How Big Data and New Research Are Transforming Lyme Treatment Transcript

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Introduction and Sarah Quillenu2019s role

Hello everyone. My name is Doctor Richard Horowitz and I am the co-host of the Healing Lyme Summit. It is my great pleasure to bring to you today Sarah Quillen,, the new Executive Director of Islands and Sarah.

It is really a great pleasure to be with you today. You know, I've met you at the recent conferences. I'm so happy you took over the organization. Things are great with you kind of on board.

And thank you for joining us today and kind of sharing a little bit about islands. Let's mission the Isla. And I think we have a great conversation. So thank you.

Thank you for having me. I'm always excited to to to see you and talk with you, but also to be able to share Eli's mission and all all the good things that we're doing as a, as a group.

Yeah. So so listen, I have a question for you. So what exactly? There's a lot of reasons why people do what they do in their jobs in this lifetime. What in the world makes you think I should be the executive director of a major league organization like Islands?

And what has that been like so far? Your journey so far doing this? Well, coming into this, I always joke, oh, I'm a glutton for punishment now. I love a I love this kind of talent.

I mean, my whole career has been in, nonprofit work in health care and human services. Most of my, most of my work has been around hospice and palliative care.

So I embrace the the challenging topics, the difficult topics. And I feel like tick borne illness is right on up there with the with the challenge and all that. And I came into it.

I mean, I think a lot of folks know by now, I'm from upstate New York. I'm from Dutchess County, which has the highest Lyme incidents in all of New York State. Yay.

Right. I'm living in Dutchess. No, no, I did not know you are from Dutchess County. Where are you from exactly? I'm from Poughkeepsie. So my. Oh, no. There we go.

My father was a now retired career IBM in Poughkeepsie, and I've lived in grown up, grown up and lived in, and my folks are all in the same house. They've been there.

They've been there over 50 years now in the small town of Wappingers Falls, outside of Poughkeepsie. Oh, well, you know, it's funny you say that, though, with, with moving to Dutchess County, because when I moved to the area from Bayside, Queens, after doing my residency, I had absolutely no idea how bad the Lyme epidemic was up here.

And interesting enough, the ibmers the way I would always know, when they had Lyme disease, the ibmers who were there for, like, you know, decades, right?

Until some of the changes happened, they couldn't remember the keystrokes to their computer. Oh, yeah. The memory and concentration was so bad. And that was actually some of the reason I started getting involved more deeply, because a lot of my boomers were coming to me early on when I started to do this.

And my father was was one of those, he I mean, he's, he's, a PhD engineer. He's he was in the research department his whole career through IBM and for for such a brilliant mind to start thinking like something's wrong.

What's going on? And he he had Lyme disease. Gosh, he probably had it 5 or 6 different times. And he he was one of the early he was doing the clinical trials of the early vaccine back in the night.

He's I mean, so he's he's been dealing with it for years. But it was the it was sort of what they what we now know is like the, the brain fog that comes with Lyme disease. I mean, he had the, the joint pain, the fevers and some of the other very typical.

So I'm not looking for patients. But you do know if your dad needs help, maybe we could figure out something. He has an eye doctor. He's had one for years.

He and I argued about that long time ago. So he now he he I will say. But that's what got me.

Why Sarah joined ILADS and her background

That's what got me involved in in even understanding Lyme disease and finding I, I mean, that's how we found Eilat, to find a practitioner, to be able to help and figure out what was going on.

Yeah, yeah. So, you know, islands, as you know, I mean, I was one of the founding members 25 years ago. And, you know, I remember the time when I was when in this little hotel room with Nick Harris and Joe Briscoe and Steve Steve Phillips was there.

Andrea Gatteau, my wife was there, Barbara Buckland. We were sitting Nick paid for this little hotel room in New York City, was sitting around signing documents 25 years ago thinking, you know, there's just a need, you know, for doctors to learn a little bit.

And if you would have seen these conferences early on. Andrea Gatto, when she first started heading this up with with Terry McKnight, who was also there, we had these little rinky dink conferences in new Jersey.

There must have been like 60 people there, and we'd stand up and do clinical case presentations. And I mean, it has changed. So much over the years. Right?

And you really see, we didn't know at the time how important eyelids was going to be. So question it really. Eyelids really plays a crucial word with this point in education, research and advocacy.

