Your Family Against Lyme: The Leland's Journey To Healing Transcript

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Introduction and guest bios

Good morning everyone. My name is Dr. Richard Horowitz. I'm the co-host of the Healing From Lyme Summit, and it's a great pleasure to introduce to you, Rachel and Dorothy Leland.

They are the authors of Finding Resilience: A Teen's Journey Through Lyme Disease. And we're going to discuss a mother and daughter's journey, through Lyme disease and what it took to get Rachel eventually better.

So I'm just going to read the bios for both of them, and then we're going to kind of jump in and tell you kind of the story of how, both of them, rich detailing on their journey to Lyme disease.

So Rachel Leland is a speech language pathologist. She's assistant who loves working with children. She was born and raised in Northern California and now resides in the Pacific Northwest.

She likes to film and edit videos, which features are an Instagram page. @resiliently rachel. Through her words and videos, Rachel seeks to inspire, educate and offer a beacon of hope to others dealing with chronic illness.

Dorothy Leland is President of lymedisease.org, a national patient advocacy organization, and in that role she spearheads the group's public education efforts.

In addition, she writes the blog Touched by Lyme and is co-author of the book When Your Child Has Lyme Disease: A Parent's Survival Guide, and she lives in Northern California.

So we're going to discuss today the journey that Rachel started on at age 13, when she got sick. She was seriously disabled for what turned out to be Lyme disease and co-infections.

But of course they didn't know this at first the way most people don't. And the book tells not only Rachel's story, but also that of her mom. And passages written by Dorothy are interspersed with Rachel offering a unique picture on how Lyme disease can affect the whole family.

So, Rachel, we're going to start off with you. Why don't you tell us a little bit about yourself? You're a healthy young athlete. Then things started to go terribly wrong.

Tell us about your story a little bit. Yes. so, yeah, I was 13 years old. I'd been a year round soccer player. and for the past couple years, starting probably about like 10 or 11.

I had a lot of knee pain that we noticed when I was doing soccer, but it didn't slow me down other than just we were aware of it being there. But we went to doctors and they were like, you're just growing.

It's fine. But then, on March 12th, 2005, I was 13 and I fell on a soccer game and I sprained my wrist. And although we just thought it was just a wrist injury, within two weeks, I was just in body wide pain.

I was on crutches. Two weeks later, I was in a wheelchair, mostly from knee pain and ankle pain. But I had only injured my wrist and we were very, very confused.

And it started us out on this journey of trying to figure out what was causing all of these symptoms. So, so question. When you started getting these aches and pains, a lot of the Lyme patients that I see, they have migratory pain, migratory joint pain, migratory muscle pain, migratory nerve pain, tingling, numbness, burning, stabbing.

Rachel's sudden decline and early symptoms

Do you remember at the time whether you had any migratory pain when this all started? Yes. And it was very confusing because, again, I'd fallen on my wrist, but then all of a sudden my ankle hurt and then my other ankle hurt.

And so one day I'd have like, my foot would feel like it was on fire, pins and needles. And then the next day the other foot would feel like that. And then my knee hurt and eventually both knees hurt.

But it just it moved around a lot, which was very confusing and makes it so that it's hard for people to sort of believe your story, that you're injured or something real is happening when it keeps moving and your story keeps changing.

Right, so so the migratory aspect was there, but none of the doctors early on actually knew to ask you that question, right? No, not at all. In fact, they questioned my story as soon as it started moving around.

Got it. Okay. And Dorothy, what was going through your mind while Rachel was getting this sick? What was happening? Well, my child was was deteriorating before my eyes.

And we would go to doctors. We had, you know, good relationships with doctors. So we thought and and but as it got weirder, they were starting to not believe us.

Like like you were talking about the migratory. It was like that was in their mind that was proof that this wasn't real or that, you know, she was making it up and it was, it was it was terrible because the people that we were turning to for help were shining us on.

And, you know, my child just seemed like she was, you know, just just going down, down, down and on top of the physical stuff. She was. She was scared. We were all scared.

She was, you know, kind of, you know, depressed and crazy and just. It was it was awful. It was. It was just simply awful. And there was no, there was no place to go where somebody sort of said, okay, let's just look at the whole thing here.

Let's, let's let's see what all of this is. It was just done in this very piecemeal fashion. And so apart. And obviously she was in perfect health before this.

So there was like no reason to suspect, for example, that this would have been psychiatric because a lot of the doctors and you know this from personal experience, when they can't figure out what's wrong, they tell patients it's in their head.

Right. Although Rachel was completely healthy, obviously, you know, not somebody normally had psychiatric issues. And that doesn't usually cause those kind of physical symptoms. So, how many doctors think you're having to take her to before you.

You end up figuring this out? I've never sat down and made a list. we went in addition to to ones in in our group, you know, our medical group, we were referred to a children's hospital, and there was a whole bunch of, of of practitioners there.

And then, subsequently, when we she actually spent a month in this hospital that supposedly had a pediatric pain in it, but it became clear that they, they were operating from the assumption that pediatric pain came from psychiatric reasons and the fact that she had a, an over engaged mother was part of part of the problem.

It was like the fact that I was trying to help my daughter was evidence that I was hurting my daughter. So that was a that was a very, you know, just just a very troubling time for.

The almost like, almost like a Munchausen diagnosis. Like there was really nothing wrong with her. And you were enabling the whole. Right. They didn't ever use that word.

They never use that word. But but it was it was that kind of thing. It was that I should I should chill out. And you know, this, this would all go away.

