Introduction and memoir overview

Hello everyone. My name is Doctor Richard Horowitz and I'm the co-host of the Healing Lyme Summit 2.0 with Doctor Talks. And it's my great pleasure today to introduce to you Jennifer Crystal.

So I met Jennifer several years ago and we were working on the Harvard Lyme Wellness Initiative. Jen and I work for Harvard on this tick borne disease group.

And that's how I met Jen for the first time. And Jen has a memoir that she just that just came out. It's called one tick stop the clock. So obviously very clever with the TikTok.

So, Jen, it's a pleasure to have you today. We're going to discuss your journey through healing from Lyme disease like what you went through, right. How many doctors you saw?

The disbelief that your friends and family and other physicians had and I think, you know, lessons learned, navigating this chronic illness path. I think it's important for everybody.

So tell people a little bit about you, kind of what happened, how you got sick, you know, the path of life you were on before this whole thing happened.

Just so people can get a sense of where you were and how deep that hole was that you went in before you managed to pull out. Sure. And thank you so much for having me.

Doctor Horowitz, it's great to be on here and get to talk to you about the book and about my experience. So I was bitten by a tick in the summer of 1997 while working at a summer camp in Maine, but didn't realize at the time that that is what had happened.

I had a red rash on my arm. It was not your typical bullseye rash. It was a splotchy red rash, and I didn't learn until many years later that m rashes can present in many different ways and that, many people don't even find or get a rash. So.

But, you know, because it wasn't a bullseye rash, the camp nurse and I just sort of brushed it off. But, you know, Lyme disease was not on my radar at the time, even though I was from Connecticut, even though I was working in the woods of Maine.

The camp nurse was from England that summer. It was not on her radar. And we sort of thought, I don't know, maybe it's from a sleeping bag or something.

It doesn't itch, it doesn't hurt, don't worry about it. And the rash faded and I never gave it another thought. Well, that summer, I also developed hypoglycemia, which seemed kind of strange, so that just, you know, seemingly came out of nowhere, when I was otherwise taking good care of my body, and but no one really kind of got to the answer or put together whether that may have been related to the rash.

And then, that fall, I was a sophomore in college and I had a terrible flu. They thought I had mono, and which is what they always test for in college.

And when I didn't have mono, they, you know, said you must just be run down. You must be stressed. Maybe it's all in your head. I had fevers, I had joint aches.

I had exhaustion and difficulty getting to class, difficulty walking to the dining hall. And those symptoms waxed and waned for years.

Early tick bite and years of unexplained illness

I would, you know, get better and was leading this really high achieving, high functioning life, double majoring in college and skiing and running and studying abroad.

But I would crash. I would have, you know, I would go have this this on and off again flu that would come on. And the college health center nurses tired of me eventually and, you know, said maybe, maybe you should see someone in counseling about all of this.

And I started to think maybe it is all in my head, even though I had fever, even though I, you know, but, you know, I just started to. By the way, it's difficult to make up fevers, right?

That's kind of a tough one, right? Aches and pains. Okay. You know, whatever. But fevers, that's really a tough one. Yes. Yeah. Exactly. Exactly. So, but they, they just, you know, my bloodwork all looked fine.

They didn't I didn't have mono. They didn't know what else to say. You know. And at that time particularly there was such a more stigma around mental health.

That to me to have someone say maybe you should see someone in counseling really felt like code for it's all in your head. You're making this up. And it probably would have helped to see someone in counseling because of the angst and the anxiety I was feeling from being so sick all the time.

That probably would have helped. You know, I, I have a joke. I tell my patients because your story of the patient coming in and saying, it's all in my head, I actually validate them, this is the joke and say, well, they were right.

It is all in your head. You had like spark in your head, you had Bartonella in your brain, you had mold toxins in your head. It's like it's not what they meant.

But in a sense it was right now, this was what year you got sick? In what year? Roughly 1997. So already this had already been out for a while with Lyme.

I mean, Lyme was discovered at that point in the 1970s. I mean, I was already discovering, you know, the bco and a lot of the tick borne diseases in, in the 1990s.

So, boy, it's it's a shame because it was already a known disease, but I guess really not well enough known at that point in time. Not well enough known at that point in time.

And if only I had known you then, then my whole life might have been different. But, I just, you know, it wasn't on my radar. Wasn't on the radar of any of the doctors I went to.

And it wasn't until 2003. So after I graduated from college, I moved out west, to Colorado. I'd always wanted to be a ski instructor. That had been my life dream to do that for a year.

And I had moved out to Colorado to do that. I hadn't been able to do it right away because I had torn my ACL in my knee. So I was a school teacher. Rehabbing my knee, and which turned out to take much longer than expected because there were spiral dates in my knee.

But we didn't know that. And so I had finished two years of teaching. I was just on the cusp of, okay, now I'm really going to do it. I'm going to be a ski instructor for a year.