For those who are not familiar, I think a lot are. But for those who are not familiar with eyelids, how do you describe the impact the eyelids has now on the medical community and patients and, and what we're doing as an organization?

Well, you kind of nailed it with I mean, you're you're sort of the vanguard, you guys, that small group of dedicated practitioners going, what the heck are we getting ourselves into?

25 years ago made a huge stab. I mean, that nobody else was willing to go through. So fast forward to today where we have our conferences, we have webinars, we have a whole host of education.

There's research happening, there's advocacy happening where we Ilyse is still the only medical, you know, professional membership organization focusing on tick borne illness.

I mean, we're still kind of it. And and I feel very blessed and lucky to be part of this organization that you and the other small team helped to help to promote.

So the the impact and I can actually give you some really cool numbers. So for, for the year of 2024, here's a great little impact number. And I want to make sure I get it right here.

So one of the things that eyelids offers to to patients, to, to consumers, to anybody is a free provider search, of all of our members. And it, it gives them, you know, where they serve if they do telemedicine, what kind of, clinician

they are, whether they're a naturopathic or they do, you know, naturopath or allopathic, all those.

And and last year, my first year in 2023, we had 25,000 people accessing that provider. Search this in 2024. As of December, we had, over, 40,000 individuals accessing that provider search.

So that that tells you a little bit of the impact, even, that people are seeking us out. People are looking for that care. And on the one hand, that's a horrible thing because what's the CDC says, what over a half a million new cases are or are, you know, diagnosed every year?

We all think that that's so underrepresented. Well, that enough, you know, they they also came out shortly afterwards. You may have seen this or not. They then discuss several months later, the Medicare rates were seven times higher than the roughly half a million.

So really when you're talking about seven times half a million, you're talking about 1% of the US population per year is getting affected. And that is probably accurate.

That might even be more when you think about how many ticks are out there. And I mean, all of us have had it, but I don't know anybody that's not had a tick bite at this point.

I mean, I had Lyme 30 something years ago. The only reason I never got sick is within five minutes of having symptoms. I kind of knew that my body well, I knew it was going on.

My nurse drew the blood, I dropped my pants and she gave me a by silent shot before the blood test came back. Because I knew you know what it was. So I never got sick as I treated literally within minutes.

But many people, of course, are not so fortunate. But everyone at this I know has had tick bites. At this point, it's impossible to avoid them. It absolutely is impossible.

And I think this is one of the big things that eyelids can I don't know, I feel like we have a duty, because it's part of our mission is to educate primarily clinicians and practitioners.

I met a, I met a gentleman that I think summed summed up what were what eyelids does so nicely and so innocently. At our 2024 conference, he's a cardiologist in California, and he comes to our conference every year.

And and I was having a conversation with him and he had said, like, I don't treat Lyme patients myself, but I never want to miss it in diagnosing a patient.

And I thought, wow, that that kind of sums it up right there. Even if you you don't think you want to get into this community and get into this field specifically, you've got to know what you're looking at.

And I think that's one of the best things that eyelids can provide, even in that very, very basic education to clinicians. You're correct. I mean, the literature suggests it's about 1% of the people that end up with Lyme colitis.

ILADSu2019 growth and educational impact

So, I mean, a cardiologist is going to end up seeing people who have unexplained palpitations or unexplained arrhythmias, atrial fibrillation, cardiomyopathy, whatever.

And if you're not versed in it, it's the same problem. And it's true, you're right about the subspecialties because it is called the great imitator, like syphilis for a reason.

I don't care whether you're a gastroenterologist, a rheumatologist, an infectious disease doctor, a neurologist, you're subspecialty. You're going to see patients in that subspecialty.

And if you don't know how to diagnose and treat, you're going to be at a real disadvantage. You're going to be

treating symptoms with drugs instead of getting to the source of why these people are ill.

And one of the things I mean, I always I always say I'm, I'm the one non clinician of islands that you've got. Right. So I, I'm not going to go into all the diagnosing and things and I, I love when, when all of you guys geek out on all that kind of stuff.

But one of the, the big things that I talk to so many people about is that talking about the great imitator you've got, it's never just Lyme disease. And I think Lyme disease has become this catchall phrase, the the, the eyelids mission we changed in 2023 to include chronic inflammatory illness because we understand there's there's co-infections.

There's there's never just one simple thing that you can just, you know, hit with, what is it, three days of antibiotics and you're done. Like that's we know that's not realistic.

