Introduction to Dr. Ginger Savely

Greetings, everyone. My name is Dr. Richard Horowitz, and I'm your co-host of this particular DrTalks summit healing from Lyme. And it's my great pleasure today to introduce Dr. Ginger Savely.

And the talk for today is Morgellons disease This is a very highly controversial, dermatological disease. Ginger is one of the world's leading experts.

She is a family nurse practitioner with a doctorate degree in nursing practice from Case Western University, where she was honored with the Dean's Legacy Award for her research on Morgellons She is highly experienced in the diagnosis and treatment of vector borne illness, and is the world's leading clinical expert on Morgellons disease.

She's treated approximately 12,000 Lyme and Coinfection patients since the year 2000. About a thousand Morgellons disease patients, in the last 20 years, and the first health care provider in the world to advocate for Morgellons.

And she wrote a book on it called Morgellons Legitimization of the disease in November 2016. Ginger, it is a great pleasure to be with you today. You and I haven't connected in a while. It's great to see you.

Please tell people a little bit about yourself and how you got into Lyme and Morgellons disease. Well, hi. Hi, Richard Thank you so much for for including me in this.

I'm very, always very pleased to talk about this topic, which is kind of become the most important thing in my life. I got into treating Lyme disease the way many of us did, is through a family connection.

my daughter got very sick in high school. Basically, we had to take her out of school, and, and homeschooler, she was in a wheelchair. She was on I. V..

She was very sick. And at that time, I. You know, I just wanted to learn everything about it that I could. So that got me into the whole thing of becoming very interested in and learning as much as I could about it.

How Lyme Led to Morgellons

And then next thing you know, I was treating more Lyme patients than I could handle because I was in Austin, Texas, and we just didn't really have a lot of people in Texas who were who were recognizing this.

And the way I got into Morgellons is, my colleague and friend, Dr. William Harvey in Houston, who unfortunately is now deceased, pointed out to me that a number of the patients were complaining about, fibers, filaments coming out from their skin.

And so I started to notice this too, and I would I was always noticing it in my Lyme patients, no other, you know, other patients. And people would come in and say, you know, I, I have these strange things coming out of my skin, long fibers, and sometimes they're blue and red in different colors.

It was something it was hard to even believe what was going on. And since I saw this in so many of my Lyme patients, I decided to, well, let's trend for Lyme and the other tick borne infections, that they may have co-infections.

And so that's how I first proceeded in treating these patients is just treating whatever underlying infections I might find, helping them detox from mold if that was found to be an issue.

Basically just playing detective, figuring out everything that could be burdening their immune systems, that made

them susceptible to this, and then working on eliminating those burdens from the immune system.

And so I did find that people started to get better. it wasn't perfect. but people were improving and they were very happy about that because most of them, of course, had been to doctors and were told they were delusional.

I'm probably saying a little too much right now, so carry on. if you need ask me something else. Right. So, so question. just you started explaining a little bit about Morgellons disease.

Can you tell people exactly what this is? Because a lot of times in the literature and you know, this, people are told it's in their head, it's a delusional parasitosis.

The disease doesn't exist. Talk a little bit about exactly what is Morgellons disease. Right. Well, the thing about it Morgellons disease is definitely not a psychosis.

It's not a delusion. these people really do have some unusual objects coming out of their skin. And the the main symptoms that people have are, first of all, they have systemic symptoms that are basically the same symptoms as and co-infections.

These people come in with brain fog, body aches, you know, the, insomnia, a lot of neurologic symptoms. and those things are very familiar to us to treat these, diseases.

But the unique feature is that they also have lesions spontaneously appearing, slow healing, and they can appear anywhere on their body. And they have these, filaments or sometimes even really thick shards of objects coming out of their skin.

And so far, all we know is that these are made out of the body's own proteins. These are not the foreign objects. People think they're worms, or people thinks there's something else, but they are filaments made of the body's own proteins, like keratin and collagen.

Right. So so in other words, they're not making this stuff up. This is the body's collagen. The keratin that is actually that's what these fibers are actually containing.

Exactly, exactly. And and a lot of these people, they're complaining of like the stinging, burning sensation. I mean, I've seen, you know, a handful of Morgellons patients, this stinging, burning sensation, it's kind of resembles a little bit the neuropathy.

Right, that you see what Lyme Bartonella has. It does with a big difference.

What Morgellons Is and Its Symptoms

you know, and some of these people may even have paresthesia like we see with Lyme patients just, you know, sensations that something's crawling on the skin or biting you.

But the difference with these folks is they do actually have these objects coming out of and traveling underneath the skin. So when they feel these sensations, what it actually is are these these filaments, the people describe it as being stuck by a pin, but from the inside out, because these, these hurt as they come out through, you know, keratin.

That's what nails are made of. And that's pretty tough. Hard stuff. And so it hurts when it, when it comes out of them. Now that this there's obviously a lot of unknown questions about this disease.

Right. I mean we're learning a little bit marine middle thing. Right. Every couple of years there's a kind of a new paper that has come out. so can you talk a little bit about the bugs that they're finding at this point in Morgellons and like, and, and do you think actually this is common?

I mean, obviously I find a lot of co-infections in my patients. It's the rule, not the exception. And it turns out with Morgellons it's the same. Can you talk a little bit about all these infections are finding.

Right. Well you know yeah. As you well know the laboratory is a little bit different setting than the clinical situation. and in the laboratory they've found a number of different, bacteria within the lesions.

However, of course, we have no idea whether these or are the cause of the disease or just something we find. They're opportunistic. Whatever. So, they have found Lyme bacteria, and they can, also, some dental bacteria Treponema denticola as well as Bartonella.

But to me, what is most important in this case, because we've had very little research done on this, we never can get funding for it. So it's always been volunteer research, and the clinical information has kind of become the most important thing.