And, for the summer, I was heading back to the summer camp where I had the initial tick bite. I was driving cross-country and, got so sick and it turned out, ironically, I actually did have mono after all those years of being tested for mono.

I finally actually did get my and I was in 2003 and my body could not fight it off because it had underlying

underlying tickborne infections of Lyme disease, babesiosis, or Licky also, which we later discovered, and so.

By the way, many people that I see have immune deficiency when they have chronic Lyme disease. So it's not unusual at all to get these viral infections, that keep coming back.

A large percentage of my patients have EBV. In fact, with Covid now, it's become even more frequent to get these EBV reactivation and herpes virus six reactivation.

You know, it's never usually one thing, right? In my world, when people are sick, my my model is the 16 point eminence model. And it's like going into a doctor with 16 nails in their foot saying, you have pain.

The doctor flies one nail. So with the motto, of course there's no great treatment. So at that point when you were having these flu like symptoms, were these monthly, was it around your peer because many women around their menstrual cycle right before, during or after, that's when the symptoms come out.

Was it that for you or was it like on and off throughout the month when you had it? It was kind of on and off throughout the month. Later, once I actually was finally diagnosed with tick borne illness and was undergoing treatment, I did notice that my symptoms were much worse.

Around the time of my cycle. Right during my period, I was get these excruciating migraine headaches, and just all of my Lyme symptoms seemed much stronger, at that time.

Thankfully, now that's that's no longer the case. But I definitely noticed that, once I had been diagnosed. So. So we're now to 2003. It's at least six years at this point that you're still you're still sick.

They called it mono. Which, of course, there's no great treatments for. There's a few new ones, by the way, that have come out, but we're trying them so how many doctors do you end up keep seeing at this point with the symptoms and tell us, was it brain fog, memory concentration, fatigue?

Was it migratory pain, which is the hallmark of this disease? Absolutely, yes. I had I had, pain in various points of my body, often had migraine headaches.

On one side on the left side, the, you know, flu like, fatigue was excruciating, you know, not just, a little bit tired, but I'm bedridden. I can't, you know, I cannot get out of bed.

And again, I'm a person who's a skier, who's, you know, a teacher who's, like, always burning the candle at both ends, highly active and, you know, so for me to to say I can't get out of bed is really, like, I'm completely exhausted, completely spent, completely wiped out.

So how many doctors did it take? I mean, roughly along the and and I understand you were gaslit, because in reading your book, you were definitely gaslit by some of these doctors.

Tell it tell us some of the stories of, like, what you told these doctors and what what they were actually telling you was wrong with you. Yeah. So there are more doctors than I could count.

But dozens of doctors, I would say, you know, the mono was easy to diagnose because that was a blood test. And so then, okay, you have mono and now it's slipped into chronic active Epstein-Barr virus so that, you know, I'm not sure what what number doctor we were on at that point.

But it was, you know, many doctors before then and then many doctors after that trying to say, is it, you know, is it still just EBV, you know, trying to figure out, what else was going on?

But yes, I describe one experience in the book, a couple different experiences in the book. One was a primary care physician who had diagnosed the mono in the Epstein-Barr virus and had originally told me when I went to see him, it's very unlikely someone your age would have Epstein-Barr.

I don't think that's what's going on. We're going to test for other things and we'll get to the bottom of this. And then he tested for other things, didn't nothing showed up.

And he said, you have Epstein-Barr virus. And I said, but you had, you know, said when I came in, that's unusual for someone my age. And he said, well, yes, it is, but that's what you have, and there's nothing I can tell you to do but rest.

And I describe in the book I was, you know, it's like, is there anything else I can do? How about, you know, diet? How about supplements? His response with diet was, well, eat things low to the ground.

And I said, what do you mean by low to the ground? Well, you know, turkeys, chickens, plants, they're they're closer to the ground. They're better for you. So that was kind of it.

That was the answer for, you know, you know, healthier diet. Okay. And then he suggested I see a psychiatrist and there's only acknowledged. And the psychiatrist made of my physical illness was to ask if I had a living.

Well, then. Yeah. Oh my God.

Misdiagnosis, gaslighting, and worsening symptoms

So not only did they not discover what was wrong with you, but actually putting in your head, this could even be a life threatening problem that no one's figured out.

So you better get your affairs in order. That was the message sent. Wow. And then she totally switched gears, and, suggested that I buy a social anxiety workbook.

And I looked through this workbook and I thought, I have I do not have social anxiety. I have always had, you know, very easy time making friends, love going out and doing things anywhere, anywhere I've been.

I'm just too sick to do so right now. And she got very upset with me and said this, this workbook is very helpful to all of my patients. And I realized that, well, what category have I put been put into here?