So one of the great things that eyelids can then provide is so much education. And one one of the great things, you know, thanks to, I guess, Covid or whatever, you know, we all can do this education virtually from the comfort of our own homes. And you can get the most basic information from eyelids of like how to treat and prevent tick borne illness.

Or you can go all the way to so many different really cool specifics that this is where I kind of geek out and only half understand some of the things.

When you talk about methylene blue and Morgellons disease and mix and, and some of the, some of the very cool specifics that that our clinicians, that our members, our veterans, like you do webinars and do virtual learning and seminars and things like that, for for Eileen's members.

But I think to the larger community, I mean, in 2024, we educated, over 3000 clinicians from our two conferences and from all of all of our webinars. And all of those things are are evergreen, right?

We we put them on our learning system where you can access them at any time. And I always think that's one of one of the best things that I can provide.

Is that education, no, you're you're right. And and by the way, what you said mimics exactly what we've been finding in our clinical practice for years.

When I discuss chronic Lyme, I the words I really use is Lyme McDs. And for multiple systemic infectious disease syndrome because the 16 point message model, just having seen over 13,000 chronically ill patients during the last 40 years, I kept discovering, you know, these it was like going to a doctor's office with 16 nails in the foot, and the doctor finds one nail, pulls it out and says, come back in a month.

Let me know how your foot pain is. We find at least six factors driving inflammation. Apart from the bees, Borrelia bbca, Bartonella mole toxins, and heavy metals are like right underneath their driving inflammation, followed by leaky gut and mast cell disorder, with patients then having microbiome issues driving inflammation, insomnia, vitamin mineral deficiencies and then the ten downstream effects of the inflammation the hormones are thrown off.

The men come in with low testosterone or low adrenals. You get pops dysautonomia, which you get from mold. You also get from long Covid. So, you know, we find these 16 factors in most of the people.

And you're right, what was great about the recent conference in San Antonio is a lot of this was also a functional medicine conference. I think people don't realize at this point for those people that have not taken, you know, the IFM training or the rest, you are getting functional medicine training when you come to islands, because it's all of us who do functional medicine.

You can't avoid doing it at this point in time to help your patients. And with long Covid, now that you know, the National Academy of Sciences is calling infection associated chronic illness.

But honestly, it's a cop out for me because it is a chronic infection. It is chronic Lyme disease. It is like memes, but the problem is you said the word chronic.

Lyme doesn't sum it up because it has all these overlapping factors. And you're right, that's where doctors now at least have one place that they can go, right?

And they can learn about it. So these websites and, seminars, can people just go on the islands website, like how do they access this to go on the website and find this information so they can learn? How did they do that?

The magic of Google come you can you can actually just go to Eilat Sword. And in the search function, if you're looking for a specific topic, you can type in that topic and a whole host of things will come up.

We're we're revamping our website to really focus on the patient and the clinician. So if you're a patient coming coming to islands, maybe you've just got a diagnosis or maybe someone you knew you got bit by a tick or someone mentioned to take, oh my God, what do you do can be overwhelming.

So we're we're reformulating our website to make it a little more easier to understand for the patient, for the clinician, if you're looking for very specific topics.

Good gosh. We have hundreds of very specific topics, just like I was saying, like Morgellons and methylene blue and things like that. You can type those things in and search it.

Or if, I of course want to recommend everybody become a member because then you have access to all of those things at no cost. Usually we, we charge a nominal fee to outside of our membership.

We want to make sure that the members are getting everything that they possibly can. So, we we host, we do at least one webinar a month. We're now getting to two and three a month, trying to bump that up.

And again, those are all included as part of your eyelashes membership. So any which way to to search you can you can come to our website. That's a great start. Yeah.

And of course I've been a member for the last 25 years. So I mean, I know about all of these and you know, and it's and it's also gone a long way when Joanne, when jobber is gone.

You and I were actually heading up the island. Yep. And for those who just are looking in the background just so people know what it means, Isla DF is the international alignment Associated Diseases Educational Foundation.

I was the president of the organization many years ago and Joe Bor, Scott Owen I actually used to run those trainings years ago, you know, contributing slides.

It's come a long way. Can you talk a little bit about some of the things that the elected office is doing right now? Well, so first and foremost, I'm so proud of this.

