this a long time. I've been researching things. Believe me, you're not going to find anything out there I've never heard of, which they are sure they're going to do.

But I say, if I'm not doing something, it's usually because I've tried it, it didn't work for my patients. It's too expensive. There's a reason. I think you said the three most important words a minute ago.

I've got you. Like I can't tell you how many times I've said to a patient, listen, I've got you.

Dental symptoms, research gaps, and hope for patients

Cite searching like your job is to now go calm yourself. Stop searching frantically like I've got you. Right. And it goes so. You're here. You've been searching.

You're here now. And I had a patient one time tell me when we were, I was talking about this with a patient and she said, this reminds me of an expression my dad used to use.

He used to say, don't hire a taxi and run along beside it. And it is funny because people do, they come to me and then the whole time they're still out there searching and it's like, wait a minute, come on.

We're together, we're a team, we're doing this thing. You don't need to keep on doing that. You were doing that before, but let's stop that now. Because it makes them crazy.

It just makes you crazy constantly. And then you read different things and you read one thing and it's like, oh, now this is the opposite. And then it's like, ah.

You know, so you got to find somebody and just take the leap of faith. I mean, it is a leap of faith, but that's what you need for your own physical and emotional wellness.

You just need to find that person and then just Here I am, take me. I say this lovingly, but sometimes patients just really need to get out of their own way.

Yeah, like if you want to do something, focus on your breathing, do some guided meditations, you know, go for a walk, like do things to really like help to calm your nervous system and just back into your body so that you can heal.

So, are there support groups that you can share with our listeners? Well, I have an online support group for my patients, and I keep it my patients because Why is your treating through a support group, which never goes well?

Right, right. And then, you know, my patients complain that they've tried to get on online ones, but there's too much craziness going on. And so they kind of get off of them for that reason.

So I just don't know what to say about that. My patients certainly, before they came to me, have been on a lot of different things they found online. But the complaint I always hear is that, mixed in with all of it.

There's all the people that believe that, you know, outer space aliens brought this to us or just all these different things. And it just confuses the picture and makes people even more anxious because there's just too much information coming at them.

So I wish I didn't know. I wish I knew. Well, yeah, I just don't really know of one that I could get. Well, I just don't know. I don't know one. Okay.

So what message do you want to share with the medical community about more talents? I just, when people come in and they say these things to you, they say, please don't be prejudiced.

Don't just remember that five minutes in med school where you learn about the matchbook sign and you go, aha, they're bringing stuff in, okay, delusional parasitosis, check.

No, I mean, pay attention. You may learn something, and you probably will. And so you've got to spend the time, you've got to talk to them, and you've got to examine them for heaven's sake.

That's medicine. We have to examine patients. We can't make a diagnosis standing across the room from 10 feet, which every Moore-Jones patient tells me that, that the doctor barely looked at them.

barely isn't that crazy too, because it's like, well, I don't believe you and you're crazy. But by the way, I'm not going to come near you in case you are crawling critical.

Yeah. It really is, it really is crazy. So, but in regard to the thing, the biggest worry they all have is that transmission, you know, person to person.

And I always tell them, look, I'm your perfect test subject because for years I was in a place, now my patients are from all over the world, so it's different.

But when I first started out, my patients were all local. They all came every visit in person. I've always been a touchy-feely person, so I always hugged my patients and never took precautions.

I never took gloves or anything like that. And if anybody would have caught it by now, it would be me. And I have not caught it. So I really don't think that person-to-person transmission through casual contact is anything to worry about.

But I do tell them, and my patients always say, if I sit next to somebody, I see them going like this. I say, yeah, because You are shedding fibers. They do.

They do shed them. And I feel it too when I'm in the office with one that happens to be shedding a lot for 15 minutes after they leave. I'll be kind of, you know, almost like there's fiberglass in the air or something.

I will notice the irritation. It doesn't mean they've given it to me. It's just the byproducts or whatever are flying out in the air and are irritants.

but then that dies down and then I'm fine. So the filaments are not infected agents, that's what they're always afraid of. I don't know, I just call them byproducts.

They're not anything to worry about. They're annoying, they're very annoying to the patient, but they're always quite worried that those filaments are going to cause somebody else to come down with it.

So finally, what can you offer, you know, as far as hope or advice or anything that you want to say to patients that might be hearing this and are struggling with Borge Allen's disease?

First of all, there is hope. So don't give up. Way too many suicides in this group. Please don't give up. You know, there is hope. If you can find a sympathetic doctor that maybe has known you your whole life or something, I will always help at no charge or anything.

I will always help that doctor treat you. And I have a lot of people where I'm doing this now, you know, doctor in a small town or something that's been someone's doctor all their life, and they get in touch with me and then I help them figure out how to treat the person.

And that's been working really well. Because when I go to a conference, I have these people come up to me and say, you don't know me, but thanks to you, I got well because my doctor contacted you.

So anyway, there's that. And then my book has a lot of suggestions in it, too. Unfortunately, I can't take on every single patient in the world. But I currently happen to be open to accepting new patients.

It kind of comes and goes. Sometimes I have to close it down for a while. But right now, I am accepting new patients. So how would a patient find you if they want?

They just need to send an email to limedc at gmail.com. So that's Lime L Y M E D C as in District of Columbia and then at gmail.com and just ask for new patient information and We send out electronically a packet of just a lot of basically common question answers and then the paperwork to become a new patient if you decide you'd like to.

Wonderful. And the name of your book is Morgellons, the Legitimization of the Disease. Yeah, it's right here. Morgellons, the Legitimization of the Disease.

And is this on Amazon? It's on Amazon and it's for Kindle too. So the only drawback with Kindle is photographs never kind of are as good. But you can go to my website and I have all the photographs from the book on there in color.

So you can kind of really see them better through the website. Wonderful. If you want to look at the photos. Great. Well, thank you so much for joining us.

Thank you. You're such a great interviewer. Thank you. Such a pleasure. Thank you. For our listeners, if you'd like to hear more from Dr. Savely, you can join us at the Lime Bites Symposium.

February 14th and 15th in Pompano Beach, Fort Lauderdale, Florida. And if you can't come in person, you can join us virtually from anywhere. So thank you for joining us for the Lime Bites podcast.

We hope that this brought you one step closer to true healing. And if this helped you, please share it with others that you think need to hear it too, because together we all heal stronger.

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