You know, by the primary care who recommended me, you know, by the psychiatrist. And, and what does that say for people with legitimate mental illness, who, you know, for other people, they're being sort of used as a catchall.

Well, so, you know, other people with a physical illness that we can't figure out. It must be a, you know, a social anxiety disorder. Well, and the part that's kind of sad here is both.

Lyman Bartonella caused tremendous mental health problems, you know, in the, in the ICD 10 or 11, you know, diagnostic manual, every psychiatric illness, depression, anxiety, OCD, we've had patients who are psychotic, who are schizophrenic, you know, who come in on schizophrenic medicines, who have Bartonella rashes, and the psychiatrist never bothered to do a full physical exam and examined to say, hey, what are those unusual rashes?

You know, this is unfortunately with the medical system, you know, is not fully taking a history and understanding what Bob Banfield will say. Mental health, you know, the microbes in mental health that microbes cause mental illness.

So by the way to environmental toxins in many things. So did any of these people really do a full physical exam and really go through everything because you had a multi systemic illness, it was fevers on top of it, as you said, which you can't make up.

Migratory pain is the hallmark. Did you also have neuropathy tingling, numbness burning, stabbing? I did I had all of that in, in my extremities. Particularly the burning sensation came on after I was diagnosed with mono, and I would be lying in bed at night and my feet would feel like they were on fire.

And, you know, people would say to me, oh, like you're comforters too hot. No, it's not an external thing. It's an internal. Like, I literally feel like my feet are on fire and I have to take, you know, cold, wet towels, to, you know, to put on my legs.

And, and did this migrate because migratory neuropathy is the hallmark of chronic Lyme disease. It did. It would be in my feet. It would be in my legs.

It would be in my arms, all over, you know, my appendages. You know, this is why I've recommended to doctors and for the patients out there who are listening, you know, the the the MQ, the Horowitz M6 questionnaire that was based on Doctor Boris Schiano's work years ago.

I published this back, I think it was 2017 with researchers from the State University of New Paltz. And it's a pretest probability where you just take this questionnaire of 38 items and there are several other sections, and you get a score.

And if you're over 63, it's two standard deviations above the mean. You have a very high probability of having chronic Lyme disease. If it's questions one inch 22 day sweats, night sweats, chills, flushing air hunger.

Can't catch my breath? Cough. Those are symptoms of the BCA. Now did you also have some of those symptoms? I did, yes I had air hunger particularly was was a big one for me.

The hypoglycemia I guess was eventually linked to that to the BBC. I had night sweats, pouring night sweats where I would have to get up in the middle of the night and change my pajamas. Change my sheets?

A couple times a night. And you told this to the doctors, even with the drenching night sweats? Yes. And they never. Everything was just sort of looked at separately.

First of all, you know, never all put together and things like that were just considered sort of idiopathic, like. That's interesting. I don't know why.

And it's funny you mentioned that idiopathic because that that's of course, the term in medicine, it's kind of a joke among the medical profession that idiopathic usually refers to the doctor being a pathetic idiot because they didn't.

I'm sorry for any out there who actually are a good diagnostician, but, you know, in the HMO models and I don't know how many HMO doctors you saw, you're allowed to take, you know, maximum 15 minutes.

Did any of these doctors actually even spend a fair amount of time with you, or they you came in with this prior diagnosis and it kind of even gaslit them.

They thought, you know, you had something so they didn't even bother to look further to see what was going on. Right. And they and that's exactly what would happen.

Like, one person read to me from a dusty medical textbook about, mono and about Epstein-Barr virus. But no, no one had the time or the bandwidth or the, you know, interest or whether it was, you know, because of insurance a lot of time, probably, to really take a complete exam and to look at things like risk factors for tick borne illness, and to look at my complete medical history, to look at my lifestyle history, you know, just to to really look at a head to toe.

Nobody had the time to do that. The first time that that happened was I, went to see a naturopathy physician after I had been dealing with the Epstein-Barr virus for a couple of years and wasn't getting any better.

And though he wasn't, ultimately you know, able to figure out the answer, he at least did, you know, very thorough exam, was very thorough with me and validated me and said, like, we haven't yet figured out what's going on, but that doesn't mean that something isn't going on.

It means that we haven't gotten there yet. Right? So a doctor that actually understood that because I couldn't figure it out, it's not in your head. Right.

Exactly, exactly. So, Well, that that's good. At least you had one doctor along the way. But this is, again, many years later. So how many years where you're suffering with all of these symptoms until you actually finally got to a real diagnosis eight years.

Yeah. I was diagnosed with tick borne illness in 2005. And the reason that came to be, I was drying my hair one day, which is notable because I had such fatigue and such pain that doing something like that was difficult for me.

But I was drying my hair one day, maybe I was cold. Maybe I was having lunch with someone I don't know, and my elbows were up like this, you know, but for from drying the hair so I could see my elbows in the mirror and on each elbow was a bullseye rash.