Yeah. This this 2024 this year, we awarded about $25,000 in scholarships to clinicians so that they could attend our conferences were were expanding. Obviously, it's it's the 500 and C3 Foundation.

Right. So it's you know, we're raising money and we want to be able to do more. And we rely heavily obviously, on on the donations of individuals. So I look forward is just the easiest way to give to that.

And, and we do fundraisers and things like that, which obviously you and I talk about. So for people that want to give funds to help with this worldwide epidemic, I al ADF dot you got it.

Absolutely. And so one of the one of the key features of I would add is our physician training program, which I know you've been a key component in creating.

And that the way that our education kind of works, you've got the fundamentals, which is the base baseline, get stem to stern everything on tick borne illness.

You want to then continue your education. Obviously you've got conferences, you've got webinars, but then you've got islet s physician training program, which provides a huge foundation of evidence based treatment in line tick borne illness.

And it goes into detail on the diagnostics therapeutic challenges. You have hands on training with a preceptor in real world clinical settings, where you can actually go with the preceptor through their daily, through their daily work in and sort of build that confidence in diagnosing and treating, tick borne illness on your own.

That's one of our signature programs. I feel like one of the other big things that islet F is really working on, and it's going to be one of our key strategic priorities in the next couple of years. We're calling it our big data project.

We need to come up with a better name with that. But for the moment, that's that's what we're calling it.

Clinical complexity of Lyme and chronic inflammatory illness

And we're we're realizing that we've got this fantastic cadre of members all have this, all our patients, all have data. So let's gather all this data in an anonymized fashion and be able to utilize it for for folks who want to research for our own and, and utilize all the really cool tools of AI and, and all this machine learning to be able to help the the next generation of practitioners and the next generation of patients.

So there's much more to come on that. And it's that's one of the super cool things, I think that'll be coming down the pike. Knowing it and it know it's very important.

And big data, of course, is where it's at these days. And I had just, you know, we Bob Messina, I spoke just a little while ago and I'm for the first time now that I figured out as many pieces of the puzzle as I feel I need to.

And I have a protocol that's working quite effectively for patients. We're applying for NIH grants to be able to do a multicenter, placebo controlled, randomized trial on its own.

And so we will have some big data. But of course, the more that people contribute, right, the more we have big data, the better. Of course, this gets.

So yes, it's it's very important. And for people that want to contribute to that cause I think that's a great cause because I mean, that's kind of where it's at.

We have I now to analyze the data and we start to need to use it. And we know there's this there's this chicken and egg. Right? I mean, we're we've got eyelids members who are serving patients today and treating and doing all those things.

But then we've got to be forward thinking and try to figure out how do we end this, how do we get ahead of it, how do we find vaccines and find treatment protocols and, and not get folks misdiagnosed and all those things.

And that's how we're going to do that? No. All this data, it would be super helpful even for someone like me. Because let's say I have a question. I use a drug, for example, is enemy that I use for Bartonella.

But if I had ten or 15 or 20 medical practices using it, some with some without, and I had a way of comparing the data, it would solve the problem of knowing how effective really is it for Bartonella.

So you're right. I mean, we definitely need this now. You were bringing up patients a moment ago. We hear from a lot of the patients. They do not have timely diagnoses.

We know many people go through ten, 20 or 30 doctors before they get a diagnosis. Any suggestions you've seen

from your perspective as far as how we might improve that, how we can do better to get those patients an earlier diagnosis?

You know, it's so interesting. And again, this was this comes back into my history in hospice and palliative care and things like that. And and even like my own health journey, right where we all have to be our own health advocates in this day and age and in and in this medical system that we we live in here.

So I always tell folks, like, if you're not satisfied with with what your doctor is telling you or if you think you're being gaslighted, be proactive.

Find find a second opinion. And if your if your primary practitioner gets insulted by you wanting to get a second opinion, then you need to find a new practitioner.

I mean, it's, you know, even even going outside of tick borne illness. I feel like that that's just our health care system and so apply it to this community.

I know it happens so much where where patients are either gaslighted or misdiagnosed or go through this cadre of, of care that their, their practitioner just doesn't know, but is not willing to admit that they don't know.

I mean, I've had conversations with my, my personal practitioner about eyelids and about tick borne illness. And so I live in an area now in Virginia where we kind of we're splitting the difference where it's it's pretty well known, but a lot of training still needs to happen.