And I'm very much like we seen tick borne disease. Right. So the clinical it the my clinical suspicion with this is that it's being caused by something that is Bartonella like just because that's the treatment that tends to help these people the most.

Right. strict Lyme treatment. And and by the way, I've seen the same thing. And when you say, Bartonella like organisms, there's always, you know, there's over 17 different pathogenic species at this point, right?

Right. Right, right. And they found Bartonella Hensleigh. And they, as you said, they found Borrelia burgdorferi. They found Greenie, from from Europe.

They found Hensleigh and Miyamoto even relapsing fever, Borrelia H. Pylori. The question, of course, is, is how is denticola spirochete from the mouth and H.

Pylori. How are all these things possibly getting into these things and biofilm I mean it's yeah. It's it's an interesting hypothesis to figure out how they're all getting in there.

Right. exactly. And, you know, one of the things that's always interested me the most about this is that these lesions that the patients get, they're open.

They look very much like if you had a mosquito bite, you need to scratch the heck out of it, you know? In fact, they're often accused of that. Those open lesions, they're oozing and red and wet.

They don't get secondary infections. They don't get the classic scab and strep secondary infections that you would get with a skin lesion. They never do.

And that is really fascinating. You know I I've seen my patients scar right after they comes out in one place. There seems to be a scarring and then it may come out in another place.

and it's, it's very disturbing to them. I mean, the Lyme symptoms alone of fatigue, brain fog, pain, bad enough. But the what? My at least my patients.

I'm sure it's the same for you. What they're describing is the stinging. Burning is what's really so annoying. Now, you you've like some dermatological creams and stuff also to help with the symptoms in these patients.

Yeah. With our kind of joke that we have in this is every topical works great for two weeks. And so, you know a lot of things work for a very short time and then they don't.

And so I always have doctors all over the world writing me and saying, I've found the answer. And they've been using a cream on somebody for a short time and it's working.

And I say, well, you know, get back to me in another week or two and let me know. But yeah, usually they don't.

They whatever works doesn't work for very long.

But the number one that I found so far, that is seems to help the most people most of the time is dapsone, dapsone gel yeah. That's, my favorite drug.

And the dapsone, you know, the name brand is axone and the 7.5, percent. I would love to find the generics. 7.5. but I never seem to be able to find it anywhere, but.

So anyway, they usually get the 5% gel, and I get great feedback on patients from from using that as far as healing lesions and that kind of thing. You know. That that's fast.

And by the way, I've never tried doing this, but you may want to speak to Randy, from infuser of my compounder, because every time I present something like this to Randy, like Randy, I need a dosage of a drug that I don't have right now, and he usually finds a way to compounded.

I. You actually maybe want to speak. I'll be. Oh, yeah. Randy's great. Yeah.

Infections Linked to Morgellons

I'll be speaking to Randy, by the way. On it. DrTalks soon about compounding medications in line. Oh, good good good. And now the question. It's very interesting.

You found some because of course that some creams used for acne right there. Right. Right. Yeah. What a bacterium do you do you think I mean I don't I don't think there's any answers, but do you think it's the antibacterial effect or anti-inflammatory or both.

And we just don't know. Yeah. Of course we don't know if if it were anti-inflammatory. I don't really find that, you know, where does own creams really help that much?

So it would not seem that that's the case. But the thing that's the most fascinating thing about treating this, and the most difficult thing is if there's such variability in patient to patient.

So I can use something on one patient that works like a dream, try it on the next patient doesn't work at all. So every patient holding a ball game you know start from the beginning.

Although you know we I've been doing it long enough now where I do have statistically my things that tend to work the best. So I start with that. But then I kind of go on through everything.

Some of them even respond well to antifungal creams. I have no idea why there's never been any evidence that this. When this first came out, we with their first thought that it was fungal because these fibers, the filaments they fluoresce under under the white light, you know, and so that kind of looks fungal.

And the way they branch out under the skin. But all of the, the, the laboratory work has, has confirmed that there is no fungal component to this as far as we can see.

Right. but yet some people swear that antifungals help them. Now, my theory has always been, well, those people may actually also have another problem with the with a fungal infection.

And by lowering that burden on the immune system, it enables the immune system to kind of deal with whatever's going on with more. Jones. Better because one thing that for sure is that everyone who comes down with more Jones, they were immune compromised in some way that sometimes they didn't know it, but they weren't.

You know, I was going to ask you this question, which is why, like if there are 13 or 14,000 cases in the world, but they all have Lyme and tick borne, why does this subset of patients.

Right. Again unknown. Yeah, yeah. Yeah. But but and you mentioned mold and there are mold toxins like Leo toxins that are immunosuppressive. So you think you're finding when you do immunoglobulins and subclasses or now you find that these people are immunosuppressed in general.

You know what? On paper they're not I almost never find, immunoglobulin subclasses that are abnormal. it blows me away. I don't know why they're not, but, I mean, they're clearly there.

They're clearly depleted, and they're they're, very vulnerable to whatever is is there? Because I just think that whatever's causing this is probably, you know, omnipresent.

It's just that only a select few are actually succumbing to it. And that's why you'll see, like in a family, sometimes a family will have a flea infestation.

And in fact, this often starts after flea infestation. You know, Bartonella is in fleas. So, they'll have a flea infestation, and then only a couple of family members will come down with more Jones.

And so I just think, you know, there is this and I mean, that's a true, you know, every illness, right? Every infection, every illness, there's certain genetic tendencies, susceptibility is, you know, so I think we're seeing the same thing with this.

But I always feel that the mold mold is a huge component. you know, I do the the mold up haplotype on these patients, the HLA Dr. type that, the, we learned about from Shoemaker, you know, and, 24% of the population has this genetic type that makes them very sensitive to the mold toxins.