And. You're one of these people. And by the way, this I would tell from people listening, this does not happen all that often, but it does happen. What I've seen over 13,000 chronically aligned patients in my career, but there have been handfuls of cases of people told me that there was almost like the symptoms came back from time to time, including the rash.

You don't really see that much in the literature, but I have heard that from patients. And it wasn't on, by the way, one part of your body, you had it on two different parts.

Two different parts. And at that point I had started getting used to writing symptoms off and thinking that, you know, so I actually went to the Non-Traumatic physician.

I said, I don't know, maybe I was just leaning on my elbows. Funny. And, because I was so used to people doing that to me. And he said, no. He said, you know, I have been suspecting an underlying infection of some kind.

Because you're not getting better from the Epstein-Barr virus, and those look like Lyme rashes, and you should go see a Lyme specialist. So that was finally the clue was finally those rashes that came out in a natural spastic physician diagnosing you.

Exactly. At least leading. You want me to call? I'm doctor. Yeah, exactly. Now, regarding the testing, and obviously, if you went to the right line doctor from the beginning, and I know you did see you finally a line literate physician, did anyone along the way just do an Elijah and not to a Western blot did they think of Lyme?

But just do the Eliza and say the Elyse is negative. You don't have Lyme disease. That's exactly what happened. So and and that wasn't until six years in maybe so I don't even know if I was ever tested for Lyme early on.

I don't not that I remember, not that I remember ever being told that we're even considering Lyme disease or being tested for it. Six years in, my mom ran into a high school friend of mine's mother, who it turns out had Lyme disease and was telling her my whole story.

And my mom called me up and said, this sounds really similar to you. Maybe you should get tested for Lyme disease. And neither of us yet knew the complications of Lyme disease testing.

You know, we thought you just go in and you get a test and then, you know, whatever the results say, you know, now, I know, of course, that that's not at all the case.

But I did. So I had an Elisa test done. It was negative. And I thought, oh, all right. You know, I had I had this hope for a minute of me. Maybe I have Lyme disease.

And then I got the result of that and was I said, okay, I guess I don't, and it was, it was been after a Catholic physician who later said to me, no, Lyme disease testing is really faulty.

And, you know, explain to me why, explained, you know, why that would come up negative. The two tiered system. You know, the. I didn't know any of that.

The game that I play with my patients, just again educating people listening to this is I love I Genesis in California because they do an immuno blot with recombinant DNA.

So there's no false positives. But I never just run in Eliza. But when I was running Western blots through the local labs like Quest Lab core bio reference, there's a game I used to play with patients called Lyme Bingo, and I would tell them if any one of these bands shows up these numbers on a Western blot.

Lyme testing, coinfections, and finally getting diagnosed

Bingo. You've been exposed to Lyme disease, or at least a Borrelia species like Lyme. It's the 23 out of surface protein C, 31 out of surface protein A, 34 out of surface protein B 39 and the 8393 and along the way.

So if someone comes in and says, I'm having good and bad days and they're having this migratory joint pain and I'm having migratory neuropathy, and brain fog as a young woman, and I'm extremely tired, and they score high in the questionnaire with even one band that tells me automatically they've been exposed to a really a species.

The problem with the Western blots is they only check for one strain of Lyme, and there's multiple strains at this point. You know, the adjunct checks for at least eight.

And you can have false positives with the 31 band on a local western blot because of Epstein-Barr, by the way. Or autoimmune disease. But unfortunately, you know, the state, this two tiered theory, that got out there, it's really only for health departments to screen epidemiologically large populations of patients.

The CDC, even on their website, they say this is not meant for an individual diagnosis. And I know this because I worked on the first round of the HHS tick borne disease working group.

Right. So it's really a shame because the way medical information is being disseminated, right. You go to med school, or whatever naturopathy school. I think the natural Pasteur.

Great, by the way, because I think I practice probably closer to a natural path when I've learned what they do. But unfortunately, after you get out the training in an epidemic like this because it's it's insufficient.

Like they need yearly, they give you a yearly training for narcotics, for end of life things, for sexual abuse. But they don't give you training for things like Lyme disease, which is an epidemic proportion.

And that's really a place in the health care system where we really need to make some changes. So, yeah, your story is really classic in that way. So again, so now we're get 2005, 2006 you the natural path is putting you on.

So after that, how many doctors did you finally see before you actually got the diagnosis? Thankfully just one. Because, because the person who my mother had run into that person with Lyme disease recommended me to her doctor.

All right. So I went to him. I was tested by a Gen X, I had a CDC positive test, for what it's worth. And. By the way, do you remember what the CDC test, if it was IgG m or IgG positive.

I think it was both. Okay, the reason that I say this is because in a lot of Lyme patients, when Borrelia burgdorferi, the agent of Lyme, gets into your lymph nodes and a lot of patients, it wipes out the B-cells.