But luckily I have a I have a practitioner who is who's curious and wants to learn and, and such and, and just even just asking some of those simple questions.

Have you heard of eyelids? Are you familiar with tick borne illness or what work training did you get in medical school? Or even just some basic thing?

So it's it always it hurts me to hear all the stories that we still get from patients who have gone through these terrible journeys, and so thankful that they finally found us.

And so I always say to them, well, make sure you tell other people about eyelids and about like about our provider. Search and seek us out and get information and become educated on your own.

I mean, there's some there's some really great patient organizations out there across the world who have take it upon themselves to to like we I like to work with and some of the other groups will work with to get education out there.

I mean, that's I keep coming back on broken record on education, but that's where it's at. Yeah. And and it's tough for patients because the symptoms of chronic Lyme disease overlap the symptoms of chronic fatigue syndrome, myalgic encephalomyelitis, fibromyalgia, long Covid and a host of other diseases.

You know, because it's it's chronic fatigue. It's aches and pains. It's memory concentration problems. It's sleep disorders. It's my autonomic nervous system doesn't work.

I stand up, I get dizzy, I pass out. It's like but those same symptoms are seen in other diseases that also can be caused by viruses, by toxins, in other things.

So you really need a doctor who has been trained properly to be able to do differential diagnosis. And you're right. I mean, I think interviewing your doctor, your your primary care physician every day, I mean, it's a shame that unfortunately, we've tried doing this New York State because I've served both at HHS and at the New York State Department of Health level.

There's not enough training, just like every year for me to, you know, I need to get certain CMS. And by the way,

you have to tell me how to get the CMS from this last conference.

I still do. Absolutely. I can do it that way. But but for example, I was working at the New York State Department of Health level, and they'll always tell you you need your narcotic training every year of how to prescribe narcotics, and you need your training on abuse.

Great, I understand that, but why is it not mandated at this point? Getting Tick-borne training now? Part of it is unfortunately, I think the politics, because the IDSA guidelines and the islands guidelines are a part.

But although I will say over the years and Tom Moorcroft shared this from me personally, when he's had conversations privately with Doctor Allen Steer and other people, I tend to think that people are starting to come together a little bit more without necessarily saying it, because all of the great research that's happened at the university level from Hopkins, from UVA, Shopee's group, at the University of New Haven, from Kim Lewis Group at Northeastern, at Stanford, biofilm and persistent.

But like, it's not just all autoimmunity. So I think the researchers have kind of helped us a bit to bridge the gaps. But yet, if you speak to certain doctors who are heading up Lyme clinics and I won't mention names of universities, I think the universities are still kind of stifling them a bit, because I've reached out to some of these people, even for the Daptone trial, and it's not easy getting my foot in.

So, so far Mount Sinai has said yes, thank you, Cohen Foundation. Thank you, David Petrino. Ebony Cornish spoke to me at the last I led conference that the aiming clinics look, we're getting them involved.

I won't mention the other university I just spoke to today. It'd be very exciting if they get on board. I don't want to say the name yet because. But they're big if they come on board.

But we need big universities to participate in this because again, I've been doing this for 25 years. I'm certain of what I found, but I need to prove this to the world.

And then all this politics where patients can't get properly diagnosed and treated, this will all start to go away. So it's it's a real problem because a lot of these diseases are overlapping.

Website resources, memberships, and clinician training

And I think, you know, even the way we treat patients in medicine where we've taught in medical school, name a disease, throw a drug at it, we're learning through the functional medicine lens.

You've kind of get to the underlying sources. You said this earlier of inflammation. Where is the inflammation coming from? What are the downstream effects.

It's not so easy of just you have rheumatoid arthritis throw a drug. I've had patients with rheumatoid arthritis with Lyme that the rheumatoid arthritis didn't respond because the Lyme was improperly treated.

And then the rheumatoid arthritis got better when the Lyme was it. So you cannot avoid tickborne disorders. I mean, I let's I think in the Iliad it's the most important organization at this point for a worldwide epidemic.

And I think for everyone listening, please speak to your doctors about joining the organization, getting the training. It's not a question of like, it's a good idea.

It's honestly essential because I think you'll notice most of the doctors have joined the organization they've had lined up. They're not only they're patients about it, they're they've had personal experience and and but you don't want to wait for that to happen.

You want to do it out of the motivation of want to know what's best for my patients. And you'll get that kind of information from joining pilots and getting right all of this great informational, educational events that's being

presented.