But 100% of my more Jones patients have had that genetic haplotype so far. And so obviously, these are all kind of people that are sensitive, you know, they they they don't detox.

Well, they, they these folks are very toxic. You know, when I first get them and there's a lot of work to do other than just bug killing mode, as I call it, you know, I mean, we beside antibiotics and things, there's a lot of other cleanup work to do with these.

That you do. You find it's interesting you're finding mold because the last paper that we just published in microorganisms in 2023, which was about higher dose, pulsing for Bart that the six day pulses versus four worked better.

and we're pulsing every, let's say, every two months. In that study, 84% had mole toxins. And as we talked about, a lot of these are immuno suppressive.

Do you find when you detox these patients because they're so resistant? I mean, I have a couple I'm dealing with now and some that you and I have, you know, seen together.

they're so resistant. You find that once they detox from mold and toxins, there may be a, some improvement where the antibiotics work better or difficult to say at this.

Yeah. Yeah, definitely. I've had some where we didn't even have to go on to antibiotics. once we detox. Because, you know, I always tell people, you know, there's just a certain level that the immune system can handle.

And when it when it overflows, you know, that's when you become symptom or you go over the symptomatic line. And so if you can remove some of the other burdens, you know, sometimes that will put the more Jones down under the symptomatic line so that people aren't really, experiencing those symptoms anymore.

But, you know, it's very hard, detoxing these people. And it's difficult dealing with these patients, as you know so well because they're severely brain fog.

And and it's it's always very difficult treating these patients because they confuse the directions. They don't follow

directions. They do a different thing, the wrong thing that, you know, it's just it's it's I empathize with them.

I've been sick with Lyme myself. I remember what it was like to have that kind of brain fog, but it it's very difficult.

Topical and Systemic Treatments

And that's why I wish that all my patients could have someone who, who's sort of their helper in the whole thing of getting well, you know, sometimes they're lucky, sometimes they have a spouse or a parent or a child or whatever.

But it really, really helps because you're. You're bringing out a good point. a lot of times we have had to type up a lot of the, you know, the treatment protocols that have her type. But you're right.

I mean, I've had to type up a lot of this stuff, put them on word documents, tell people sometimes keep on your tape recorder. send me back the protocol that you think you've understood, so I can look at it to make sure you have.

No, you're right. I mean, you have to check it. It's it's hard. Yeah. And no matter how much, how much detail I put in into those instructions, you know, it's always so, Yeah, the the whole thing is, is very difficult to work on.

But I do find that my patients who are very compliant, who have someone to help them follow these complicated procedures, sometimes they get well, they get well, they do and they get over the more Jones part and they start.

They stop having lesions, they stop having fibers. I will tell you, some people ask me this question in terms of people getting over this thing. I think that the older my patient is, the less likely they are to get over it 100%.

Usually my younger patients with it in their 20s or so, they can get 100% over it, you know. But sometimes my older patients, like over 60, they might get 80, 90% better to where they are feeling good and that, but they still have the occasional fiber, that kind of thing to deal with.

But yet they're able to deal with it. And yeah. Now, you mentioned earlier that, the intracellular treatments, which usually the Bartonella Lyme treatments usually work best, but I know you've also used some, antiparasitic albendazole, ivermectin, crazy.

Quanto. But talk to me a little bit how you got into using these particular drugs. Just like you didn't find fungus, but sometimes, like there was so.

Well, Di flu can study some fluconazole 30 years ago. Thought that. Oh, yeah. It hit the P450. Maybe it wasn't the fungus, you know. But the fact is, is that some of these have work.

So why do what do you think is going on? Were some of these anti-parasitic or help, you. Know, as we as we have found out, you know, ivermectin can help with viral treatment.

So of course these these things do have other uses beside the ones they're FDA indicated for. And so I'm not exactly sure why these anti-human ticks are working as well as they are, but I'd say in about 80% of my more patients, they're extremely helpful.

Part of the protocol I do have some where they don't respond at all to them. So you know, but but for a lot of people, they're very helpful. I use all of them.

But I do find ivermectin is kind of the number one as far as being helpful and praise of quantal kind of being number two as far as being helpful and when when they're helpful, what they help with.

and this is interesting. I have no clue why this is. They help with the sensation more than anything else. People will say when they're taking these, they stop having that sensation of crawling, biting, stinging something, crawling under the skin, that kind of thing.

Fascinating. Who knows why that that is. But they're so miserable with their symptoms that if we can find something like that, that helps them feel better, I mean, that that's great.

You know, because sometimes these people get so depressed with these awful symptoms that they they can't even really function to do the other things they need to do to get well.

So that's all about, you know, hey, let's let's lower the symptoms to as much as we can, even if it's not actually curing the root of what's going on now.

Of course. So a ginger how can they get in touch with you? you doing any conferences up? Tell people a little bit about anything you might be, doing in the near future.

Well, I am still accepting new patients. new patients need to send an email to Lyme disease. So that's l y am a DC, at gmail.com and asked for a new patient packet.

And it's good if they mention they think they may have more gel because I have an extra questionnaire for that. I am still treating, you know, tick borne disease patients, Lyme patients and all that don't have Morgellons too.

So I do need to know that that is one of the things they think they have. I developed this questionnaire many years ago just based on the typical symptoms that I was seeing over and over and over and over again.

And so I these patients always get almost kind of excited when they see the questionnaire and they check off the things because they're they're so shocked that somebody would be asking him them these questions, that of symptoms they've had for a long time, but they were afraid to even mention, you know, what the symptoms are when you do mention them to a provider who's not used to this.

I always tell them, you don't have to worry about what you tell me. I, I you know, I've heard it all, but but they, you know, they they really are thought to be crazy.