And any of any of these tests they did at, I mean, being a month in the hospital, that's a that's a long time for this. any of the tests that they did give any clinical clues that you remember at the time, did they bother checking a Lyme ELISA didn't know the sensitivity or they didn't even think in Northern California that, Lyme and tick borne was a problem because I know California was it's underestimated in general.

They, even though, of course, it's it's spread throughout the state. So, were they not even aware that there was a problem with Lyme in your area? Well, I was it happened that early on in our process before she was in the hospital.

But when we were going all these doctors, I mean, there had been various scans, there had been an MRI of her wrist. And that was really a turning point when the MRI didn't show anything wrong with the wrist.

Medical dismissal and hospital ordeal

And yet she was in this immense pain. It was like there was a real shift there. And it was like, oh, okay, this is really all psychiatric because there's nothing wrong with her wrist.

And she says it hurts. And it was just, I'm sorry I lost my place. I was saying there the Lyme test, the. Oh, yes. So there were various scans that were that sort of thing.

but there was a, a neighbor had said to us that, you know, do you think this could possibly be Lyme disease because they knew somebody that had a similar situation and that's what it was.

And so we asked, you know, we asked and they practically threw us out of the office. It was like we didn't know that those were those were dangerous words.

When you say Lyme disease, that was fighting words. And it was like, no, absolutely not. you know, no, you know, no, no, no, no. Lyme disease can't be can't be Lyme disease.

So when she was in the hospital, they were just going off the original ELISA that had been done before. And, and and they just said there's no reason to pursue that because she's negative here.

And I was starting to learn more. And I had found that there was this thing called a Western blot, but I didn't know enough to know that. It depends on what lab you go to.

So they finally did order a Western blot and it said that it was negative, but they wouldn't, even though I asked, they wouldn't even give me the paperwork that came from that, that so that we could know anything about it.

They just said it's negative. And so it was just it was a very it was a very bizarre time. And when we finally left the hospital, they were just, you know, these very important, specialists were telling me there was a whole committee of them that sat me down and said that, you know, that this she just needed to to get over this.

She needed to continue having therapy, you know, psychiatric therapy and and physical therapy and that I should give up my thought that it was actually written in the hospital records that the mother had an unrooted word, something an unrealistic, suspicion that this was Lyme disease.

That was right. I mean, of course it's unrealistic when they see a whole team of doctors. Your daughter's in a wheelchair. She she can't walk. She's suffering.

and God forbid you, as a mother should actually say, well, gee, my daughter has been fine her whole life. She's not a psych case. I mean, it astonishes me.

And by the way, when they wouldn't give you the Western blot results. This was through a a local lab like quest lab core by reference. I finally got it.

I don't remember what the lab was, but it was. It wasn't hygenic. Okay? It wasn't hygienic. And it was something that, you know, as it said, I, you know, it's been years now since I looked at it, but it was just the the one that doesn't test for the for the bands that count.

Oh, so they, they had left off like the 31 bands. Right. And. Oh, absolutely. And they just and they just said negative. And when I asked them anything more about it at the time, they, they just said it's negative.

That's all you need to know. And I don't think, you know, it was just it was it was very bizarre. And, and it was just it was time to move on. And once, once we were on our own basically, you know, kicked out of the hospital and told to, you know, go away.

we did finally go to, I was I was looking for anything. And we finally went to, a local acupuncturist and herbalist, and she was the one that said, you know, I think we're dealing with Lyme disease here.

And, and I was going, oh, well, all these other people that I talked to said, you know, it couldn't possibly be Lyme disease. And he said, I think it's Lyme disease.

But he then said that he didn't know how to deal with it. And he said, you've got to find somebody that knows how to deal with it. And so at that point it was like, okay.

And so then I really turned to online patient support groups because those were the only this was 2005. You know, there wasn't Facebook, there wasn't all of these other kinds of sources there.

There weren't even even the organization that I'm now heavily involved with didn't have much information on its website at that time. And and so it was really the online support groups that there was California Lyme was one of them. And, that was it was a Yahoo group.

And I just I found a doctor through that. And, I found information and other kinds of sources. There was very there was very little information out there.

There was there were very few books with the word Lyme in them even listed on Amazon. It was just it was just right before a lot of this stuff, you know, came to the fore.

Well, you know, your, your book and I don't remember what year your book came out, but I mean, that was. Well, Why can't I Get Better came out in 2013.

Right. As a pilot. Yeah. Yeah. No it's fine. It was eight years later. It just wasn't the information. I didn't just wasn't there. Right. And so anyway, so then we did find, and I had doctor that was two hours from our home and, and that started our, our, our lives just pivoted in a different direction at that time.

Got it. So, so, Rachel, your your mom's searching. She's searching. She's, like, desperate. She loves you. She wants to get you better. What was going through your head at this point?

You had all these doctor visits. You're in the hospital for a month. Nobody's giving you any answers. What was going through your head during this entire time?

You know, it's like that hospital was a really pivotal time in my life because I went into that hospital very innocent and believing that we were going to find answers and believing that the medical community and that doctors were going to like, help us, and they were going to just like we were drowning.

And we really needed someone to help us. And so we went into the hospital, and I fully believed that they were going to help us. And then we left the hospital, and I'd been told that I was just looking for attention and that I

wanted to get out of school.

It's like I couldn't fathom. I loved school and I loved soccer, and those were the two things that were now hard to go do or impossible to go do for soccer.

And so that just didn't make any sense to me. And I spent a month telling people that I was in pain and just being flat out told that I'm not, and that, like, that's not the reality.

And so I left there so much worse off. And like, I was barely walking. They had taken the wheelchair away and wouldn't let me have crutches, wouldn't let me have wheelchair.