So you only make IgG antibodies and you don't make IgG. So these people come in with CDC positive exam, immuno blots, Western blots. And the doctors will sometimes say it's a false positive because you've been sick for so long.

And IgG is only early disease. But in Lyme it's early and it's late because of what happens immunologically to the body. So yours was both. You actually had a.

I my recollection is it was both. I do remember seeing on the bloodwork it's you know written it's in CDC positive with a big circle around it like no.

No. Question and. But BS. Yeah. Because you were having those nights where the BCA test came in. And are looking at as well. Okay. And the test was it I Gen-X was it a fish.

Was it active BCA or is a the BCA micro D Duncan age you remember at the time. Like what strain. At the time. Yeah. Because again a lot of patients they the doctors are smart enough to say, oh you're a young woman, you've got night sweats.

They do a differential diagnosis like you're not in menopause. You don't have hypothyroidism. You didn't go to India for malaria. You don't have tuberculosis or non-Hodgkin's lymphoma.

In other words, they do a real differential. And then they realized, like, okay, it's the BCA, but if they don't check for all the strains because there's the BCA, Mike protein and the BCA.

Duncan I others that are now in the US like MI1 K1, they will also miss it. So the advantage of the eugenics test with the fish test, it'll tell you even in people that are immunodeficient it, you can see it under the microscope.

And T labs also does a very good job with this, including a new species called, the BCA, OTA coli, which comes from Canada. So we're starting to see these species, in our practice.

So when you finally saw your live letter at doctor, did you do a separate BCA treatment apart from the line treatment? Yes, yes, I did, I did, and anti-malarial medication.

And this is the thing that I'm always saying to patients or, you know, people when I'm trying to spread awareness about tick borne illness, is that other tick borne illnesses require different treatment, particularly the BCA.

And so I'm always saying to people, if you only think you have Lyme disease and you're only treating the Lyme disease, and you actually also have the BCA, then you're only fighting half the battle.

So, so yes, I was on anti-malarial medication, and, and I wouldn't have gotten better without that. Right now, when you did this, you did this treatment for with the Antimalarials back in like the late 2000.

So at the time when this happened, actually, now at the time. Mehran, is this from acceptable? Was that remission was the classic treatment and it did work.

I mean, my first case in Dutchess County, I had a woman in a wheelchair for five years who couldn't walk with chronic Lyme with drenching sweats. I did the differential.

We sent out the checks from Dutchess County. We sent out her blood positive and she ended up walking months later from Mapmyrun. Is this from now? Fast forward, you know, almost 20 years later, the map from X is not working so well because the parasites have become resistant.

So where it's I mean, it's becoming a nightmare, honestly, for some of the clinicians out there, because even though there are some newer treatments like, it's a fan of Quinn and a Tova clone, I don't find it works for every patient who comes to see me.

And it may be because it's these new strains of the bco to Coley. But thank God for you. It did manage to make you better because. But makes all your symptoms three times worse.

That's, And it's the one I've struggled with the most as a, you know, as my journey has gone on, it has been the

symptoms relapsing more than other symptoms.

That too has gotten better and better and better. Knock on wood. You know, so it used to be that I would have to be retreated for a Busia every six months or so.

Now, I haven't been treated for by Busia in at least five years. And, and I'm feeling great, knock on wood. And so. You know, with all this trauma that you went through, I mean, one of the hallmarks of your book is the resilience that people have to get right and speaking up right.

Not not just accepting like you. Unfortunately, in this day and age, with these diseases, you actually have to, in fact, be your own advocate. Tell us a little bit about that journey.

Like do you think you had resilience as a kid and it was just something you came with or something you developed? And because it's really important when you're dealing with these chronic illnesses to have resilience and to get to the place where you are now, you think it was something innate in you, something you developed over time.

How did you develop it? What what do you think was responsible for it? That's a great question. And I think it's a little bit of a combination for me.

I think I learned resilience as a child, ironically, as a camper at the summer camp where I got the tick bite when I was 19. That was the summer camp that I went to every summer for seven weeks.

And, we just, you know, you had to really work through things. Work through, different honors and challenges and, you know, the skills that we were learning.

And part of what we were learning at that camp was resilience. And, and so I feel like, you know, the place where, where I happened to get sick is also the place that gave me the skills to survive that illness.

That's fascinating actually. Yeah, yeah. But also, I think, it was my friends also, who were my stalwart supporters, even when we didn't yet know what was wrong, they, you know, believed me, stood by my side, believed that things would get better, kept the faith for me even when I had lost it completely.

And I think that that really helped me to be resilient and to not give up, even at times when I wanted to or I was ready to, so I think, I think it was sort of a combination of those things and probably also just always sort of being a, a go getter.