And, when I first started treating this years ago and everyone thought I was crazy, too, because, you know, they they thought I was playing into the delusions of these people, but I, I used to always whatever.

If I was working in a group practice, every time I saw something unusual, I'd call a doctor and say, look, look, I want you to see this. I want another human being to see what I'm seeing.

Because when you see a bright blue fiber coming out of somebody's forehead and you can't pull it out with tweezers, no matter how hard you try. I mean, you know, it's the seeing is believing kind of thing.

So that's that's the thing I wanted to show people like these people, there's something very unusual going on here. And, and I've always been a little surprised at the lack of intellectual curiosity in some of my colleagues.

dermatologists said, found or not that interested in this, they're very quick to call it the delusional and not even to look. And I'm all I've ever said is just just look, you know, you need to look with magnification.

You're most of the time you can't see this with a naked eye. You do need, like, light in magnification and, you know, just look and see what you see, and you'll see some amazing, unusual things.

And most of them we can't explain yet. We have no, no idea what's going on, but I, I have heard the same symptoms over and over and over and over for years now from people of all walks of life, you know, different professions, different ages, different races, different socioeconomic groups, and it's all the same group of symptoms.

And this was even before we had the internet thing. People often say, oh, yeah, it was kind of internet delusion. No. They get online, they find the symptoms and they report them to, you know, when I first started seeing this, I was practicing in Texas.

I was taking care of ranchers, you know, stuff like that. And they they were not the type to surf the net, you know, they were hardworking guys who were out in the fields.

And, they didn't tend to be hypochondriacs either. And they came in and they were telling me all these same unusual symptoms. So, no, you know, all of our patients, I mean, most of them have gone to 20 or 30 doctors right before they see us, but the system doesn't believe them.

In fact, there was an article in The New Yorker that just came out about the same problem with Long-Covid that they had in the beginning. These people were told it's it's all in their head.

And when people used to come to me and tell me that, I used to say, well, the doctor was right, it is in your head. You got spirit in your head. You got. It in. Your head.

But any new disease long-covid Morgellons disease, chronic Lyme disease, right. They're put in this category of just because we don't know. It's got to be in your head.

And it's it's really it's a strange phenomenon because obviously science takes a while to discover what the underlying causes of these things are. Exactly.

And, you know, I remember years ago, we we, a bunch of us applied for a grant from the NIH to to study this.

Mold, Detox, and Immune Burden

And the response that we got was, well, we don't provide research for diseases that don't exist. Well, oh, yeah, we're going to find out, you know, what causes it, if that's the case. Right.

But so we haven't been able to get much interest in research in this. And there was a very, non genuine study done by the CDC. Now it's been like 15 years ago or so, and it was a very poorly done study.

And it was ingenuous. I mean, honestly, they they clearly just wanted to get something done so they could because they had a lot of people calling the CDC asking about this.

They wanted to be able to say, look, we've looked into it. We can't find anything. And in fact, the bottom line of their report is we were unable to find any pathogen associated with this disease.

They did not say this disease is all in people's head, but the media decided to report it that way. So the media reported it that, the CDC says this is all in people's head, and that's not actually what they said, you know, but the they just kind of and, you know, the media, that's what they do sometimes that because they want it to be more sensational.

Now and, and it's difficult because celebrities like Joni Mitchell. Right. She's one of the famous ones that have had it. They get this. These are clearly not crazy people.

They're very well known. and they get this, that it's like, now what? Right now, what do I do? Right, right, right. Yeah. And that's why people are turning to you.

Because you've taken a particular interest, right? In this. And by the way, I mean, I have also, as you have seen, some results where some people have gone into remission, in fact, early on and one of the first apps on studies I was doing in 2016, one of the cases I wrote up, she had Morgellons and got better.

But I have to admit, the ones that the few that I still have in my practice boy, they're they're really resistant patients. And, it's kind of like, in fact, the last one that I just treated, I treated or a few months ago with this newer high dose DAP, some pills.

She told me that it did bring out the lesions and healed in one area, but like it was strong. And this is like a Lyme

Bartonella protocol. So I think, you know, this, these mixed infections that are showing up in these people.

I think you're right. I mean, based on marine middle things, work and everything that's going on, I think these are going to be biofilm mixed infections.

But the question is, is it some combination of some Bartonella species or some combination of Bart and other Lyme and relapsing fever and mold immunosuppressive as to why only 13 or 14,000 people get it?

Like why is every. Initially I heard, oh, I got a rose prick. It was like, early on with Morgellons. What I remember is it was like something punctured the skin.

So that's if. You remember this right early on. But that. Oh yeah. That, that's that's often I mean something always. People always worry a lot about transfer.

You know. Oh I don't want to come on the plane to see you because I'm like, give it to the person next to me. No, we don't have to worry about that kind of it.

It's it is, by the way, if I want to point out it is not transmissible. Correct. It's not transmissible through casual contact. I always tell people think of Aids, you know, it's it's body fluid, body fluid kind of thing.

So normally, you know, like riding on the plane or the bus or whatever, you're not going to have to worry about that. But most patients are concerned that the fibers coming off of them are going to land on someone else and give them the disease, but that's not the way that work.

You know, these are these are just sort of, excess. You know, these are not contaminants. In other words, the fibers themselves, they're not contaminants.

But, a lot of patients are very concerned that they are. So, you know, it always happens with something going under the skin. So a rose thorn, a cactus thorn, as a dirty splinter, a, I've had a lot of landscapers get this.

I've had a, that that that's a and then I had a person one time who worked out in the fields where they were in a lot of muddy water a lot, and they they had a lesion and then, you know, got in there.

so it's always kind of a and then of course, the bites and, you know, the bites are the big thing, flea bites a huge I mean, so many people tell me this all started when we had a flea infestation in our house.