So then we went home. I basically didn't leave my bed for the most part, except for when I absolutely had to, and I was in so much pain. So it's like leaving that hospital.

My mental state just deteriorated because everything that I had known to be true was questioned. And then I was also just feeling so much worse because of it.

And so at this time, I didn't even know my mom was looking. I mean, like, things were so bad, that mentally I was just really struggling. And so, I mean, I didn't really know she was looking until she finally said, we have an appointment the day before Thanksgiving in 2005.

So. And things were hard. When you were suffering this way. I mean, you mainly focused in the beginning talking to me about, migratory pain, which is the hallmark of Lyme.

And by the way, for those people who are listening and tuning in, there were only seven diseases in medicine that caused migratory pain. acute rheumatic fever, hepatitis Dis, people with, Crohn's disease, your inflammatory bowel disease, people who have what's called Reiter syndrome, they may have salmonella.

You're skinny and it affects their joints. really? Lupus will cause it early in the course of an illness, and gynecol arthritis. And and by the way, and I used to joke with doctors, unless you're at the bottom of your medical school class, those other six diagnoses.

Pretty easy to be able to tell. Migratory pain, Lyme disease from those other six. so did you have other systemic symptoms? Because, for example, co-infections is the rule in my world.

And I know you diagnosed with them mostly with the BS, but Busia, Bartonella with Borrelia, Lyme did. Were you having like day sweats, night sweats, chills, flushing air hunger, but Busia symptoms, were you having those symptoms?

I was having every symptom that you just said. Yes okay. So and yeah. And none of the doctors asked you about those symptoms. They either didn't ask or they didn't care.

I don't remember at the time my biggest, my biggest issues were severe knee pain, severe back pain, and my shoulders were so hypersensitive that like any touch, my clothes bothered it, but like any touch, was absolutely not okay.

Finding a Lyme diagnosis

So those were like my biggest thing was pain at that time. Just. And those pain and those symptoms. By the way, you're describing, when clothes touch your joint or touch your skin and is so sensitive, that's called high precision medicine.

That's basically a form of neuropathy, right? That's when your your skin is so sensitive you can barely touch it. And it tells a doctor, right. If they've done this for a while that that is a symptom of neuropathy.

We also having the multi systemic symptoms of fatigue, headaches, brain fog, cognitive issues chest pain, shortness of breath, palpitations, difficulty falling asleep, waking up with you, having a lot of those other symptoms.

A lot of those symptoms, basically all of the symptoms you just said they started, pretty much when we started antibiotics. So once I saw the Lyme doctor and we started antibiotics, then every symptom you could imagine just piled on, right?

It came out like a hard time, a reaction. It came out when you were kind of pissing off the bugs. Yeah, it came out. And then it just, like, never left. And.

And this path when you got home and they wouldn't allow you to be in a wheelchair or walk with crutches. How long was this going on for at home that you were suffering this way while your mom was looking for answers?

We went home in August and then we had in November is when the Lyme appointment was so from August to November. But we got even though they forbade us from having the wheelchair, we we went in October and rented a wheelchair again because it was just, you know, it was it was just clear.

It was when she was home, we actually would push her around or she would scoot herself around on a wheeled office chair because that was something that we could do at home.

The wheelchair wouldn't, you know, wouldn't work. But with school, it was just impossible. It was, you know, it was just impossible. If she was going to get from one place to another, she had to have a way to do it.

And so we we went back to the wheelchair. And, you know, it's interesting, I mean, I, it seemed to me there's a, there's a whole psychology apparently around wheelchairs.

And they often accused me like when I, you know, when I would ask questions about something and when I say them, I mean the before the line doctor, the other people that we saw, they acted like the fact that I had gotten her wheelchair had been, like, giving in to her.

And, you know, just just enabling her. Well, it enabled her to go to go across the room when she couldn't, couldn't do it otherwise. It was it was it was very strange.

It was, it was, it was very, very strange. Right. And Rachel, during this time when you're in the wheelchair and you were getting around the house, you were still in severe pain.

You weren't sleeping. And I understand you were even bleed while you were trying to go to high school. And you you kind of wrote about this in a journal.

So what what was your journal like at this point? Can you tell us a little bit about like, what that experience was in and writing about it in the Journal?

Yeah. So we used my journal, I kept a journal. It ended up being over 500 typed out pages. And so that was a huge, part of what helped us write this book.

And so, yeah, we speak about bullying. I mean, it was I know a lot of people that have, you know, bullying is a really big thing. That had never been something I dealt with.

And then I show up at school in a wheelchair and, and there was just one girl that took great offense to it, someone that I had like, never, you know, never had anything to do with before.

She just always been in the background and she just like honed in and would just be telling me I was making it up and I was stupid and she would be swearing at me.

And it just it was just ridiculous. I mean, it was just every day she would just see me and she would just say some

hateful thing towards me. And it was very much maybe she thought I was taking attention away from her because I was sitting in a wheelchair.

I mean, it was very bizarre. I was in seventh grade. Right. And did you have friends or support? I mean, high school can be a brutal experience for many people.

Like I can remember, actually, the bullies in high school where I had to actually get in a fight once or twice to stand up because it was like the only way you were going to be able to have them leave you alone is you couldn't you had to stand up.

But, you know, you're in a wheelchair. You're you're disabled. did you have any friends or support in school with this? Or you were pretty much alone at this point?

No, I was very lucky. I had a really good, network of friends at home, but then also at school. and so, yeah, so I had a whole bunch of support, which I was really grateful for.

So, I was very lucky in that. And were your teachers aware of the situation with the bullying of what was going on or wasn't something like you talked about with them?