And, and a people pleaser and, you know, wanting to do well in school and at my job. And so I wanted to do well in healing from Lyme disease. You know. Right.

Because you don't make it onto the Harvard Lyme Wellness Initiative without being a go getter. That just doesn't happen by accident, right? At at that point in time.

So, no, it's great. You're kind of giving back to the community and let them know your write your story with it. But so your friends were really I mean, everyone needs a good support system, obviously.

And by the way, many of these support systems, people get burnt out. I mean, I've had patients divorce where, you know, the husband, the wife was sick for many years and the husband couldn't take it.

He just didn't have it in them. And I don't think we're trained in the society. You know, we get married in. It's for better, for worse. I don't really think we are taught the tools that we need.

In marriage, my my wife and I are about to do a, stand up comedy soon about our marriage and, things that I've decided in my medical career.

Treatment, Herx reactions, and relapse

It's time to branch out a little bit. We're actually talking about our marriage and after 20 years. But I will tell you, even resilience in marriage of, like, the tools you need to get along with someone and to make it work.

I wish they would teach these things in school because they don't teach parenting skills. Could be an important tool, considering about 97% of the kids that come in have dysfunctional parents.

I see three out of 100 come in with loving one parents. I look on them, I go, hold on, I just want to examine you for a while and take this in because I barely ever see it.

I your family, it sounds like they were supportive, but do they believe you in the beginning or they were not really on board and, like, couldn't understand, like, who you were and what was happening to you?

How how did your family react to this and how did you react to them? They were skeptical, skeptical in the beginning. And they were scared, you know, which I understand.

Like, you know, when I look back now from a point of reflection, I can see how hard it is for caregivers, how hard it is for families. When you know someone in the family is suddenly sick and they're not supposed to be.

It's not at all times a time in their life they're supposed to be out on their own there. And then, you know, young 20s supposed to be, and then suddenly they're sick and they're back under your roof.

And so, so I can look back now and see, like, that was really hard for them because, you know, they didn't know what we were dealing with. But yeah, they, you know, definitely had that had the skepticism in the beginning.

And then even once I was diagnosed with Lyme disease, there really was, and other tick borne illnesses, you know, tick borne illness, there was still not really an understanding of, you know, what those illnesses were.

I was mostly going to doctor's appointments on my own, you know, it's that's changed a ton. Now, my stepmom will come with me and, you know, ask questions and take notes and is very Lyme literate.

But there was a definite learning curve for all of us. And actually, I write about in the book, you helped change it for them, Doctor Horowitz, because they went to there was a Lyme conference in Connecticut one day with several speakers, including you.

And, I said to them, I would tell my dad and stepmom, you know, I'm too sick to go, but I would, you know, would really, you know, love it if you might be able to attend this conference.

And they came back from the conference and they had heard you say that you could see a thousand patients and have a thousand different protocols, and that every case is different.

And they came flying into the house and said, you really have Lyme disease. Yes. So directly by speaking at that conference held, by the way, at those Connecticut conferences, I know which ones you're talking about.

Senator Richard Blumenthal was governor. Connecticut, the time it used to joke that every time I was in Connecticut speaking at a conference, he would somehow come to the conference and interrupt me during my talks.

I don't know if this happens at the time when you were there, but I used to have this joke with with Senator Blumenthal about how does this even happen?

It happened, I think, 3 or 4 times, like, but it's funny, but I'm happy that somehow I was able to play a role in convincing your family. And by the way, it brings up a great point, the education for for Lyme disease.

It's not just the patients. It's got to be the caregivers. It's got to be the family members. Because if you're not believed and you're not supported, right, in a healthy way, kind of makes the healing road difficult for people.

Right? So yeah, until that point, I felt like I was getting a lot of pressure from my family of like, when are you going to get better? And, and not understanding that, like, there are some good days and there are some bad days and this isn't going to be a linear path.

And I felt like after they went to that conference, there was a greater understanding of that. And, and the difference for me, by the way, when I if I would have said that at the time and it and it is true, by the way, that if I saw a thousand patients there would be a thousand different protocols.

But now after doing this for 40 years with 13,000 people, for me, in my world, the Daptone protocol daptone combination therapy hitting these biofilm, persistent forms, pulsing it, looking for a BBC, treating Bartonella with pulses, looking for mycotoxins, mold illness, checking for leaky gut and food sensitivities, looking at the microbiome, making sure there's sleeping, checking vitamin minerals.

These are all the six factors that drive inflammation with pots, too. So on anemia with low blood pressure. Which which happens from Bart and mold and long Covid and and it's complicated now because the patients with chronic Lyme we're seeing now never of course, just have chronic Lyme disease.

They always at this point, are showing up with other factors. But the long Covid piece has made it difficult with Epstein-Barr reactivation. And I'm in the middle right now trying different protocols because the adaption protocol is highly effective and is getting many people into long term remission.