You know. Again, in implying Bartonella is one of the major. Exactly, exactly. So, you know, that's what over the years, I realized that. Hey, wait a minute.

These people, even if they test negative for Bartonella, even if they don't really have the red flag symptoms, although most of them do have red flag symptoms for Bartonella.

that's the approach that's going to help them the most. And so usually, you know, three intracellular drugs, particularly something like with a butane with with the sulfur drug with chloride, the myosin, that little trio there has always been sort of a golden trio.

Get getting these people. Well, but with the addition of an anti helminth for certain patients because for certain patients that's, that's just a very helpful part of the protocol.

Again I always tell them look these are technically d warmers. You don't have a worm. These are not worms. You know they're not worms. But medications sometimes help for for other things than what they were intended for.

You know, I mean, we see that all the time in medicine, right? So do you have to do you have to rotate these protocols like when you're talking about these intracellular.

Hopkins had published a few years ago, which is why I kind of published my last option study, trying to see if I could prove it. They found in culture six days of Zipser Max rifampin, or if imputing with methylene blue was necessary to kill Bart.

What they didn't say is what was the dose of methyl. Yeah, they never do. But what we found in our studies is that we extended the pulse of dapt some from six day, from four days to six days with the high dose, with the higher dose methylene blue.

Some of these Bartonella patients are finally getting better. Now you've tried a little bit of these persistent drugs like disulfiram DAP. can you speak a little bit about what your experience has been so far?

well, what I found with the disulfiram is that, it helped a lot with all of the. What I just told my patients are the systemic symptoms. In other words, all the limey kind of symptoms, the body aches, brain fog, etc.

helped a lot with that. But the actual more gel and symptoms, the lesions, the fibers, different filaments, things coming out of their skin didn't seem to touch that.

Now with the methylene blue though. And see, that's the thing I've always seen the disulfiram help more with lime and Vizio myself I don't know, that's kind of seems what it is clinically then.

The methylene blue though, helps a lot with Bartonella and the methylene blue does help my Morgellons patients. You know a lot of them. And it's it is dose dependent.

You know the higher I can push it you know, the dose, the better it works. Oh.

Patient Support and Treatment Challenges

So you've also you've also see that a more jealous because in my patients, once I got the methylene blue dose up to 300 buid with a longer pulse and I started pulsing like, let's say roughly every two months, these two week protocols, it seemed like from reading the literature and then clinically, the load of the persistence would keep going down every time until people would basically say they were a lot better.

Interesting. You've seen the same thing with the Morgellons. The higher dosing, has definitely difference with it. Yeah, I just pretty much have always thought, and intriguing these diseases, and all of these diseases we treat, tick borne disease is kind of the more the merrier.

I mean, the more, more antibiotic you can get in there, the better, because, you know, it pushes in to the intracellular spaces, which is what we need.

And so, I have had some patients with cast iron guts where I can really push those doses, but a lot of them really just can't handle it. You know, it's it's just too much on their, on their stomachs to handle those high doses, but I do I'm convinced they, they always work better.

Yeah. Well, what we've done basically to protect the stomach, there's, you know, there's a new product and we found it to be useful from design for health. It's called gastro mend.

It's a, it's got zinc kind of skin and mastic gum and a bunch of things that they use to treat age. Pylori. You want to look at this because obviously they found H.

Pylori is one of these things in the, in the work. Yeah. But, I found that I had a combine in some of these patients with GI issues like glutamine, glutamine, aloe vera, the glycerin, licorice.

It's a Xamarin product that the gastro and H1 H2 blockers for the mast cell patients. Right. Getting them off some of the things that are triggering the pill.

and of course I'm up to four probiotics at this point twice a day with prebiotics to support the gut. Yeah, yeah, yeah. That's generally how we're trying to get them through it.

What I find with the methylene blue is not so much the stomach. I find the urinary burning at the higher doses is the problem, but it is where we use perineum for nasal pyridine.

And that that does seem to help. Yes. There that that's the big issue with it with the methylene blue is the urinary symptoms for sure. And I and I do use all those things like the slippery elm marshmallow root, those things that coat the stomach and and all of that.

But, sometimes it's not the stomach. It's more the intestinal tract, you know, there's cramping and but, I don't know. It's just when I can get people to take the higher doses, it's that's what's always the most effective.

You know, it's just always been that way. Right? Right. And I, I, I don't know, it's just, we it's a slow pace with those that works really hard or can't tolerate very much.

Then it's not like we can't get there. But it's a very slow road, you know, because we have to go so slowly and titrate up so gradually. So, that's but I mean, that's the same with, with all the tick borne disease patients, not just are Morgellons patients for sure.

Yeah, but it might be interesting because this new article we published just was out a few months ago. we, you and I should discuss, actually, maybe a small little clinical trial.

Yeah, of of this new protocol with these home pulses are two week pulses for Bart. I would be very interesting because you obviously see, I only have a handful left in my practice.

A few more gallons that are, coming along, but but again, still difficult. I would be very curious to see what you notice with these protocols, because you're also finding that the more intracellular drugs.

Right, with methylene blue, these intracellular kind of Bart line treatments are helpful. And we have been finding that these pulsing with these higher dose protocols using persistent drugs like DAPs on rifampin, presented by methylene blue with the four persistent drugs, they seem to be making the biggest, the biggest difference in these patients getting them, the help that they need.

As as a matter of fact, I have read your recent paper, and I have been thinking very much about doing that exact thing. The high dose post. and so I am interested to, to talk with you about that.

I feel like that could be a good option for these patients, for sure. and, but, you know, it's just like with everything else, it's just like with all of our patients, there's so much variability.

I, I treat some people where after the first month they're 80% better. I treat people for a year and a half and they're 10% better. You know, I mean, it's just it's all over the place, right?

And unfortunately, people do get online and they talk to each other and they're like, hey, why aren't we doing this? Because this person's doing that, you know?