It was almost like you were a snitch. If you did, you had to put up with it. Like, is was that kind of the, yeah. That you were in. It was in my mind as a as a 13 year old, I was like, I need to document.

So what my friends and I decided to do because they all saw it, it was out in the open that this girl was doing it. So any, any time she would do it, we would get out the special folder or the special, notebook and we would write down exactly word for word what she said.

And so then I made it very clear I wanted it to be exactly what was happening. And so I felt like once I got enough, then I could go to the principal.

But she ended up finding out and grabbing it and ripping it up. So then that ended up bringing us to the principal earlier. But yeah, and then they were aware of it, but they didn't really do much.

But they were aware of it. Yeah. So you know, a huge part a huge part of your story right. Is, is denial. The medical doctors, first of all, they didn't know how to take a proper history.

They were in denial that there was ever a problem with the tick borne. They were in denial, right? With with Dorothy, with you about the fact that you're a mom, knowing your child, like knowing who she was and that she was not making this up. So, what was this like, just being in denial from an entire medical system that you're searching urgent, Lee.

Right? To get care. You couldn't get that care. And ultimately, it came from. Right? An acupuncturist, somebody who was outside normally the regular classical medical field.

I mean, that denial must have been overwhelming. And I know, by the way, of course, my patients who come to me, I mean, I've seen over 13,000 people at this point during the last 40 years.

The vast majority tell me the story of denial that the doctors don't believe them and that it takes ten, 20, 30 doctors. The highest, by the way, was 100.

that that is my all time high was 100 doctors before they finally got the diagnosis. So again, this this denial with the medical system, it's a horrible thing.

And at the time, of course, in the early 2000, you're right. I mean, people didn't know a lot. But I will say, on the other hand, the disease had already been around at that point for almost 30 years.

Right? Alan Stear and those guys had already discovered this in the 70s by now. So, what was it like dealing with this denial with everybody?

Treatment reactions and psychiatric hospitalization

I mean, already you were psychologically anxious and depressed, so, and then being bullied, I mean, I know your book is about finding resilience, and I have to say, I mean, my God, if there's any way to find resilience, it's like I have an illness.

It's hopeless. Nobody knows what's wrong with me. I'm being bullied. I'm being told it's in my head how do you go from that to where you are right now?

How did mentally you you managed to get through all of this? Yeah. So I mean, the the denial thing, that is something that has I mean, that was set in stone in my brain as a 13 year old.

And that's something I still deal with today. I go to a doctor for some random, obvious thing, and I'm most concerned that they're going to not believe me.

And so that denial just really set the foundation of never trusting any doctors, like, for any reason, which I feel like in our culture, people think, oh, doctors, you know, they're so great.

You just do what they say. And that totally changed for our family. Like once this all started happening, we started being like, wait a minute. Doctors are not the safe people.

They are the most unsafe people I've been around. And it wasn't until we finally met our amazing Lyme literate doctor that we got to experience what, like every doctor's appointment should be like.

We got to that appointment. And I mean, it was two hours long and he was just listening and fully believing everything we said, just believing it without without question.

And that was absolutely amazing. And so that was so important for us at that time because up until then, everything had just been written off. Right. And Dorothy, during this time.

So finally you get over to this doctor you're finally listened to. Did what kind of did you have that feeling of validation that, my God, finally, right.

I was proven as a mother that I was right, that, you know, my child was sick. What did it feel like to you to finally have somebody listen to you? After all those doctors you went through?

Well, it was it was a great sense of relief. And, our hope, Rachel mentioned it was. It was the. It happened to be the day before Thanksgiving, late in the afternoon on Wednesday because they'd had a cancellation.

And so so we went and it was two hours away. The whole family went. Rachel's brother was there too. And and we went and we came home and sort of felt like we really had something to give thanks for the next day on Thanksgiving.

And I, I think I might have noted this in the book. I don't remember offhand, but Rachel slept better that night than she had slept in months. She had really had very poor sleep.

And she's like, like slept through the night. And that wasn't the end of her sleep problems. She continued to have sleep problems, but but that night was really it was really amazing.

I think it was just just a, you know, we just just felt like a burden off of our shoulders. But the plot thickens. Once she started on antibiotics and once she started her thing, there were some things that really, really exploded in a bad way.

And, and so it was, it was a very it was a very hard time. And, but Rachel, you know, Rachel kept keeping those notes, in her, in her journal. And, I don't know, Rachel, if you want to talk about that.

Yeah. So, I mean, like, you know, we had gotten this diagnosis, we were like, finally. And life was fantastic for about a week. And then we started the antibiotics, and then the first hurts hit like, a few days or a week later, and then it just, like, plummeted so far below what we thought rock bottom would be.

I mean, physically, I deteriorated so bad that, like, I could not breathe sitting up or lying down flat. So we had to get a hospital bed. I had to be reclined at like at all times if I was to be able to breathe, and my mental state completely just fell apart to like such a deep, low, and I ended up being hospitalized in a psychiatric hospital, because of just such severe depression.

and yeah, I just got really, really bad really quick. And you were you were warned about the time of reactions by your, your doctor, like, they kind of gave you an upshot, which is, look, when you're killing off these bugs, they fight back.

There's going to be an inflammatory reaction. Whatever your underlying symptoms are, they get worse. Although based on what you told me, the pain was your most, you know, frequent symptom in the beginning.

And then all of a sudden, as you said, it all kind of came out. It was like I thought I was bad before, but this is worse. And the psych part, it sounds like you were not really expecting like, oh my God, even the depression anxiety, right?

That it all gets worse during the treatment. So, how how long were you, if you're willing to share this? Because I'm sure it's at tender time with it.