Absolutely. I can't I can't pay you as a spokesperson for Elad, but you're doing it. You're doing a fantastic job. Well, look, I mean, I've been on the ground level for years.

Look, I know the kind of benefit that I led has done. I'm again, I'm proud that I was able to be one of the people who was able to start. And I'm again thrilled you're at the helm, because I think you're you're you're the perfect person at this point with your background in everything you've done.

I didn't realize you'd been in that kind of space before with this and even had personal experience. But yeah, we need somebody who really gets it, and you do get it.

And you're listening to the patient. You're hearing from the doctors. So so I think it's going to be very, very important. So is there a current initiative that Elance is doing right now or that they're looking for for next year?

Something specifically, is it the big data project? Is it something else that I lens is looking at. So the Big Dead project is going to be one big one.

But the the next big thing and this, this actually I think Doctor Horowitz speaks to you and all the, the, the OGs, the original folks who've been part of Eli's for 25 years.

We finally, finally launch a fellowship program, which I think has been in the works. I mean, long before I ever came around the islands. It was it's always asked the question, you know, and I know you ask is like, well, what's next for me?

Like, I've been doing this for forever. I've done I did fundamentals, I did the physician training program. I've gone to countless conferences. I give more than I get what what can I, what else can I do?

And and the fellowship is that next stage for the veterans. And we just launched it at our San Antonio conference. And so we're really going to start promoting it in 2025.

And so I'm I'm excited to see what what will become of those folks who are the newer to the to this community and, and striving to, to get to that, to get to that level.

So taking fundamentals, doing positions, training program, becoming a physician's training preceptor so that the next, you know, sort of paid forward, so to speak, and, and be able to get that advanced, that highly advanced training and be able to put that, I don't know, badge of honor.

You know where that badge of honor of of I'm I and Eli's fellow. Yeah. And by the way, so because I'm and I've been a, you know, preceptor physician for the training program in the past and I can tell you the doctors that went through it who spent a week with me, usually it was when my nurse practitioner was out and they had a chance to be with me the whole time.

They usually walk away from the days the week that they spend going, oh my God, I learn. So because what happens is, and I've seen this, when you go to a conference, you're getting the basic educational, you know, building blocks, but you've got to see it in clinical practice.

And I've even gotten to the point I've had to hold the hands of certain doctors when they're treating their patients. I mean, I'm starting my own consultation model to help some of these docs that are out there, and I find that when I do it for some of these doctors, it's like, can you hold their hands and do it?

It's like, oh, now I get it. And that's what this fellowship program is really, you know, going to offer. Because we do need a whole bunch of doctors out there doing the training.

Unfortunately, some of the best in the world belong to islands and are doing that training. So that that's great that

you're launching that. I think it's going to be a great initiative.

Yeah. I'm so excited about that. And you're right. I mean, there's a lot of just attending conferences and the webinars and things like that. That's all just sort of absorbing and receiving.

And you're you're sort of a passive participant in that with, with the physicians training program and fellowship. And I want to do more of these kind of mentor ship kind of education programs.

So that you, the clinician, are the active participant and you're getting that hands on and you're seeing the, the, the actual patient and learning and all that.

So I think there's a way greater capacity to do so much more on that. But the fellowship is one of the one of the key things to do that the other big initiative, and I touched on this, and you touched on this a little bit is on the, on the eyelid side, on the foundation side is to really start bumping up our, our scholarship program, our grants.

We want to be able to start offering grants for research. To be able to do that, we've got to do some active fundraising. I think I lit up has been sort of that nice, quiet organization in the background.

Scholarships, fundraising, and the big data project

And Islands has been the one shouting and I want I lit up to start shouting, too, because there's some fantastic opportunity from within the foundation.

I mean, we're expanding the board. We've brought in some real business savvy individuals onto the board, which I don't think has ever happened before.

We're going to do some much more active fundraising. We have, we actually had a gala as part of our conference, and we'll do that again as, just a wonderful way of celebrating the achievements of the organization, as well as then being able to raise more money to be able to do more and raise quite a bit right on this last gala.

I mean, raise quite a bit of money, actually, for education and for helping the doctors to get trained. Right? We did, we did. We raised about $70,000 on just in the auction.

And the appeals that we did that night. And of course, then there's tickets and sponsorships and such that we that we brought in and of course, the wonderful entertainment that we had that evening helped as well.