And it's like, well, you don't know the whole story of that person, you know? And it just everything's so individualized. And I mean, personalized precision medicine is where it's all going anyway, right? I mean, there are I know two patients that are the same.

You know, I'm kind of curious when I, when I screen what the 16 point EMS hits, do you find also that these patients have passed this on anemia and mast cell and low adrenals and they have all the overlapping factors that.

Oh yeah, yeah, yeah, yeah. I mean, of course not all of them. But there's I would say there's probably the same percentage that fall into those. The you know, the MCI, CAC, this ers, patients, all of that.

The yeah. We we see that a lot. But I, I really want to give hope to people if there's people watching this that are patients. I'm not sure of the exact audience, but there is hope.

You know, people do get better. And I think part of the, the treatment is the validation, you know, when you can see somebody who knows you're not crazy and knows there's something going on here and, and is committed to helping you, that always is, is a big step forward.

And people do comment that they already feel a little better just just knowing that knowing they're not alone, you know, because they, they I've put them in my support groups together and they can when they can compare notes with other people who are literally going through the same thing they are, there's that's good medicine, you know, that that really helps them quite a bit.

Yeah. And so all that stuff is part of the healing process, right? Yeah. So where do you think the research needs to go? Like if you had unlimited funds for this, what kind of research would you do to try and figure out that.

The puzzle man, I mean, see, of course we can't really come up with a good treatment for this until we know what the heck's causing it. And, you know, so far, all we have really done in research is pretty much the rule out work.

It's not this it's not this is not that, you know, kind of thing. We we haven't really gone into to looking what could possibly be at the root of this.

All we've seen is what what bacteria are in the lesions. But that's kind of, you know, that that really doesn't necessarily tell us a lot about the the culprit behind this.

It's always been my suspicion. I could be dead wrong on this, but the this is some sort of, unicellular, parasitic infection that somehow is able to get into the cells and commandeer the DNA in a way to do the wrong place at the wrong time, in the wrong quantity.

So obviously, the cells at the end of our fingers, they they produce a lot of character because that's, that's where the nails. But the cells just randomly in our body should not be doing them.

You know, they shouldn't be producing slivers of fingernails, you know. And so something's gone awry. They're right with the with the programing. And so it seems like what's going to be at the root of this is finding some kind of a, of a pathogen that that has affected the cells in the way that they're doing the wrong thing in the wrong place at the wrong time.

Right. Because in and of themselves, the bugs they found so far really? Bergdorf I really a herbicide green I h pylori tripping and then to colon Bartonella in and of themselves.

When you see patients with this they don't form the keratinocytes in collagen doesn't do this in general which is why it's that interesting. You saw the flea, this tree, the landscape papers, the people that get you know, Rose, there's there's something else going on that maybe there are other organisms.

It sounds like mixed organisms, maybe under biofilms that have nothing to do with tick borne. But then it sounds like sense translocation of some like again, how does dent tickle cates and H.

Pylori. Right. I mean that that's crazy. That makes sense. And you know, there's been two studies so far, one in California and one in and Australia, showing that 6% of Lyme patients come down with Morgellons disease.

Research Gaps and Disease Mechanisms

And, you know, so there's kind of a good amount just to go by not, not, set in stone, but we, you know, that's a proxy of what, what we're seeing. And, you know, it's if so when away you think, is this a co-infection, you know, is it a co-infection or is it just that because you have Lyme and co-infections, you're more susceptible to this particular kind of infection?

You know, as we see with Aids patients, you know, the disease. So sarcoma, you know, they're they're more susceptible to that. But it's not necessarily, you know, exactly related or anything.

I mean, you know, am I making that clear. Yeah. Yeah. Yeah. So, so when you do the work up, when a patient comes to see if you the first time you're checking them for Lyme, but Busia, Bartonella, all the tick borne infections.

What, what other infections you're looking for. What other tests may you be doing that maybe other doctors aren't doing that you can share that you found helpful.

Well, I'm doing I go ahead and do all the, you know, what we kind of call the Shumaker labs to do with mold? I'm not exactly sure how entirely reliable those are, but I always tell patients we're putting together a picture, we're putting together a puzzle, and so we're just getting the little puzzle pieces until we can start to see the picture emerge.

So any one test is not going to be. You know that. It's just it just adds to, to the the emergence of the picture, the picture as a whole. And so, I do all of the, the labs, the inflammatory labs, the labs for, for mold toxicity, the, the classic tick borne disease that I don't really do all the viral things because, honestly, they're opportunistic and, found in, in great antivirals anyway.

So those usually the viral titers go down once we treat, with the antibiotics. So don't don't spend a lot of time with that. one relapsing fever is really, really coming up a lot in these patients.

And you know, of course that's kind of a why there's a lot of different Borelli is included in that envelope. It's kind of wish we'd stop calling it tick-borne relapsing fever, though.

That's very, you know, confusing name because these people don't have relapsing fevers for the most part. I don't know what you see. Well, the interesting part is when you read most of these in the textbook, like you read busy in a textbook or relapsing fever in a textbook, it's never what we see in clinical practice in these patients, right?

It's like when they get these mixed infections with immune deficiency on top of pots and low adrenals. Right. And mitochondrial dysfunction and, mast cell disorder.

It never looks like what it's discussed and especially the relapsing you're right the relapsing nature, you don't really see it. And even briefly, Miyamoto, you don't really see it unless it's someone really immunosuppressed.

Right. Exactly. So, you know, that's why I always try to tell people they'll look up online and they'll say, well, Maya Loukia was positive, but I'm not having all these symptoms.

And I'm like, yeah, but I think it just kind of goes into that chronic mix, you know, where there's like low level infection here. It's really hard sometimes when people have a lot of these co-infections to pick out really clearly, like, oh, this happens because of that infection.