How long are you in the psych unit with a understanding? At the time of what was going on, did they at least have an understanding of Lyman houses and or they were still like, oh, you need medication.

Your how how did that go? So I was in on a 72 hour hold and thank God no longer than that. Mom, my mom can explain about everything else. Well and she she she ended up there or it was like by the time we got there, first of all, you have to find, you know, we gone to the local emergency room and then you have to get a referral to a psychiatric place, one that takes adolescents.

Not many of them take adolescents. And then they have to have an opening. And so they so it was like midnight, midnight. They were at this place and and she was there and, she absolutely has.

She hated us at this point. My husband and I, I mean, she was just like all of her, pain and everything was, you know, directed, directed at her parents, and but but we were there, and, they, they had a they only had a bed that could lie flat, and she absolutely had to be at an angle.

Family strain, support, and advocacy

And, and so we were talking to them and it turns out there was one hospital type bed in the, in the place that, that had, you know, you could have it at a reclining angle.

And we talked him into it. So again, there's that pushy mother again. Yeah. That's so, so, so they were there and, it was too late to to do. They just said you can talk to doctors tomorrow.

I had brought a whole, you know, bag of, of medications. And I talked to the doctor on the phone the next morning and he said, well, he, you know, he.

Yeah. He said, I used to live in Connecticut. And so I know all about Lyme disease, and this isn't Lyme disease. And, you know, he'd seen her for ten minutes at that point.

And so. so, by the way, this was the psychiatrist who told you this. Was the head psychiatrist? This was the head psychiatrist. Lovely, lovely. Facility.

And so but so, so he knew offhand, you know, he, you know, right away this wasn't Lyme disease. And so she didn't have to be on those medications. And I offered to set up a phone meeting with her doctor and, and, to see if, if I said, you know, we could discuss this, and.

Well, that wasn't necessary. And anyway, all of my powers of persuasion, he agreed to to let her keep the. Because we were still operating. It was a three day hold, you know, let her just keep taking the antibiotics for three days.

And there were some other things, of of supplements. I don't even remember. There were various things. And we just focused on. Okay. And forget about the other stuff.

Just let it keep taking the antibiotics. And so he finally did. And then we went at my husband and I went in later in the day and, supposed to be a visiting time.

And, but we met with one of the other staff people and this guy, I think he was a psych tech. He sort of pulled us into this room and said, you know, before we go any further, you need to know that your daughter is scamming you.

And, and and I'm like, well, what do you mean? And he said, you know, she's not in pain. She doesn't need a wheelchair. I mean, it was just it was very bizarre.

It was, it was, it was, it was, it was very, very bizarre. It was like we had fallen down the rabbit hole into an alternative reality. And at that point, I just wanted her out.

I just wanted her out. The state of California, out of there 72 hours. And it was there. Our doctor had put me in touch with Sandy Berenbaum and we she and I live loaded with therapist psychotherapist in and I know you know her, but I mean I mean for for other people that are listening.

She's in in Connecticut and I remember at the time thinking, how is a person in Connecticut going to help me? And, she helped me a lot and I till I called her.

Our first conversation was when Rachel was in the second spittle and she just she listened. And then she said, you know what? You need a plan. And so we started with a plan and, we we brought her home.

And, another thing that was very important. Rachel did have a therapist at that time locally, and that woman was a lovely, excellent therapist. But she knew nothing about Lyme disease.

But she was open. And so she and Sandy consulted and and Sandy kind of trained her remotely. And and so that that person was really, a big help to Rachel and to all of us.

And so it got we got to a point where Rachel didn't perceive her dad and me as the enemy anymore. We were all on the same team, and we were all trying to get her better.

And really, it's not that things were perfect. They were far from perfect, but it was so much better at that point. And I think that that, that the therapy, it has to be the right therapist.

And in terms with Lyme disease, I have heard of other people that have Lyme disease and go to just kind of a regular therapist who has no understanding of what is going on, might be going on, and it can really be detrimental.

And so it's just as important as it is to have a Lyme literate doctor. It's also important to have a Lyme litter therapist. Right? So the the point you're making and I think for people listening and this is really important because the, you know, the family stressors that families go through, I mean, it it can destroy families.

I mean, I don't even want to tell you the number of people that got divorced, where either a mother, you know, or a father was sick with it and the family couldn't stay together.

so a landlord, family therapist for you really help to pull it together because you finally had the understanding, right, that you were not the evil people here, right? You were just trying to help. And.

And Rachel, she. For some reason, when Sandy was speaking to you, she was able to get through to you that, your parents were not the problem that Lyme was the issue, was it that she was so Lyme literate, she was able to explain the whole course to you to kind of change your mental state about this?

I mean, it's she was she was able to break through that, through this and her in denial and everything you went through. So I actually never spoke with Sandy.

She only spoke to my mom and my therapist, but she and my therapist, they met like weekly for quite some time. And so then I was helped from Sandy through my therapist and then also through Sandy working with my mom.

I have since met Sandy, but got it. And by the way, since you have a brother in the background, I haven't heard. How how is your brother dealing with all of this?

with this whole situation? do I go? Well, okay. it happened that he was graduating from high school about the time that Rachel, you know, that Rachel got sick, and so he really.

And then he went away to college, and it was it, you know, from the point of view of the parent. I mean, I still it hurts my heart to say this, but it was just it was kind of like, good.

He's a college. I don't have to worry about that anymore. I can focus on this situation here. So he wasn't he wasn't home when Rachel was going to the house.

I cost little and everything, and it wasn't until conversations, many moons later to realize that that Jeremy was very worried about us and and and concerned about us.