And we'll be able to do more of those things. And I want to be able to utilize these fantastic patient organizations as well. And, and like, deputize them.

Basically, they can help us raise money so that more clinicians in their state can be educated. This is the way to do it. I agree 100%. And the educational part is just crucial because we are really in the middle of a full epidemic.

And I suspect and Bob and I discussed this earlier, I suspect that when they finally look at long Covid and they look at the reason why many of these long Covid patients are sick, I hate to tell you folks, but you've heard it here today and from others.

You're going to find that and Bartonella and all the stuff that I lead doctors have been talking about for a long time, we're going to be underpinning some of these long Covid cases.

It's not just the virus is persisting or pieces of the virus are persisting and micro clots with endothelial dysfunction, you're going to find Lyman Bard and all the stuff that we as eyelids doctors have been finding.

They're going to find this in long Covid. We already know I've already found this in a lot of my patients. When I test them for it, I know it's going to be like, like we've been doing this for years, people.

I mean, in a perfect world, wouldn't it be awesome if I could offer basically our fundamentals course at at no charge to clinicians all across the country?

I mean, there would be just a wonderful opportunity that, you know, you if you're safe, you're just curious about it or you're like, oh, I don't see Lyme patients or I don't see any tick borne illness, but I can get some CMS out of this and I get a free lunch out of it or something and come away with, oh my God, what have I been missing?

Except the problem is they are all seeing Lyme patients that they may not know. Know? I mean, somebody comes in. I've had this happen numerous times. A patient comes in, they've got some back pain there.

You know, in their 70s, early 80s, they've got some back pain. A little bit of what's right is their memories off. They're a little tired. It's like, what do you want? I'm getting old.

It's like, now this is not because you're getting old. And then I treat them for Lyme and whatever factors I found driving inflammation and they come in and go my memories completely well, my back pain is gone.

It blows of energy. It wasn't that I was getting old and it's like, no, it was Lyme. And even the Alzheimer's epidemic, they're finding Borrelia burgdorferi code localizing with amyloid plaques in people's brains.

I mean, we don't really know how many of these cases of dementia. There's 46.5 million Americans with preclinical dementia. How many of these people have treatable causes like chronic Lyme disease?

This this is way bigger than I think people know. And we are going to be the premiere organization, really, who's going to be leading the way to give answers.

So I think, you know, they can be proud of joining eyelids, becoming a member, being part of the FDA. I'm happy that you and I have been involved with it and that you're on board.

But yeah, this is a really important mission. And again, doctors that don't think they're treating it. You're fooling yourself folks. Epidemic is epidemic.

And it mimics the gastroenterologist. It causes all kinds of GI symptoms where people don't move their bowels or they have vomiting because the vagus nerve dysfunction, the psychiatrist that see people with resistant depression, anxiety, OCD, psychosis, Lyman Bartonella causes this not a subspecialty that the tick borne disease doesn't cause overlapping symptoms.

So yeah, we're we're in a place that fortunately we're in a really sweet spot that the lights, the light bulbs going to go on and people are going to be turning to our organization going, okay, we need your help, kind of guide us.

And I think you're right. That's where the training is going to be even more important. Absolutely. And talking about Alzheimer's and the older stages drive backwards, go back into infancy.

And even in utero, I mean, you you've got such a broad spectrum from, from stem to stern, from birth to death that that eyelids can affect that our practitioners can be a part of.

If people just understand, have even just a little bit of understanding. So coming back to that, that cardiologists who say, oh, I don't I don't treat Lyme disease, but I never want to miss it even that.

Let's even get folks to acknowledge that part of it. And then I'll have to take care of the rest. We've got you. We'll we'll be able to educate and and advocate and do all those things.

Well, ultimately, I mean, I think some of the recent things that happened at the level of the CDC regarding pregnancy and Lyme as far as transmission, you know, which, again, which had been a political issue for years.

Oh, is it's really not even though the science was there, even from Alan MacDonald's work and Alan Steer's work

from years ago.

Improving diagnosis, fellowship training, and hope for the future

It's ultimately I that's really that that's kind of kind of pushing these issues forward, working with the other Lyme organization. So yeah, we're playing a crucial role. You're right.

From from pregnancy, from women having healthy pregnancies to afterwards. It's just absolutely essential. So great. So Sarah, I think is there anything else you want to I mean, I would like I have one thing of hope I will share.