This, you know, because there's just so much crossover there. And but for some reason patient do and sort of really enjoy having a culprit. You know, they want to be able to say this infection caused this and this because that but it just becomes one big mess.

You know, we don't sometimes it's hard to pick out what's doing what, but, you know, it could be that the Bartonella treatment is working not because this is Bartonella or anything like it.

It just whatever it is, if it's something we brand new to us, just happens to be sensitive to those same medications, you know, so people sometimes just say, well, gee, it must be Bartonella.

It Morgellons must be caused by Bartonella because of these treatments. But not what do we know? I mean, there's just so much we don't know. And, so many infections out there we are not even aware of.

Yeah, yeah. And you, by the way, do you find the biofilm agents? Do you use them in your treatments? Do you find the biofilm agents and open them? Makes a difference in these patients when you're treating.

It does for the most part. you know, just based on the real, you know, the, the laboratory studies, you know, I, I do use it as a tool for, for biofilm busting, but I do, you know, the other things too, like the fiber analytics, you know, that we can use for that.

But, for many of the more done patients, that's a it's a it's a game changer. You know, it's it's very important to include that. Now, one thing I want to point out though, you know, how with our tick-borne infection patients, they for the most part they usually have a herk Slimer.

And which is can be, you know, a flu like feeling or worsening of already existing symptoms or even the appearance of new Lyme like symptoms that they may have personally never experienced before.

Now, with more Jillian's patients, what happens is that's all true. They get all that. But the thing that's very difficult for them during their, initial diet period, huge exodus of, filaments, shards, all the little things that come out of their body mass exodus when you first start to treat them.

For some people, it's reassuring that they like that other people, it's terribly frightening, you know, it's just so much they just can't handle it. And therefore, and those people we do need to do adjust the treatment a little bit, maybe pull it back a little so that the that the exodus of fibers isn't quite so intense, you know, because it's just I mean, these people are very fragile.

They've been dealing with a horrible situation for a long time. Most of my patients have lost everything. They've lost their jobs. They've lost their families.

They've you know, these are some very, very sad people. And the very high suicide rate too. And this group I've, I've already, you know, had quite a few suicides in my patients.

And you know what it E-1 was can understand it in some cases because it's their life is pretty miserable. You know what this these horrible things are happening to them.

And just to add insult to injury, everybody's telling them they're crazy. You know. So it's it's a really, really tough, tough road going through this.

And I used to always say, you know, I used to think treating Lyme and co-infections was hard. But the it's a walk in the park compared to treating war zone because we're really, you know, don't even know what we're dealing with, you know.

Right. But but the point is that you're bringing up and it's an important point, is that Lyme patients should never lose hope because even in the last couple of years, we've made major strides, right, in the treatment protocols the last couple of years.

And, just like again, with chronic fatigue myalgic encephalomyelitis, fibro long-covid, a lot of these diseases are not well understood. In the beginning, people are told it's in their head.

It is not in your head. These are real diseases. Science, right? It takes time to figure these things out. But we've made such progress in the last couple of years.

I would, you know, tell patients truthfully, there's absolutely no reason to give up hope. And I'm glad you're hearing the same thing that you you are making progress.

Even though more Jones is a very difficult disease. You are seeing patients get better and some are going into remission. Exactly. And what I do truly feel is if they can really follow the directions, you know, if they can take their medications, their supplements, their herbs, everything as directed really stick to it.

Really be committed to the process of getting well. They get well. You know, the ones that usually don't get well have kind of, I don't know, given up hope.

And they're not really doing what they need to do. They're eating a poor diet or you know, everything. And so there's usually when somebody is not getting well, there's usually a reason you can you can find out for that, you know, and but people hear a lot of things online.

You know, people go online and say, oh, it's hopeless. You'll never get better. There's no, no treatment that will make you better. But that's not true.

You know it. It really is not true. It's just one thing I've always pointed out is the people who do get better.

Hope, Remission, and Clinical Experience

They don't tend to be online. The only people that are online are the people that didn't get better, you know? So all of the rest of the people go on their merry way and go back to living their life and, you know, don't turn around and look back for the most part.

And so they're not they're not on their, you know, talking about the situation. But I know, I know, I have my patients up with a, with a hopeful person, somebody a new patient who's very, you know, overwhelmed.

I try to pair them up with one of my patients who's better, much better or totally. Well to be their, their reassurance person, you know, because I think that's really important.

In and in our patients when we find that they hit a wall and they're not getting better. Oftentimes since this has been coming up lately, I'm finding mold and toxins are playing a huge role.

I just recently had two patients, one in, in Europe and one in Florida. No history of mold exposure had done the nine week Daptone protocol, did several pulses of this high dose zap zone for barred barred fish positive, would get better, but would never really move ahead.

I asked him about mold. They said no, but I tested them. Their mold toxin levels were off the wall, and in both cases this happened. By the way, this past week they told me that once their detox pathways were open, the mold toxins were coming out.

All of the tickborne symptoms, they were associating fatigue and brain fog and pain. Yeah, but it all started getting better. So clearly the mold and Neal, Nathan and I have this conversation all the time.

That mold overlaps Lyme. It causes immunosuppression. So the symptoms overlap. And now you're telling them in Morgellons you're saying exactly the same thing we're seeing also.

Right. And solutely and that's one thing that's changed over the years over the decades. And my approach is I used to sort of leave mold as a last ditch thing.

Like, gee, they haven't gotten better in a long time. Maybe there's mold. You know, that was the way I used to do things. But now, just right off the bat, just almost assume there is because of the fact that I have seen if we deal with the mold, a lot of these people, they don't even need antibiotics, you know, because they're actually below the symptomatic line after you deal with the mold, get them away from the mold, detox from them, all of that.