And when he came home, it was like life was different and everything was was revolving around his sister's needs. And he felt like he was just sort of this peripheral person.

And I feel like, we all got through that and, and, and we have a good relationship now, but I'm aware of of families and you may be aware of this, too, doctor Horowitz of where the sibling that isn't ill in a sense, sort of divorces the family kind of just goes off and says, you know, I'm not a member of this family anymore.

And so I'm grateful that that didn't happen to us. But but it does. I think it's it can be especially hard when, when the siblings are still still in the home.

But I remember, you know, after, you know, Rachel went through some of her more difficult episodes, sometimes I would even realize I hadn't even thought about Jeremy for, you know, like a long stretch of time.

And then I would feel I would feel guilty about that. And, it just it was it was it was very difficult. It was it was just very difficult. It was very hard on on every member of the family.

And although I have, I have many wonderful friends in my life, I'm blessed for that. I wasn't turning to my friends for the support. I'm sure they would have happily given me because I was so totally to.

All of my bandwidth was taken up with the dealing with, with, with my daughter and her and her immediate needs. That even tell somebody else what was going on, even if I knew they would be sympathetic and love me and support me.

It was like that was beyond my capabilities of doing and I had, I have one very good friend that lives across the

street from me, and one one that she had an inkling of what was going on.

And one day she just said to me, you don't have to tell me anything. Just if you need something, you just tell me what you need. And I called her up one day and said, I need you to go to the drugstore and pick up a prescription.

And and she went and she did it. And it was a long time before she ever really got the story of what was going on with us. Just because, you know, all of us were were so consumed by what was doing that we just we just had nothing.

We had nothing extra. And I now I hear from so many other blind patients that are in the same kind of the same kind of problem, same same, you know, difficulties of, of just you got to, you know, to even explain to somebody else what's, what's going on.

They just, they just don't have the energy. It. And I think one of the important points you're making here is, is that this is not just affecting one person.

When someone's sick in a family, it's affecting the entire family, including brothers or other sisters that are not particularly affected. And I think the point that's important for everyone listening is that, you know, getting a family therapist, getting therapy and support for the entire family, right, is really crucial when you're going through something so difficult because one, you know, a person like Jeremy could have felt ignored by the whole process.

Like, you know, even though it wasn't true. Kids sometimes think to themselves, oh, I'm not loved this much, or I'm not cared about as much as all the attention right is going to someone else, right?

This happens in divorce families with kids all the time when these things happen. So you ultimately, from what I understand from your book, you ultimately found that these online life support groups were really important, right, in helping you to get that support.

Can you talk a little bit about this? Yes. At that time, see, now there's actually all kinds of of groups on Facebook and other other kinds of things.

But at that time there was something called Lime Net, which is, is still around. and then there were these, state groups like California Lime, you know, New York Lime.

There was a there was a whole collection of them. And those were really the only place that I could find, that, that that I could find one information and to support for what I was going through.

And even though people have excuse me, have different, you know, experiences, different lime patients have different experiences. It's there's there's a commonality there.

Recovery, resilience, and advice

And, and so that that is just really important, you know, after Rachel was a substantially better, I actually helped form an in person lives support group in, Sacramento.

And and I facilitate that for eight years and, and and I, I've since moved on to other things, but that was amazing to have people people come in in person.

And there was there was one woman that lived in a homeless shelter, but she she would come to our meetings. She would come to our meetings once a month.

And she said that this was the only place for anybody that she could talk freely about what her experience sources were. And, and there were just there were people, you know, a whole spectrum of people that would would come into that.

And just there was a there's a very basic need to be heard, to be understood, to be seen. And, and most, most people are, are ourselves included, felt very unseen, certainly by the medical establishment, but in our case also by the school system and, you know, other, you know, other just, just just being out in public because we weren't, we weren't out in public.

We were basically in our house most of the time. and, it just, people need that people need connection of somebody that accepts them and understands them.

Yeah, we have some. We've got some local Lyme support groups also. I know that that helped patients with it. And I think can be very helpful. But I will also tell you that the flip side sometimes that people have to be careful with is that some of those people in the support groups who are still chronically ill, who have not gotten better, sometimes it's difficult because you're listening to the same people stories.

It's almost like a PTSD reaction, you know, will I ever get help? What's going to happen? I mean, the support obviously is crucial, but I think, you know, you have to be careful sometimes when you're a sensitive person listening to it because all of a sudden you're listening to all these people with these stories that if you're still on your healing journey, it's question like, my God, they've been doing this for eight years.

will I ever get better? And of course, people do get better. And Rachel, in fact, you know your story as you as the book goes on. You did oral antibiotics, you did I. V.

antibiotics, you did detox protocols, you did hyperbaric, with those game changers for you, like, did those ultimately help you? And what finally got you across the finish line?

Yeah, I mean, throughout I was in the wheelchair for over three years. And throughout that time we just tried, you know, as many things as we possibly could.

and we feel like they all helped a little bit. But the thing that just never wavered was my constant body wide paint, like it was all the time. And it only got worse.

It never got better. And so, it didn't matter what we were doing. I just kept having this deep pain in my bones and my joints and shooting pain and my hypersensitive shoulders like, none of that got better.

And then finally, you know, as a teenager, most of us don't like listening to our our parents, specifically our moms. And so my mom would always be like, here's a new treatment we should try.

And I would just turn it down and and here's the new thing. No. And just like, I just wasn't even interested in it. But then through, and like, you know, I had friends with Lyme through online and we talk on the phone and one of them had tried this specialized chiropractor, and specifically focusing on the upper cervical, like the Atlas, of the spine and it had been in a wheelchair and had gone to him and, and it had worked wonders, and she'd been able to walk and take like 12 steps. And it was this whole thing.