But anything you want to share of hope. Now that you've been with the organization for a couple of years. Final message of hope you'd like to share with people from your perspective.

Now that you've seen what you've seen, absolutely well hope for for patients and hope for for consumers and clinicians. I mean, it's out there. We're out there. It's the science is changing.

It's catching up with, with just like what you've been saying, like you've been treating this for years. And finally, people are paying attention on the on the horrible side.

So many celebrities are coming forward with their stories, which, I mean, I'm I'm so glad. I'm sorry that they get the these illnesses, but I'm so glad that they're using their platform to be able to shed some light on it.

And I think that's helped immensely. The joining of integrative practices for folks. Whether you think you're a primary care doctor and now and I'm only allopathic, everyone's dipping their toe in both sides and the naturopathic and allopathic and and again, this is the science and the research and the awareness.

It's raising all the boat. So I in a general sense there is hope. There is is a way if you yourself if you are patient, there's treatment out there. You can I can help you find a practitioner that is in your state or can help serve you within your state.

There's more funding that's getting out there from other organizations to help your care and to help the research and to help move that needle so that insurance companies might be able to, you know, pay for some of this care and, and change and all for the better.

So, yeah, I mean, I, I, I'm sort of, gobsmacked at all the changes and all the good things. But there is hope. It's exciting. It's exciting to be in this community now. Yeah.

And and you know, and from my perspective, although we've been helping patients for decades, it's really in the last 8 or 10 years since the PhD, researchers discovered that Lyman bard are biofilm persistent bacteria, it has completely changed the way I practice.

I've been publishing my research every year, presenting at the islands conferences, answering questions from doctors. You know, who contact me with this.

It's a really hopeful time because I have patients going into long term remission now that I was unable, to get to that point with much shorter term protocols.

Right. Not long term antibiotics, staying on antibiotics forever. And that's why now we're you know, I'm applying for NIH grants for a, a multicenter, placebo randomized trial.

And I hope I, by the way, be able to work with the big data project about islands and the Ala DF is looking at because I will be accumulating that. In fact, we have to find a way to store the data and share it.

That's actually part of what I'm working with with Eva Garland Consulting. So I'm sure our paths are going to be crossing during this trial where we'll be working with islets.

And fortunately, Ebony gave me another option through the in clinics, which is great because if I can get some of their neurocognitive testing and things on board, we're going to have some really fabulous results for people in the next couple of years.

So you're right, there is hope for those people that are struggling. And I think the other part of the hope is, are the folks like you who who've been in this, in this realm for, for many years and are are doing your own education, are doing your own consulting, are helping to pay it forward.

I mean, I, I this hasn't cornered the market on, you know, by any means and I I'm excited to see I'm excited to see all the different options that are out there in terms of education, in terms of help, help for care and and furthering that needle and being able to collaborate with all of you and with all these different really cool things that are coming down the pike.

So I think that's that's the other part of hope for me. I love collaborations, I love partnerships, and this just puts that right into right into this community.

So I think that's a that's a huge part of hope. Thank you. Right. Well Sarah, thank you so much for taking the time today and again for people again who want to contact islands and islands.

Please give them one more time how to contact you so that they can become members. They can also donate to this really important cause. Oh, absolutely.

Go to Elad Sorg, Elad Sorg you can click on Isla Def right there. You can always email me at S Quillen at Elad Sorg. Or by all means go on to our social handles.

It's at eyelids dot great. Thank you so much. Really. Look I cannot tell you and you know this. I told you this privately before. I'm so happy now to have you at the head of the organization.

I think we are really going to be making some great strides forward. And I'm I feel very confident with you at the helm and all the doctors I met in San Antonio that are now part of my leads.

We've really got a great organization, and I think it's going to grow bigger and bigger and have more and more importance as the years go on. So thank you again for participating.

It's it's it's great to have you with us. I'm really looking forward to the years ahead. Thank you. And thank you for being so a part of it for so long and continuing to be a part of it all.

It's my pleasure. So if everyone again, who is listening, my name is Doctor Richard Horowitz. I am the co-host of the Doctor Hawk Healing Lyme Summit 2.0.

We've be discussing Isla DF and Islands with Sarah Quillen, the executive Director. Thank you for tuning in. We'll meet you again very shortly for another episode.

Thank you.