And then, you know, they realize, hey, you know what? I feel pretty, pretty good now. So I think it's, really important. And it is, even more important for some reason.

And these Morgellons patients, a lot of patients will say it will think I'm saying more a mold causes more gel. No, it doesn't cause it. It just makes you much more susceptible to it.

And so that's that's the the thing I want people to understand is, is and I'm never saying Lyme causes Morgellons, mold causes Morgellons or any of these things.

It's just these things are all a burdens on the immune system. And, you know, there's only so many burdens the immune system can take at one time. And so it's all about or.

And the model fits I mean the, the it's interesting that I posted a couple of years back on long Covid. I want you to do a study at UCI looking at the 16 point M6 model before we really knew much about it.

8 or 9 factors on the M6 model have now been associated with long Covid, and in the Morgellons you see the same things. You see multiple tick borne infections, you see sleep disorders, you see low adrenals, you see mitochondrial, you see microbiome disruption.

You see Marcell disorder. Right. We're seeing a lot of the same plots. Dysautonomia. The overlapping factors are being seen in these different diseases.

So what I think people are missing is that what I call the three eyes infection immune dysfunction inflammation, whether the bug is a virus or the bug is a bacteria or several bacteria or parasites, as we may be seeing here with Morgellons, since they seem to be playing a role here. We don't know.

There's a lot you know, but still it's the same kind of infection. Immune dysfunction, inflammation. You got to find the underlying sources of inflammation.

You got to find the downstream effects. And then when you detox the body and treat the infections, the skin lesions get better and people do get better.

Exactly. And one thing I do want to point out just a little extra side here. Not all Morgellons patients have lesions. I have probably maybe even 20% of my more Jones patients have no lesions.

They but they but the the the diagnostic feature Morgellons. The thing that's unique because I in my book I compare it to just all these other dermopathies and they it shares in common many many features with all of these other things.

But the one unique feature is these filaments, the filaments coming out of the skin that is unique, that is diagnostic of the condition. So if people write me and say, oh, I feel like bugs are crawling all over me and I'll say, yeah, but do you have filaments coming out of your body?

Oh, no, I don't have that. Well, you know, that's probably not a morgellons patient then. Right. And the itchy what's also interesting, the itching and stinging sensations they describe.

Although Lyme patients, Bart patients get neuropathy with tingling numbness burning stabbing is almost a certain flavor right to what the morgellons patients are discussing with the itching stinging sensations with these, that seems a little bit different.

Well, I've always said with my patients, be really careful about how you describe what's going on with you. you have to describe what it feels like, but don't give it names, because that's what leads them to being called, psych cases.

You know, they go into the E. R. and they say something like, I have little shrimp coming out of my face. Well, they're not shrimp, obviously. but they're little pink, curved things and then kind of look shrimp like.

But I always say, don't say shrimp because that then immediately you're going to be categorized as crazy. Just you. You should just describe what it is, you know, just this this is what, what is happening.

And even then, they're probably going to think you're crazy. But, I mean, you know, forget it. If you go in there and

say something like, give it. Given a name like that.

And people are also very, very convinced the filaments are worms. they're not worms.

How to Contact Dr. Savely

They're not, they but this is the interesting thing that's always, always perplexed us is when you remove a filament, or sometimes even when the filament is still coming out of the skin, it will appear to move.

And this is why everyone says no. These are living creatures. These filament. But I think I've always been convinced that this is electrostatic movement.

Early on, about 20 years ago, we had a patient who had access to electron microscope, and they looked at one of the filaments and it was just coated with minerals.

You know, this this was just under electron microscope. Of course, we can't see this with our little magnification in the office. And they were coated with, with various minerals.

And so I'm, I'm just I believe that the movement they see is some sort of electrostatic kind of movement. And that's what convinces people that these are the problem.

These are the infective agents, you know, these are the things that are going to fly off them and infect, their friends and family. Right. And the those are they're more like waste products, you know, than anything else.

Yeah. No, Ginger this was this is very helpful. We're getting to the end of our interview. You're almost at an hour or so. just last parting words. Tell people again how they can contact you since you are taking new patients.

how can they get in touch with you? Yeah. it can be helpful to, to just, you know, read my book. That's on Amazon. the it's in Kindle format to, Morgellons, the legitimization of a disease.

I have to admit, the book is now six and a half years old, and I totally expected to come out with a new version every year. But honestly, there's nothing new to tell.

There's nothing new to tell. There have been no new findings or anything like that since I wrote this. And so, although it seems kind of old, is pretty up today, unfortunately, so does the pandemic hit everything kind of ground to a halt in the world of Morgellons research.

But anyway, to get in touch with me, just, send an email to Lyme DC Lyme as in Lyme disease, L Y M E, DC because my practice is in District of Columbia and at gmail.com (lymedc@gmail.com) and asked for a new patient packet and I do a lot of telemedicine.

So, also, even if you live far away, don't don't worry about that. Right. Well, thank you, Ginger, this was very enlightening. I'm really glad you decided to specialize in this because somebody had to go.

Right. Who spends their time looking at these very difficult diseases? it was great connecting with you and speaking to you. And, you know, I look forward.

Maybe you and I can work together on doing some of these capstone protocols. These newer ones for the. Pulses would be great. I think it would be fascinating to try this in these resistant patients, and then maybe get a publication out next year and, and give some more hope to the Lyme community who suffers with Morgellons Thank you. Thank you for everything you do, Richard Oh, it's my pleasure.

So thank you, everyone again for joining us for this episode of DrTalks. I'm your co-host, Dr. Richard Horowitz, with the other co-host, Myriah Hinchey.

this is the healing from Lyme summit. You've been speaking to Ginger Savely and Morgellons. We look forward to speaking to you again, in the next episode.

Thank you so much for joining us.