And she was so excited about it. And she was like, you got to do it. So then I was telling my mom, I got to do this. And so then we ended up going to that same doctor, and that ended up being what got me out of the wheelchair.

And it was really like it was a specialized thing, very focused on that top vertebra. And then after 14 treatments, it was like the pain that was everywhere just switched off.

And so then after that, life was was very different and I was able to walk, I still had Lyme, I still had fatigue. I was still treating it, but the pain had just like the thing we were searching for was the last puzzle.

Puzzle piece there was that specialized chiropractor. And as you kept doing the oral in the Ivy and these detox, I mean, did you find that like, the perks were less over time, like, even though you would, you would still flare and things get worse that eventually like it was layering like an onion.

Like it would start to get better. But it really was this, A-plus. The, I know, I know, chiropractors that do it, by the way. And by the way, you were never diagnosed with cervical, instability because, you know, part of that, some of the people who respond to that have cranial cervical instability, where it's difficult to keep their head up, they're out of alignment.

Were you ever diagnosed with that or not even specifically? No. It was just like quite out of alignment, like on the x ray. I mean, like it just it showed it was just quite out of alignment.

And the chiropractic was explaining that when everything's so out of alignment, it can really be harder for the brain to communicate with the rest of the body.

And I've definitely noticed that to this day that I continue to see an upper cervical chiropractor. because when I am out, everything is worse, and when I'm in, everything is better.

And this and these were just like neighborhood friends of yours. This was just like a girl in the neighborhood who was talking to you about this. Who kind of gave you this suggestion?

No, this one was a long time friend that I knew, from online. Okay. She had, but she lived in California. Got it. But you also had, like, a series of friends that ultimately came to your support in the neighborhood.

And how did they help you to get through this? Oh, yeah. I had an amazing support group of friends, that I had grown up with in my neighborhood. I'm still friends with all of them.

I talk about them a lot in the book. and they were they were my everything. They would come over after school, you know, I was out of school for a long time.

they would come over after school. They would sit next to me in my hospital bed, in my room. We would play games on the PlayStation, and film videos. And they really kept me sane during a very, very crazy time.

That's great. It was really it's it's a it's a remarkable, group of now young women, girls then where, the youngest one of the group was like nine and the oldest ones were college age and everything in between.

And they just would they would come over, they would hang with their they would, you know, just do things. They watched, you know, probably every episode of Gilmore Girls several times over.

it was really, when we were going to the, the chiropractor, the chiropractor was two hours away and, one of the friends would come with us and, and just, you know, just just, you know, be the company on the trip.

And so that was really and one of the things that I realize in talking to, to parents of kids with live most that's not the the situation for most people.

You know, that many, many kids are very isolated adults too. But many kids are very isolated. And once you know, particularly if you're not doing the kinds of things you used to do, school and, and sports and things like that, that, that kids just have, you know, have, you know, have no friends.

And I one of the things that that I think really, really helped us and I know that that Sandy, suggests this to just about all of her, her, you know, clients.

Is that the child or the adult really needs something to be interested in. They they need something that that that captures their imagination and, and keeps them going.

And in Rachel's case, she and her friends really got into making little videos and editing them and putting them on YouTube and that kind of thing in just, just a real, just in a real big way.

And, that was, you know, it was creative and it was something that they could do together. And that was, you know,

just just people, people need something for some people that might be, you know, playing the ukulele from bed or, or harmonica or something.

If you could do that, you know, music or art. The the girls did a lot of artwork. at our house, we had lots of different art supplies, and they did a lot of, a lot of painting.

And that's the thing, you know, your life can't be just about medical treatment. Just be about other things that that. No. Of course. Joy. You know, and a lot of the patients who, who are treated, who are better and I joke with them, that's actually one of the first things I ask them when I, when they come to see me is when you're better.

What is it you're going to want to do with your life? Because that throws them off. It's like, what do you mean? When I'm it's like when you're better and your life is better, what is your goal in life?

And it throws them off. And it's true. It's a very important question to ask people. It's like, what are you interested in? What do you want to do with your life?

Because without that goal, that motivation, like something to work towards, towards the future, it's kind of like it's a little bit difficult. And I've actually had some of my patients go through, nurse practitioner training, PA training, some have become doctors.

Rachel, you're not interested in going to medical school at this point and joining my medical practice, by any chance, are you? Because, you know, I'm getting older and I could probably use some help at this point.

You're sure you don't want to go to medical school in California somewhere? No, I'm okay with that for now, but that is awesome. I actually I love that you say that to your patients, because that is something that we actually end the book talking about that for, for my part of the end of the book, we go back and forth with me and my mom, but, that like, not my Lyme literate doctor, but another doctor that we've been working with had not had that same viewpoint and definitely, you know, was treating Lyme and was treating detoxing and everything and working with my Lyme doctor.

But but this person was really giving me, limiting belief and was like, and even when I was the one kind of saying like, oh, I want to be able to do this.

And they were like, you know, you're always going to have to kind of lessen what you're going to do. You got to be more mellow. You have to be kind of accepting that, you know, you might not be able to do everything.

And I really believed that until actually just the last few years, like I really believed that, like, oh yeah, I'll always be kind of sick. I'll always be on medication and stuff.

And, and I would definitely. I love that you say that to your patients, because that is far from what my reality is now. And, you know, I'm going and doing all of these physical things.

I've been learning to snowboard. I did trapeze this last year. I, you know, travel all over the place. And so that is the message that we need to be able to be instilling in people that are so sick is, you know what?