My my wife is six years in remission without one symptom. But, the long Covid patients, I must admit, we don't have answers yet for them, and I'm still trying to work it through.

It's it's becoming a very I think from my standpoint, we need chronic disease centers of excellence. You know, your story of the doctor doesn't take enough time to listen for me, because chronic diseases are like 86% of our health care costs and 70% of the deaths in this country are chronic disease.

I've always stood up and said, I think the model, we need a paradigm shift and we should have chronic disease centers of excellence. So someone like you, you're you're a bright young woman.

You went through college. You don't have to be a psychiatrist, by the way, to look at you and go, this woman is not crazy. She is sick. Forget just the fevers, all right?

I mean, it's a whole nother story, but but. And that you if you go to a few doctors, it's like, go to the Chronic disease Center of Excellence in Connecticut, in Maine, and let them spend a couple of hours running through protocols.

We really need this at this point in time because our system is just not equipped to be dealing with people like you. And, you know, the Lyme docs out there, I train them and I do it.

There's only so many of us, right? This this is why I'm now trying to go for, NIH funds for randomized, multicenter, placebo trial. I'm in the process of working with an agency.

So maybe by the end of 2025, I will actually have funds to start a randomized trial, because there's so many still questions about Lyme, right? Even almost after 50 years, roughly, of discovering this, you'd think we would have made more progress.

We have in my world. But people like you, right. Who didn't, you know, see me years ago or others. You go from doctor to doctor looking for answers. And I think we really need a shift in the paradigm of how we're looking at chronic illness.

I think that would be fantastic. I highly support that idea. I think that would have been really helpful for me. Would

be so helpful. For so many patients with chronic illness, you know, to help, to get to the bottom of their symptoms and to, you know, help recognize that they do have multisystem infections, whatever those infections might be.

Multisystem complications, illnesses, inflammation, you know, looking at all of those different factors and, and, you know, looking at the whole person and their whole history, and truly helping people to get, well, not just a 15 minute appointment, you know, check off a diagnostic box, maybe get treatment, maybe not get treatment.

I think that's an excellent idea. How many years did it actually take through the treatment? Now that you got the treatment, you finally were with a line literate doctor.

How long did it take you to go through the treatments before you really started noticing? And how bad, by the way, with the time of reactions? Because people also sometimes need to know this healing journey can be a roller coaster ride for people. What was it like for you?

It really is. And sometimes, you know, they they talk about two steps forward, one step back with tick borne illness. It can actually be one step forward, two steps back.

And you feel like, you know, I'm really not going to get it anywhere. But you are. You are ultimately moving forward. So I was on nine months of intravenous antibiotics, as well as on the anti-malarial medication.

And when I first began all of that, the Herkimer was horrendous. I felt worse than I had ever felt. Everything came out, you know, worse than ever. I called the doctor, I spoke with the physician's assistant, and she said, that's great news.

That means everything is working. Stay the course. And I'm thinking, what? Why is that great news that I'm feeling terrible. But I think it just. I mean, killing me.

You're killing off the bugs. But but I to tell for people, you know, listening out there, there are also good hurricanes and bad hurricanes. And there is a difference because the good works is wow, I worked and had all my symptoms come out.

My fatigue, my aches and pains, my brain fog could be a couple of days, could even be weeks. And then when the heart stops, you move up to the next level of health.

But there have been people in the past where it's a barracks where they works and hurts and hurts. They stop the treatment and they're back to where they started.

And that means there's something usually interfering, right, with people getting better, that there's other inflammatory factors or downstream effects from the inflammation that's interfering with the healing process.

Fortunately for you, yes. I mean, ultimately you had good hearts and ultimately the load of the bugs got better. And, and you did improve. And it took probably about a year to really see improvement, to be declared in remission.

And my life was not back to what it had been, but it was, you know, so much better, than what it was when I was totally bedridden.

Resilience, family support, and advocacy lessons

And I went off of treatment entirely. And dove dove back into life. To quickly, I sort of had this mentality of like, great. I've been sick for years now. I'm done.

I'm finally getting back to life. All I could talk about was that word back. I can't wait to get back to life. I can't wait to get back on track. I can't wait to get back to work.

And so I dove in. I moved to Vermont. I was trying to get back to that skiing lifestyle. And I, you know, started

working, and I relapsed completely within three months because I had no defenses in my body.

I had no, you know, I was on no medication. I dove in way too fast. Put in, put my body under way too much stress and was all the way back to 2.0. And then, you.

Know, and just a point about that, I've had patients on 12 months survivor herself and not through me, but through other doctors who relapsed within a month off the treatment.

And then I gave them a persistent biofilm rock protocol like that, some combination therapy. And they stayed in long term remission. And at the time when you were being treated, by the way, we did not know about biofilms and persistence.