This can be your reality. And that's something that I take seriously. And I try to post a lot about that on my social media and have that be my my presence is showing like, this is where I came from, but this is where I am now.

And I firmly believe that this is what your your goal should be. That's what you should be working towards now. That's great. So is there any other advice you would give to people, for example who through and I got that. It's good to have a goal.

You know you're going to get better, get a support right in place for you know what the UPS and downs are going to be, what any other advice would like to share with people as we're kind of finishing this off?

my advice, like what? My mom said something that's been so important to us, is find something that brings you joy, like she said. And for me, that was filming and editing videos and it still is.

And I, I still do that. But I definitely recommend wherever you are. And if that's in a hospital bed in your room, find something that brings you joy.

Because that absolutely got me through like the hardest, you know, even the hardest of times. If you have something that brings you joy that you can do right now, like it's great to have goals for something that brings you joy in the future.

Snowboarding. But if you can't snowboard right now, find something that brings you joy. Right now. Great. And Dorothy, what would be your advice to parents who found themselves in your situation?

Well, I think it's important to believe your child, first of all, particularly when there's a lot of, outside forces that don't believe your child and then find out as much information as you can because it's, you know, I was saying in our time, there wasn't much information.

Now it's almost like there's too much information. But you have to you have to find what you need. Find find the information that you need, believe your child and find the support that you need to to to keep going and to and to keep faith and that it that that it will get better.

Yeah. You know that the, the hope aspect. It's a really important aspect because, you know, with everything that's happened with Covid, so many people lost loved ones during this.

There's, there's a real, truthfully a problem with depression and anxiety now in the young people in, across our population. And it's made much worse when you have tick borne.

I know you know this, but but this year makes things three times worse. Bartonella makes things worse. It can cause a lot of sick reactions. It's really important to know that there are answers.

And, you know, at least for me and my situation, the reason I'm even co-hosting, you know, the Summit at this point and sharing this with people, is that the 16-point MSIDS that I've been developing for the last 35, 40 years?

And these Pulsed Dapsone protocols with persistent drugs and biofilm agents. I've been looking for answers for my second suffering patients. and people know my story a little bit.

But the one story for me that was the most important is getting out of medical school. When I asked one of my Tibetan teachers, you know, what was the most important thing you want to to share with me as a physician before I went out into the world?

And Iam again then said to me, Richard, the most important thing is exchange yourself with others. Put yourself in people's shoes and do for them what you would want done.

And if you do this, everything will go well. And you know, if you put yourself in the shoes of someone who's suffering with pain or a mom who's suffering with this, you notice a doctor, just tell them it's in their head.

You basically go looking on a journey to figure out, like, what is this exactly? I mean, that's pretty much how I've figured this out. Unfortunately, these protocols, now that, you know, I've been developing, I've got it down to nine weeks of oral dapsone with two week pulses, much shorter protocols than we've done.

and I'm curious, I didn't get this necessarily from your story, but like Rachel, when you had a lie down and you need to sit up in the hospital bed, did anyone ultimately diagnose you with other factors?

Like, I had parts this autonomia, I couldn't hold a blood pressure. There was Bartonella, my adrenals were low. I was filled with mold toxins like, did they ever get a lot of these other underlying issues? Like, are you completely

well?

Are you mostly well at this point? Is there still part of your healing journey? You're still on? So at the time, I don't know if anyone really was talking about the fact that, like, I couldn't, you know, sit up straighter, lay down other than just I mean, because the thing is, it wasn't just pain.

It was severe pain that caused it, but it was also I couldn't breathe. And so I think a huge part of it is that we sort of attributed it to being super out of alignment, because that did really help that.

But since then, then I went off to college, and when I was in college, that's when I got diagnosed with mold issues. And so then we treated the mold and the lyme together, and that's when I was able to get off antibiotics.

I was not able to get off antibiotics for ten years straight. And so that's when we finally got off of them. And then since then I've done some brain retraining.

I did dynamic neural retraining system DNRS, and after that, in 2018, I've been doing really well and really, really pretty stable here. I mean, little hiccups.

And then we get on it right away and then back to. No, that's great. So, we've that was a very fast hour of a discussion. This was fascinating and wonderful to speak to you both.

And and, Rachel, you're looking great. I mean, it looks like you've you've been through it all, but, your book, Finding Resilience: A Teen's Journey Through Lyme Disease.

I mean, you've definitely been through it. And I think your book will kind of explain to people. Right. The hope that really is at the end of the tunnel, right?

That you don't give up. You keep at this. And again, at the time when this happened, you didn't you have the tools, right, that we have right now to get people better.

So I just want to thank you, Rachel and Dorothy, this was this was a great conversation. I think people are going to get a lot out of it of, like, what it's like for families to go through this, the fact that, you know, families therapy is really needed for these kind of cases.

Don't give up. Right. Believe your child. and know that the support is there. But you've got to you've got to reach out for it. So, I just want to thank you both for taking the time to do this today.

Rachel, I wish you well on your journey. And please consider medical school, in the future. No. I'm done. I'm just joking. thank you so much for having us here.

It's my pleasure. And, Dorothy, keep up the good luck with, the good work with your blogs. Your blogs are great. lymedisease.org and everybody, they're just doing great work.

Right. not only in your state, but but really across the United States in the world. So, thank you for becoming an advocate and helping people. I know it's really making a difference.

so for everyone who's been listening, my name is Dr. Richard Horowitz. I'm the co-host of the Healing From Lyme Summit. We've been talking with Rachel and Dorothy Leland about their book, Finding Resilience: A Teen's Journey Through Lyme Disease.

I know you're going to get a lot of reading the book, and and thank you for joining us today. And please tune in for another episode soon.