No one knew about it. So you were it's not like it was the dark ages, but you were being treated with the best treatments that all of us had at the time.

But it wasn't until I think 2000, it was about ten years ago, 11 years ago, when Johns Hopkins researchers and the ever shot me from the University of New Haven and Stanford, Kim Lewis, they all started then talking about biofilms and persistence.

That's when the light bulb went off in my head, because I had similar patients to you that went to doctors for a year on row seven and relapsed. And by the way, when I check people's adrenals, we always do their adrenal function and hormones.

I tell people not to do what you did, which is go slow when you start going back into life because adrenals are in up to speed. It's like the battery of your body, right? With the adrenals.

Apart from thyroid and everything, you don't have the bandwidth right to, to be able to to do that. And I have people feel so good on the treatments, they rush out and play tennis for six hours and they're in bed for three days after that because they just overdid it.

Yes, that's exactly right. Yeah. I didn't know the term post exertional malaise then. You know, that's now part of the lexicon because of long Covid. We didn't have the same treatments then, you know, just as you were saying, I was on IV seven because that was considered the best at the time, and I did lose my gallbladder as a result of it.

We knew that that was a risk at the, you know, and it's just so treatments are different now. You know, like, as you said, we did the best with what we had at the time.

Yeah. No. So, you know, you're this is a great. By the way, this is a great story. And I want to remind everyone for people have not read this, you really need to read one to stop the clock, because Jennifer is very eloquent.

In this book explaining it. And I think for people out there who have suffered and have gone through it, it's always good to like, hear from someone else, like, hey, I wasn't the only one.

This is exactly my story. Your story is really many people's stories who are out there with this. So, so just a final word of advice. You've been through all this.

You're obviously much better. What words of advice would you give to the doctors you've seen before? To the health care system, to friends, family? What would you say after everything you've been through?

What with what do you think needs to change at this point in the system so that people like you are believed? So, I mean so much. First of all, I think the most important thing for doctors is listen to your patient.

You know, listen to your patient, and they'll tell you what's wrong with them. So, you know, really take into account the patient narrative. And I know that the insurance companies make that nearly impossible with 15 minute, you know, appointments, you know, but but figuring out a way you know, to, to get a patient's full history, what I

recommend to patients actually is to write out their history and write a synopsis of it in 1 to 2 pages to bring in to the doctor.

And sometimes give it to the doctor beforehand that they can read, so that, you know, you're saving some time. It's all, you know, it's all written out there.

So that's one piece of advice I have. And, you know, for others out there just to believe these patients, you know, even if someone doesn't yet have a diagnosis, it doesn't mean that they're not sick.

It means that doctors haven't yet figured out what's wrong with them. But no one knows their own body better than that person. No one knows your body better than you do.

And so, you know, for patients, just, you know, continuing to be your advocate, to speak up for yourself, to say, no, something is wrong here. I know something's wrong. I know you know.

And pushing on to the next doctor, you know, until you get an answer. Because you deserve that and deserve to be, well, yeah. You know, I think the validation has become a little bit easier in this day and age.

Mostly from long Covid because a lot of people weren't believed with long Covid in the beginning. And then, you know, all of it now you can get disability payments for it.

It has been believed. And, you know, the the American Academy of Sciences are talking, you know, infection associated chronic illness. I don't particularly like the term because and the reason I love chronic Lyme, which most people say it's an outdated, but it is a chronic infection.

Sorry, folks, it is, and I like Lyme since because by saying it's for me multiple systemic infectious disease syndrome, it tells people there are 16 factors that you need to look at.

So at least you have a map to go on a journey for someone like you, you know who is sick and you're not. Just like, where do I look? It's like the model gives you hope.

To know that is the road that you need to be on to find the answers. But I think it's gotten a little bit easier. But I will tell you, I'm reaching out at this point for, you know, people to do randomized trials.

And it's interesting. Some of the responses I'm getting even back from research is still like, well, we have so many questions about this, and it's like, you're not really in my world.

It's like I don't actually really have that many questions. The biggest questions I have is what is the best treatment for long Covid? Because it's one of those nails in the foot that is interfering with some of my patients getting better from, some combination therapy and some have gotten better with disulfiram.

The other persistent drug that, you know, Doctor Lehner has published on, Jen, I want to thank you so much for taking the time to write your story. Get it out there for people.

I, I've written books, and I know what it is to write a book. It is not an easy process. And you know this yourself after being through it. So thank you for taking the time today again for everyone.

The name of the book is one take Stop the Clock by Jennifer Crystal. Jen, thank you again for today. I think people are going to get a lot out of our discussion today.

My name is Doctor Richard Horowitz. I'm co-host of the Healing Lyme Summit 2.0 with Doctor Talks. We look forward to seeing you again soon. Thank you for joining us. Thank you.